Family Experiences Raising Children with Autism Spectrum Disorder in Lithuania



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Abbreviations

ABA – Applied Behavioural Analysis

ANOVA – Analysis of Variance

ASD – Autism Spectrum Disorders

CDC – Child Development Centre

CP – Cerebral Palsy

CSI – Couple's Satisfaction Index

DHT – Daily Hassles Theory

FAAR – The Family Adjustment and Adaptation Response Model

FGD – Focus Group Discussion

FST – Family Systems Theory

FESS – Family Experiences of Stigma Scale

GP – General Practitioner(s)

ICD-10 – International Statistical Classification of Diseases and Related Health problems

IDK – I Don't Know

MOCHA – Models of Child Health Appraised

M – Mean

PEP – Psycho-Educational Profile

PEDI – Paediatric Evaluation of Disability Inventory

P – CRT – Parent – Child Relationship theory

PPS – Pedagogical Psychological Services

PSI-SF – Parental Stress Index – Short Form

SD – Standard Deviation

SDT – Social Dominance Theory

TEAACH – Treatment and Education of Autistic and related Communication Handicapped Children

TD – Typically Developing

TMSC – Transactional Model of Stress and Coping

List of original articles and public engagements

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Abstract

Objectives. This thesis represents a unique collaboration with the parents of children with Autism Spectrum Disorder in Lithuania. The focus and direction of this study was to examine how psychological experiences (parental stress levels) and socio-cultural factors (professional's services and societal attitudes) interact. It used parental experiences to capture more elaborate picture of stress while raising child with ASD. The studies sought to gain a better understanding of the influence that socio-cultural factors have on parents more specifically to measure whether stress is linked to the experiences of stigmatizing behaviour.

Methods. Combinations of quantitative and qualitative methodologies were used to provide a deeper and broader understanding of the research questions. Parenting Stress Index (short form) questionnaire provided psychometric estimates of parenting stress. Semi-structured interviews and focus group discussions (FGD) were conducted and explored further stress phenomena and parental experiences in Lithuania. FGD with professionals informed about their services, and attitudes on ASD children. While interviews with siblings informed about family experiences from the point of a TD child. Grounded Theory and Thematic Analysis were used to analyse the data. Finally, I used knowledge, attitudes, and practice scale to understand the existing tendencies towards ASD among the general public.

Results. Overall, parents reported a significant increase in parental stress (M=102.6, SD=19.5) with a positive correlation of experience of stigma (r=.68) and negative correlations with relationship satisfaction (r=–.30). The parental stress model has showed that ASD characteristics were the most influential

factor, followed by support received and experiences of stigma (AIC 2768.2 p<.0001). From qualitative data, *Time* emerged as a crucial factor for parental stress. Lack of support from professionals and guidance after diagnosis were additional factors. FGD showed agreement between medical professionals and parents on future improvements with regard to support after diagnosis. All participants reported on high levels of stigmatisation in Lithuania and reflected on the detrimental effect it has on families. Siblings' interviews informed about the high levels of responsibility and isolation experienced by growing up with an ASD sibling. Finally, it was found that Lithuanians are aware of ASD but have poor knowledge about the disorder. There was a gap between positive attitudes about people with ASD and motivation to assist such people.

Discussion. The findings showed that Lithuanians experience high levels of parental stress while raising child with ASD. It is unrealistic to eliminate all the stress, but it is important to develop coping strategies to protect against the negative effects of parental stress. Also, it has been shown that cultural and external factors contribute to the experiences of parental stress in Lithuanian population. Both professionals and parents agreed on the need to provide support after the diagnosis and to address the socio-cultural issues when thinking about families with ASD children. The siblings' experiences added valuable information on family dynamics with ASD children through their own personal experiences and highlighted the risk factors of favouritism, isolation, and overcompensation. Finally, the lack of knowledge and pervasiveness of misconceptions about ASD strengthened the case about prevalence of stigma towards ASD in Lithuania. The limitations and suggestions for future research are discussed for each chapter individually.

Chapter 1. Introduction

1. ASD and its Prevalence

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that impairs a person's social communication and is associated with stereotypical behaviours or interests (Boshkoff Johnson 2014). It is a disorder that is known for isolation, withdrawing from socialization with others, and also an inability to interact and respond appropriately towards people (Frith 2012). The causes of ASD are not clear, and there is no known cure (Fernell, Eriksson, and Gillberg 2013).

The number of children diagnosed with ASD has increased tremendously over recent years. There has been a 17.1% growth in the last ten years, demonstrating that 1 child in 59 cases will have ASD in the United States (Baio et al. 2018). Even though the prevalence of ASD has increased, there is slow rise in the services available for ASD patients (Scherzer et al. 2012). ASD can be diagnosed early, which is important for access to interventions and treatments (Wallace et al. 2012). However, the interventions and treatments vary across the globe due to the cultural and social understanding of the disorder (Scherzer et al. 2012). Depending on the region or country, parents' reactions to ASD diagnosis - and their actions towards it - will largely depend on the cultural and societal perceptions of mental health (Mansell and Morris 2004; Krasauskaitė 2010; Canino and Alegría 2008). Cultural interpretations not only influence parental or clinical understanding of ASD, but also the methods of treatment: whether it should be based on biomedical or social aspects of disorder (Yu et al. 2008; Carona et al. 2014; Epstein et al. 2008; Ustilaitė et al. 2015). Although ASD is defined as neurodevelopmental disorder

with genetic variations and neurological differences in the brain, it is also a social construct, because it is social norms which define abnormal behaviours (Fernell, Eriksson, and Gillberg 2013). Thus, when assessing ASD, it is crucial to consider not only neurological aspects of this disorder, but also the sociocultural constructs of the individual's country.

When a child is given a diagnosis of ASD, it can be a devastating blow to any parent. It is reported that parents of children with ASD are more likely to experience high chronic levels of stress (Bluth et al. 2013b; Eisenhower, Baker, and Blacher 2005; Silva and Schalock 2012b; Rutgers et al. 2007; Schieve et al. 2007a). The studies demonstrate that maladaptive behaviours alone elevate levels of parental stress (Hall and Graff 2012b; Giovagnoli, Postorino, Fatta, Veronica, et al. 2015; Shawler and Sullivan 2015; Davis 2015; Sikora et al. 2013). Maladaptive behaviours that characterize ASD include obsessive behaviours, tantrums, and self-injurious behaviours which tend to increase and prolong the stress that the parents experience.

Unlike other disorders, families of children with ASD experience lengthy delays before receiving the diagnosis compared to other neurodevelopmental conditions. These different diagnostic processes add to parental stress (Braiden, Bothwell, and Duffy 2010; Moh and Magiati 2012). Parents, who are typically primary caregivers, experience an increase in anxiety, self-blame and a decrease in self-esteem (Johnson et al. 2011; Miranda, Colomer, et al. 2015; Padden and James 2017b; Rezendes and Scarpa 2011; Al-Farsi et al. 2016; Estes, Munson, et al. 2009). Studies have also shown that parents of children with ASD have greater conflicts with their TD children and more problems with family integration as a whole (Weiss, Wingsiong, and Lunsky 2014; Jellett et

al. 2014; Meirsschaut, Roeyers, and Warreyn 2010). In addition, parents of children with ASD have elevated levels of marital discord and are more likely to divorce than parents without children with ASD or other developmental disabilities (Hartley, Papp, and Bolt 2016; McStay et al. 2014a; Brobst, Clopton, and Hendrick 2008). Parenting a child with ASD requires great amount of psychosocial resources and it comes with specific challenges and rewards. These aspects are explored in literature, however there is lack of consensus in findings on parental stress (Hartley, Papp, and Bolt 2016; Brobst, Clopton, and Hendrick 2008; Lyons et al. 2010). I have investigated these issues in order to understand parental experiences in raising children with ASD in Lithuania.

1.1 Parental Stress and its Theories

Parental stress is "a complex set of challenges associated with a parent's role of taking care of their children" (Rutgers et al. 2007). A concept of parental stress is adopted from Transactional Model of Stress and Coping (TMSC) by Lazarus (1999). This model states that stress is the result of a person's interaction with internal or external environmental demands. It is based on an evaluation of the coping resources that could be used in stressful situations. Stress is thought to affect physical and psychological well-being of the person and requires restoration of balance (Lazarus 1999). The stress is mediated by primary appraisal – individuals' assessment of the stressor; and secondary appraisal – individual's judgment on the available coping resources (Lazarus 1999). Parental stress is based on evaluating the provoking situation (e.g. the child's tantrum) and assessing the parent's control over the situation (i.e. calming the child).

There are a number of theoretical constructs that can be used to study parental stress. One of them is Family Systems Theory (FST), which states that a family is an interdependent unit, meaning that the family members cannot be understood in isolation from the family system (White, Klein, and Martin 2015). Individual family members have certain roles and duties that they are expected to perform in their family setting (White, Klein, and Martin 2015). If a family member is not behaving in accordance to their assigned role, then the family is obliged to look for a new equilibrium or adapt to different roles. There are four relationship patterns that inform where the problems might occur in the family: marital conflicts, mental state of the spouse, emotional distance and impairment of one or more of the children (White, Klein, and Martin 2015). The latter problem is usually the main one for parents of children with ASD (Jones et al. 2013). For example, if the family has a child with ASD, the roles of the mother and father may radically change compared to mother and father of a TD child (Jones et al. 2013). Both parents will have to work in order to pay for the child's treatment.

Another theoretical framework that explains parental stress is the Family Adjustment and Adaptation Response Model (FAAR) created by McCubbin et al., (1980). This model examines family stress and concentrates on factors before and after the crisis, that assist families in adjusting and adapting to the stressor (McCubbin et al. 1980). During the adjustment stage, families are trying to gain equilibrium after facing the stressor and manage the family functionality. The stressor forces families to use their coping strategies and family resources. After adjusting to those resources, families move to the adaptation stage and reduce the stress levels that were elevated due to the

threat by controlling the situation with their resources (McCubbin et al. 1980). For example, parents of a child with ASD have to adjust their parenting skills in order to adapt to raising such a child.

The review on parental stress by Pisula (2011a) shows that there are 3 main factors that mediate stress levels in parents of a child with ASD:

- Child's maladaptive behaviours (i.e. self-harm or aggression) are the highest predictors. Most of the parental stress occurs because these behaviours are difficult to accommodate.
- Lack of professional support predicts parental stress. Usually parents are disappointed with the capacity of institutions to admit and diagnose children, as often they will have to wait to receive an accurate diagnosis. There is often a lack of information on what to do next or what steps to take for the child's care. Furthermore, there are not enough educated professionals that can offer services for children with ASD. As a result, arranging the educational, social, and other services becomes the parent's responsibility.
- The final predictor of parental stress is the society's views and perceptions about individuals with ASD and lack of understanding of the family experiences while raising such a child. Society's perceptions about ASD - which are usually based on old stereotypes like poor parenting of the child, malnutrition, and vaccination, among other things - can isolate the parent.

Multiple studies suggest that an increase in awareness on parental attitudes regarding their stress may be an important point of intervention to

facilitate changes in behaviour from negative to positive (Shepherd et al. 2018b; Lyons et al. 2010; Thomas 2017). King et al. (2006) reinforces that the research tends to adopt a narrow perspective of the child with ASD, where the child is viewed as a "stressor", testing parents' ability to cope and negatively influencing their psychological well-being. Instead, researchers should seek to understand the meanings parents assign to having ASD child. For example, the study by Gray (1997) demonstrates that "normal family life" for these parents was not associated with the outward signs of domesticity (e.g., owning a house or holding a job), but was linked to factors such as their ability to socialize, the emotional quality of their interactions among family members, and the routines and rituals that comprised their perceptions of what "normal" families do.

Facilitating the shift from internally based factors (child ASD severity, parental psychopathology) towards the external factors (low levels of support, lack of access to good quality services) may deepen understanding of the parental stress. This broader framework can help to identify aspects of parental stress theory when considering external factors and can prove to be more practically relevant. As a result, interventions and support may be effective, if they consider this broader framework. Each new study on this topic has had the ultimate goal of adding information to the literature that could enlighten the field regarding the dynamic and complex puzzle that is parental stress. Many research reports find that parents of children with ASD are particularly vulnerable to stress, with high levels of distress found in up to 70% of mothers and 40% of fathers of severe ASD children (Loepp 2015; Tripathi 2015). Thus, reduction of parental stress may be advantageous for parental

well-being, which can have positive effects on the health and upbringing of the ASD child, as well as the longevity of the parents' relationship.

1.2 Parenting and Couple Relationship Satisfaction

There are additional factors that contribute to stress: lack of support network, ineffective coping methods and negative attitudes towards ASD. Higgins, Bailey, and Pearce (2005) found that when controlling coping strategies (i.e. high levels of self – esteem, optimism and/or spousal support) the relationship satisfaction among couples with ASD child were lower than in the general population. This shows that the coping style may not be sufficient to protect against parental stress in couples with ASD children. Therefore, it is important to identify the most distinctive factors influencing relationship satisfaction for these couples.

Relationship satisfaction is an overall evaluation of the state of the relationship and a reflection of its function. It is described as one of the main characteristics of family welfare (Benson & Kersh, 2011). Couples report that it is challenging to evenly distribute time between children and their partner. This can be intensified when the child has special needs and requires more time and effort (Brobst, Clopton, and Hendrick 2008). Studies have highlighted that stress in families of children with ASD contributes to a higher rate of marital discord (Hartley et al. 2010; Higgins, Bailey, and Pearce 2005; Risdal and Singer 2004). Parenting a child with maladaptive behaviour can be especially difficult. This has been supported by studies which show that mediating factors for higher marital discord in these families is atypical behaviour of the child (Dunn et al. 2001b; Tarabek 2011). In addition, relationship difficulties depend on both environmental circumstances and the family characteristics (Sim et al.

2016). Research found that the key environmental circumstances are family income level (because poverty reduces the quality of life for family) and lack of acceptance from the community (because it isolates the family) (Park, Turnbull, and Turnbull 2002). Also, if the couple has existing marital difficulties, the added stress from children with special needs tends to decrease relationship satisfaction and increase divorce rates (Higgins, Bailey, and Pearce 2005). There is existing disagreement between the effects of having a child with ASD on a relationship. Higgins et al. (2005) highlight that parents of children with ASD have lower marital satisfaction, family support and family flexibility. While a study by Havens (2005) points that children with ASD have not decreased relationship satisfaction in parents, but strengthen couple's relationship and provide common goals. These inconsistencies require further exploration.

Another factor to consider about relationship satisfaction is the parent's gender. Parenting a child with ASD may affect the mother and father differently. Studies report that there is a strong gender difference on how parental stress is experienced by father and mother (Johnson and Simpson 2013; Jones et al. 2013; Knafl and Deatrick 2003; Smith et al. 2010). In their meta-analysis Jackson et al. (2014) state that marital satisfaction is higher in men than in women. These variances are explained by gender differences and family roles in marriage, as they are dictated by the culture (Sim et al., 2016). For example, employed women encounter additional responsibilities (being wife, mother, homemaker, and employee), compare to a men who usually are responsible for financial provision and not child-rearing. Hence, the reason why the woman's role is nearly always more demanding than her husband's.

This leads to higher levels of emotional and mental demands for women (Sim et al., 2016). Dunn et al. (2001a) reported that mothers of children with ASD who did not receive support from immediate circle of friends and family, especially from spouses, report higher levels of depression symptoms. Even though family roles and attitudes are changing, the pace at which these alterations occur in the society are slow. Traditionalist view of gender roles still prevail among many cultures (Sim et al., 2016). For example, Lithuanian families are based on traditional roles, i.e. the mother is a care giver, who is responsible for the household, and the father is financial provider of the family (Melnikienė 2005; Simanavičienė 2011). Therefore, it is important to consider cultural norms when it comes to gender differences.

Research by Jones et al. (2013) tried to examine the parental role differences in parenting children with ASD. They studied 161 mother-and-father dyads who reported on their own well-being and their child's functioning. The main hypothesis was that mothers and fathers would score differently on positive and negative psychological well-being. The results showed that mothers (M=10.57, SD=5.19) reported significant levels of distress compared to fathers (M=8.08, SD=5.11) β=–2.26, p<.001. It confirmed that mothers are more stressed (46%, p<0.001), depressed (72%, p<.001) and anxious (100%, p<.001), while fathers were more positive towards their children (75%, p<.001). However, the difference between the parents' on their stress remain significant even though, demographics (age, education, finances) and child's behavioural characteristics are accounted (18% of variance, p<.001).

Mothers of children with ASD are generally more stressed than fathers due to the fact that they spend more time with the child and do all the

housework leaving little or no time for personal leisure activities. Smith et al. (2010) showed that mothers tend to stay more at home with their children due to their child's behavioural problems. The reluctance of getting out of the home with the child can lead to isolation (Blacher 1990). This observation was confirmed by Johnson and Simpson (2013) who also informed that mothers fear to go into the public with their child due to the unpredictable behaviour of the child. Thus, they tend to isolate themselves from the society as the way of coping and avoiding more stress. These findings highlight the importance of family roles, and that the responsibilities are different on mothers and fathers in the family (mothers usually carry more psychological burden than husbands as they spend more time with an ASD child). This factors may explain the differences in parental well-being (Bölte et al. 2016). As women in the general population tend to report increased levels of depression and anxiety than men, it is important to establish whether the same variables mediate the impact of potential stressors when parenting children with ASD (Jones et al. 2013).

1.3 ASD and Professional Services

Although research on ASD is increasing, most studies across different nations have reported a wide variation of knowledge among health and educational professionals regarding diagnosis, treatment, teaching programmes, and prognosis of ASD (Eseigbe et al. 2015; Imran et al. 2011). A study by Heidgerken et al. (2005) found that there was significant variation in knowledge about ASD between primary care providers and specialists in United States. Similar findings found in Nigeria, where health care workers hold misconceptions on treatment and causes of ASD (Igwe Monday et al. 2009). Research in India and Pakistan informs that there is variation in

knowledge about ASD based on the age of the health professionals (Imran et al. 2011; Rahbar, Ibrahim, and Assassi 2011). Younger specialists are more informed and better at diagnosing ASD compared to their older colleagues (Daley and Sigman 2002).

Studies report that education provides life skills and social background and, as a result, equip children with ASD with tools for independence. Also it offers hope for parents for their child's future (Midence and O'neill 1999; McCabe 2008). Moreover, learning strategies of children with ASD differ widely from neuro-typical children, requiring teachers to be trained with specialised skills (Fabri et al. 2016; Simpson et al. 2005). Knowledge about ASD, training and educational practices to assist such students varies across the globe. The study by Alnemary (2017) found significant differences between specialised and general school teachers' knowledge about ASD based on position, teaching experience, exposure to ASD, and training received. Special education teachers provide a more advanced level of education for pupils with ASD than general teachers. However, this limits the possibility for such children to join mainstream schools. In addition, the parents of children with ASD perceive general classrooms as the gate of integration to the society and aim to have their children in neuro-typical classrooms (Fabri et al. 2016; Parsons et al. 2011; Simpson et al. 2005). However, a lack of knowledge about ASD and its characteristics creates tensions between parents and mainstream schools, because the child's behaviour is considered as "badly mannered or constantly misbehaving" (Parsons et al. 2011). On the other hand, parents perceive this lack of knowledge as unwillingness to help their child to succeed (Parsons et al. 2011). These tensions between parents – professionals

consume unnecessary time and energy. Professionals' knowledge of ASD, in any health or education setting, is crucial to the provision of optimal services and support for the family, which reduces the burden associated with ASD for the society (Eseigbe et al. 2015).

1.4 ASD and Lithuania

There is substantial research done on parents with special needs children in Western cultures, however less is studied in other parts of the world. This division is noticed in Europe as well, where significantly more research on ASD is produced in Western Europe compared to the Eastern Europe (McConkey et al. 2008). The relevance of findings on ASD may be restricted only to similar regions because of differences in resources and support available. Different attitudes towards mental health and differences in legal and social policies are observed between Western and Eastern Europe. The heritage of communism has left an imprint on societies' understanding of mental health, which is still experienced in Post-Soviet countries (Puras et al. 2004b; Querdenker and Meirhofer 2014).

Lithuania gained independence in 1990s, after being part of Soviet Union for 50 years (Slay 2009). The existing view of mental health of that time was highly influenced by Moscow School of Psychiatry, which concentrated on treatment with medicine and institutionalisation of patients with psychiatric disorders (Lesinskienė et al. 2002). Eastern European Governments did not recognize mental health problems and did not seek to integrate vulnerable people into society (Puras et al. 2004b). Moreover, treatment relied on a biological approach, with few non-pharmacological therapies offered. There was no family care or support provided by the government (Lesinskiene et al.

2008; Puras et al. 2004a).

The situation has changed little in the 28 years since independence. In Lithuania, child psychiatric services are still behind the majority of European countries (Alma et al. 2017). For example, referrals for diagnosis occur in multiple settings. Diagnosis is assessed by variety of professionals and services: family doctors, paediatricians, psychological–pedagogical services, psychologists, and school or kindergarten administration. Most of these professionals have a very specialised understanding of child and adolescent psychology and development (Lesinskiene et al. 2008). When the family receives a referral from above-mentioned institutions, accessing the services is a particularly complicated and lengthy process. Families have to wait approximately 6 months to receive the place for assessment and diagnosis (Lesinskiene et al. 2008), because there are only two places in Lithuania that provide assessment and diagnosis: the Child Development Centre (CDC) in Kaunas (http://www.kaunoklinikos.lt/kk/en-GB/) and another CDC based in Vilnius (http://www.vaikuligonine.lt/category/centrai/vaiko-raidos-centras/).

Long queues at medical centres and delayed access to services postpone pivotal and altogether necessary support for families in the early stages directly after diagnosis. They are faced with the dilemmas of the further treatment of their child (Ruskus 2003; Ališauskas 2006). The report by the European Commission "MOCHA" informed that in Lithuania there are no multidisciplinary services that would continue to support families after the diagnosis (Alma et al. 2017). The report stated that the responsibility to inform each services and coordinate appointments, as well as the daily parenting of the child with ASD becomes the parent's duty.

For parents to receive benefits from the government, the child has to have a disability assessment. The place providing the assessment is the Disability and Working Capacity Assessment Office at the Ministry of Social Security and Labour (DWCAO). Parents have to bring medical and other documents required for the disability level assessment from the Child Development Centre (CDC). Having received all the necessary documents, DWCAO territorial branches – within 15 working days – take the final decision on the individual's disability level, its reason, onset and duration. It must be pointed out that DWCAO is the only institution in Lithuania which is responsible for assessing a person's disability or capacity to work (Raistenkis, Skvarciany, and Gurevicius 2015; Zagorskis 2018). This system is deemed to be time-consuming and stressful for parents, especially when considering that one has to bring their child for another evaluation, after having already received a medical diagnosis (Muiznieks 2017). After the process of acquiring disability status for their child with ASD, parents are directed to municipalities which assist with the provision of care, such as constant supervision or purchasing specialised gear and compensation for technical adjustment i.e. transportation expenses (Zagorskis 2018).

While Lithuania has a relatively developed institutional and policy framework for mental health, there is a considerable gap between the state's policies and the implementation thereof. Most notably, there is a prolonged process of coordination between national and municipal authorities (Muiznieks 2017). For example, the understanding of the provisions for children if they are severely disabled or mildly disabled is still debated. For the majority of cases, ASD is treated as severe disability in order to receive the maximum support

from the government. However, that usually prevents a child from accessing general school or later in life to receive a job (Raistenkis, Skvarciany, and Gurevicius 2015). This ultimately reduces the chances of independent living or inclusion in so-called “regular society”. As such, Lithuanian legislation does not make any provisions for the social integration of these people and they are predestined to remain isolated and invisible in the eyes of society. The report by European Commissioner for Human Rights Muiznieks (2017) has showed that the disability assessment system urgently needs to graduate from a purely medical disability assessment and develop towards a bio-psycho-social model to ensure more objective assessment of disability. Lack of individual assessment and focus on a medical model of disability leads to discrimination, increased risk of poverty and health issues due to stress and anxiety (Muiznieks 2017).

To summarise, services for autistic children and their families are poor and undeveloped. Reliable diagnostic tests and effective therapeutic programs are not implemented into clinical practice. The psychosocial and educational management often depend on the financial possibilities of the families, thus for many autistic children qualified specialized care is not accessible (Muiznieks 2017). These services are not available at all community levels, and the services that do exist are found almost exclusively in cities. Consequently, families in rural areas are struggling to access support and even post disability assessment (Muiznieks 2017). The out-dated regulations regarding medical and social care (including rehabilitation, education and social care) often neglect to mention the diagnosis of ASD, therefore the diagnosis of childhood autism is often hidden under another name as “mental retardation” or is

changed to another psychiatric disorder, as a means to preserve the patient's right to access support services (Raistenkis, Skvarciany, and Gurevicius 2015; Muiznieks 2017). Disability allowance is often the only social help that autistic individuals and carers receive. The current recommendations and standards in Western countries recognize that early assessment and intervention, as well as multidisciplinary specialist care services, facilitate greater outcomes for the children with ASD and their families (Mitchell and Holdt 2014; Gulsrud et al. 2014; Feinberg, Augustyn, Fitzgerald, and et al. 2014).

In Lithuania, there are over 240 000 people with disabilities, this nearly the size of the population of Kaunas; the second largest city in Lithuania (Lithuania Ministry of Social Security and Labour 2017). Disability indirectly (the people that are exposed to disability in the close environment) touches every 14th citizen in Lithuania (Kuodytė and Pajarskienė 2012). Thus, the problems that people with disability face are relevant to many. However, there is still an existing narrative about mental health patients being dangerous and unpredictable. These beliefs influence society's perception of various disorders, fostering the opinion that institutionalisation is preferable to integration (Kuodytė and Pajarskienė 2012). There are studies that have provided insight. Firstly, there are differences in the disorders themselves; the physically visible disability is reported to be less stigmatized in Lithuania compared to the mental health related disabilities (Puras et al. 2004a; Kuodytė and Pajarskienė 2012; Dobryninas and Gaidys 2003). The survey by Dobryninas and Gaidys (2003) showed that general public in Lithuania felt the most uncomfortable around people with mental health issues. In addition, society valued people with physical disability more favourably than people with

mental disorders (Dobryninas and Gaidys 2003). It also showed that older generation (age 50 years and older) were exhibiting more stigmatizing and intolerant behaviour towards people with ASD and their family members compared to the younger generation (that grew up in Independent Lithuania). Survey by Dobryninas and Gaidys (2003) highlighted the existing tendencies towards people with disabilities in Lithuania. However, there is still lack of information about society's knowledge, attitudes and practices towards people with ASD. Lack of exposure to ASD may lead to lack of awareness and comprehension of this condition, which is supported by the absence of integration of children with disabilities into regular schools (Kišonienė and Dudzinskienė 2007).

The Lithuanian government has been reforming its education system since 1991. Firstly, one aim is to provide education to everyone regardless of their physical, social, cultural or racial differences as guaranteed by Lithuanian Constitution (Kišonienė and Dudzinskienė 2007). Secondly, another aim is to bridge the gap between the mainstream and special education schools, and create the inclusive educational model in every school. Thirdly, schools should not expect children with disabilities to reach the normative level, but allow them to thrive and provide the conditions and opportunities to reach a personal level of success (Kišonienė and Dudzinskienė 2007). The Ministry of Education report that 90.4% of children with special needs are integrated in the mainstream schools (Galkienė 2006). This is a great achievement in the past 15 years of the Legislation of Integration Act, but it does little to influence the attitudes of professionals towards ASD. The study by Ališauskas (2006) investigated methodology and perception of Pedagogical Psychological

services[1] (PPS) in the process of pedagogical-psychological assessment of the children with special needs and found that professionals concentrate more on the deficit model. Also, they focus on negative characteristics and the child's lack of skills during first time assessment. For the follow–up visits, the evaluation focused on difficulties children experienced, relating it to their personal characteristics rather than educational environment. These perspectives of professionals towards ASD influence the quality of service the child receives. Studies highlight the existing tensions between the aims of integrated education and the practical implementations of it in Lithuania (Galkienė 2006; Ruškus, Gerulaitis, and Vaitkevičienė 2004) .

The legislation in Lithuania has done much to protect rights of children with disabilities, however it does not guarantee that parents and professionals will have cooperative relationships with each other (Miltenienė 2005). In other parts of the world, the parent–professional partnership has shifted the treatment from only professionals to parents as collaborators and experts of their child. This helps to individualise needs of the family and open the access of personalised intervention. Despite these compelling findings, there are no official parenting programmes in Lithuania and the relationship between parents and professionals is still hierarchical (Kišonienė and Dudzinskienė 2007; Šukys, Dumčienė, and Lapėnienė 2015).

1.5 ASD and Siblinghood

Relationships among siblings are the longest lasting relationships among humans (Beyer 2009). It develops through life and it is an extensively

[1] Pedagogical Psychological Services were found to evaluate child and provide educational guidelines for the school to help with child's needs (Ališauskas 2006).

researched area (Beyer 2009). However, there is still less known about the relationship among siblings when one of them has ASD (Benderix and Sivberg 2007; Mascha and Boucher 2006; Orsmond and Seltzer 2007). The reported findings are mixed. In some studies siblings do not experience negative effects and report positive outcomes; while in other studies they talk about isolation, increased stress, and depression, without positive outcomes (Angell, Meadan, and Stoner 2012; Beyer 2009; Smith and Elder 2010). Sibling experiences are usually reported through the parents' or teachers' perceptions, which provide a less objective reality of the actual needs of siblings of children with ASD. Studies show that parents tend to view the relationship and psychological well-being of siblings of children with ASD more negatively than of typically developing children (Macks and Reeve 2007; Ross and Cuskelly 2006). Sibling conflict is one of many parental child rearing concerns (McHale, Updegraff, and Feinberg 2016). In addition, parents of a child with ASD experience higher levels of stress and anxiety trying to balance the attention between the child with ASD and the typically developing sibling. The study by Petalas et al. (2009) revealed that families of children with developmental delay have favouritisms more frequently than in neuro-typical families.

The current study by Angell, Meadan, and Stoner (2012) highlighted that sibling relationships serve as a platform for early development of interpersonal skills. These findings were based on social learning theory by Bandura (1977), who claimed that challenging behaviours among siblings are generalised to other settings and help with problem solving. The development of sibling relationships also contributed to child's personality and intellectual progress. For example, the relationships between parents and each child differ

in the expression of warmth and relatedness. This makes siblings aspire to be unique and different from one another and compete for parental attention (Orsmond and Seltzer 2007).

There are additional factors that contribute to the dynamics between siblings such as age, gender, severity of ASD and relationship among the parents (Beyer 2009). Research found that sisters of children with ASD have higher levels of competence, compared to brothers of children with ASD or sisters of TD children (Kaminsky and Dewey 2001; Verte, Roeyers, and Buysse 2003). The study by Macks and Reeve (2007) highlighted that elder siblings of children with ASD have more difficulty in psychosocial and emotional adjustment compared to younger siblings. Pilowsky et al. (2004) demonstrated that severity of ASD negatively affects a sibling's adjustment and that aggression was most commonly identified as key factor that challenged the sibling's relationship. In contrast, the study by Macks and Reeve (2007) demonstrated positive influences; siblings of child with ASD are more tolerant and have greater levels of control towards their behaviour and emotions than TD children. Hodapp and Urbano (2007) highlighted the importance of balanced views of sibling outcome and reporting both positive and negative aspects of sibling experience. Thus, studies should try to understand benefits that can strengthen family dynamics, while addressing the underlying difficulties that assist families and professionals to develop support structures for siblings of children with ASD (Kaminsky and Dewey 2002; Hastings 2007).

1.6 Stigma

Historically, individuals with disabilities experience discrimination,

ostracism, and isolation. The study by Colella and Varma (2001) reported that negative attitudes towards people with mental health is hard to identify in research, because it is masked, rationalized, or not reported in the countries around the globe. Today, United Nations policy mandates that individuals with disabilities should be afforded equal access to education, vocation, and community living (Human Rights Act, 1998). Inclusion - the practice in which individuals with disabilities participate in community life alongside their counterparts without disabilities - requires not only an accessible physical environment but also an inviting (or at least accepting) attitudinal context. Positive attitudes towards individuals with disabilities are critical for successful inclusion into all aspects of society. In addition, personal experiences, opinions, and attitudes can play a crucial role in the inclusion of individuals with disabilities (Corrigan, Roe, and Tsang 2011). Inclusion is particularly important for individuals with ASD since the social deficits are a cardinal characteristic. A number of factors make ASD particularly vulnerable to misconceptions, including the unknown aetiology of the disorder and the variable manifestations of symptoms. False or insufficient information can impede inclusion by contributing to misconceptions and stereotypes that impact not only the attitudes held towards individuals with disabilities but also the person's behavioural intentions (Corrigan and Miller 2004; Corrigan and Watson 2007).

Those behavioural intentions and common misconceptions are usually defined as stigma. Krajewski, Burazeri, and Brand (2013) described stigma as "the loss of the status and discrimination triggered by negative stereotypes that have become linked in a particular society." Stigma can be internal (individual

based) and/or external (society based), with the latter divided into governmental and social levels. Both internal and external aspects of stigma are co-dependent. For example, if the society stigmatises specific group of people, they tend to internalize those beliefs as part of their identity. Social or interpersonal stigma is based on the general population's cognitive or behavioural expression towards a person. This stigma level usually operates through common beliefs and attitudes (Krajewski, Burazeri, and Brand 2013). However, the governmental stigma is the most detrimental out of all levels (i.e. policies that are disadvantageous to specific group) as it has the direct impact on person's life (Krajewski, Burazeri, and Brand 2013). The studies have shown that awareness is the first step to challenge one's stigmatising views (Dillenburger et al. 2015; Durand-Zaleski et al. 2012; Lu et al. 2018).

The increase in prevalence of ASD is attributed to a broadening diagnostic concept, however the greater awareness of ASD in the general population may contribute to that increase in prevalence (Bernier, Mao, and Yen 2010; Masi et al. 2017). The rise in awareness of ASD is not universal (Rice et al. 2012). Around the world, the knowledge about ASD varies and most of the general population exhibits common inaccurate perceptions concerning disorder aetiology or intervention options (Bernier, Mao, and Yen 2010; Dillenburger et al. 2013; Dillenburger et al. 2015; Durand-Zaleski et al. 2012; Liu et al. 2016). Katz (1981) in the psychosocial model of stigma stated that there is an exposure aspect. Perception gives the first impression then those impressions form initial knowledge. The initial knowledge allows one to predict behaviour and that behaviour provides information on threats in the

environment. The biggest threats are behavioural deviants as they are hard to predict.

The Katz model informs that ASD is not detectable through usual perception pathways (i.e. vision, hearing, touch and etc.). In other words, due to the fact that ASD could not be visibly noticed, makes children and their families more vulnerable to stigmatization (Corrigan and Miller 2004). Also, first impression fuels perceived responsibility. Perceived responsibility is attributed accountability to the person, for example the question of whether it is genetically based or the result of an accident. The perceived responsibility is usually experienced by close ones of an individual with stigmatized identity (Corrigan and Watson 2007; Katz 1981). According to the families of children with ASD, problematic behaviour is attributed by the public to wilful disobedience or bad parenting (Ooi et al. 2016). Some parents are actively engaging themselves with the public and explaining their child's diagnosis to improve the public understanding. Other parents tend to deny and hide their child's disorder (Eremin 2011). The latter might be due to the second aspect of stigmatization by Katz (1981); the blame that is placed on the carer. Society tends to put the blame on the parents for not being capable of raising a normal child. Therefore, the society's misconception that ASD is a result of bad parenting invokes even more guilt and shame in the parents (Eremin 2011). As these stereotypes have not only direct effects on the person who has the disability, but also towards the closest family members (Bashir, Khurshid, and Qadri 2014; Baškienė 2015; Krajewski, Burazeri, and Brand 2013; Gray 2002; Corrigan and Miller 2004).

A study by Bornstein and Hendricks (2013) reports key findings of knowledge, attitudes, and practices towards children with disabilities in Eastern Europe. They underlined that a high level of stigma occurs when the relationship becomes distant (neighbours versus acquaintances). In addition, a report by UNICEF showed that ASD was the most highly stigmatised group compared to others such as those with Down Syndrome, deaf or blind, and children with physical disabilities (UNICEF 2014). In this study, they reported that people had limited understanding that inclusion should be everybody's business, instead they attributed this responsibility to parents and relatives (86%) together with the education (83%) and health care systems (85%) more than its citizens (62%) (UNICEF 2014). Krajewski, Burazeri, and Brand (2013) in their study showed that there is experience of self-stigma (33%) and social stigma (67%) in six European countries. It was found that social support helped to reduce self-stigma. The highest societal stigma was in Croatia and Lithuania compared to other countries. The study claimed the national health system played a significant role in providing opportunities to cope with stigma, this was viewed in the countries which have strong health systems such as Sweden, Malta, or Israel (Krajewski, Burazeri, and Brand 2013).

There are studies reporting internal and external stigmatisation for people with mental illness. However, fewer studies analysed how parents/care providers experience stigma and what methods they use to cope when raising a child with ASD (Bernier, Mao, and Yen 2010; Dillenburger et al. 2013; Dillenburger et al. 2015; Durand-Zaleski et al. 2012; Liu et al. 2016). Thus, it is likely that delays in societal and governmental support contribute to considerable amounts of stigma experienced.

1.7 Objectives

In defining thesis objectives, I was guided by the complex social history of ASD as a neurodevelopmental disorder. I was particularly interested in the parenting of children with ASD, with a special focus on parental stress. I referred to existing theoretical frameworks on parental stress. The overwhelming focus on the clinical aspects of ASD and tendency to underestimate or ignore the wider context in which the parental experiences were embedded motivated me to explore socio-cultural influences on parenting. This thesis investigated the impact on Lithuanian parents of children with ASD:

- I will collect the data and analyse it systematically to understand the research gaps in Autism Research in Lithuania.

- I will produce a systematic review on the parental stress tools and analyse their psychometric properties.

- I will measure parental stress, relationship satisfaction and experiences of stigma among Lithuanian parents raising children with ASD, Cerebral Palsy (CP) as well as typically developing children (TD) using established questionnaires and then analyse the findings and build the model for parental stress.

- I will interview parents raising children with ASD and generate a parental stress framework based on the experiences reported.

- I will use focus-group methodology to interview professionals (clinical and educational) on their views, knowledge and practices when working with

children with ASD in Lithuania. After that, I will disseminate the data and aim to understand the similarities and differences of the experiences described.

- I will interview siblings growing up with ASD children, collect their responses and analyse the data based on potential risk factors. Thereafter, I will build a framework that encompasses positive and negative experiences according to the data reported.

- I will measure the general public's knowledge, attitudes and practices towards ASD in Lithuania and produce an analysis on the results building the model that explains the findings and refer them to the overall narrative of experiences of stigma.

Chapter 2. Scoping Review-Autism Research in Baltic Countries: What is Known and What is it Still to be Studied?

This Chapter is part of the journal article:

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2. Background

ASD is a relatively new diagnosis in the practice of psychiatry and medicine across all three Baltic countries. It was introduced only in the early 1990, after the Soviet Union collapsed (Puras et al. 2004b). Little is known about the current situation of ASD in Baltic States (Puras et al. 2004b; Querdenker and Meirhofer 2014; Mikulėnaitė and Ulevičiūtė 2004). This makes it hard to understand the existing research gaps and direct the future research.

2.1 Aims of the Chapter

The current scoping review was conducted with the aims to:

- describe the scope (i.e., amount, focus, and nature) of research on autism spectrum disorder (ASD) across Baltic countries;
- summarize and disseminate main findings, settings and methodology across Baltic countries;
- identify the gaps in ASD research across Baltic States.

2.2 Methods

The goal was to identify, retrieve, and summarize the existing knowledge on ASD in Baltic countries. The scoping review was chosen as a main method for analysis because it is broader and more inclusive and it provides summaries of research findings more than the methods used to obtain them. The main phases of this scoping review were:

- searching for relevant studies;
- selecting studies based on pre-defined inclusion criteria;
- extracting data;
- collecting, summarizing, and reporting the results.

2.2.1 Data Sources and Search Strategy

The initial search was implemented on March 31st, 2016, in three electronic databases: PubMed (medical sciences, 1964 – March 31st, 2016), PsychINFO (behavioural and social sciences 1966 – March 31st, 2016), and EBSCO (multidisciplinary, 1900 – March 31st, 2016). An updated search was conducted on August 31st, 2016, when an additional 17 studies were included.

These databases were chosen for a broad range of journals available and more inclusive studies across different disciplines. The search engine consists of the key terms: autism spectrum disorder and the country's name. Articles about ASD in Baltic States in the databases suggests a low level of research on ASD in the Baltic countries. Most of the studies are published under state universities that the researcher is affiliated with; therefore, the articles are held in the corresponding university's electronic catalogue. In addition, the majority of research in Eastern Europe is published in the

language of the country it was performed and rarely translated into English for international publication. The current study used Lithuanian, Latvian and Estonian national libraries and open access databases as also the databases of all universities in each country (*Table 1*).

Table 1. Country databases used in this review

Country	Library name	URL
Lithuania	Lituanistika	http://www.lvb.lt/primo_library/libweb/action/search.do
	Libis (National Bibliographic data bank)	http://nbdb.libis.lt/
	Vilnius University	http://www.mb.vu.lt/istekliai
Latvia	National Library of Latvia	http://www.lnb.lv/en/search
	Riga University	http://www.rsu.lv/eng/services/library
Estonia	National Library of Estonia	http://www.nlib.ee/en
	University of Tartu Library	https://utlib.ut.ee/

The review was based on these search categories: country, diagnosis, and language. Article included patients with ASD or people in close contact with patients such as parents, teachers, siblings etc. (*Table 2*). Studies were excluded if - after reading the full text - the study did not consist of any above-mentioned constructs. Lastly, if the study was found in more than one database, only one paper was retained.

Table 2. Constructs searched across databases

Area of interest	Construct's Searched
Country	Lithuan*, Lietuv*, Leed*, Latvia, Latvij*, Läti, Estonia, Esti*, Igauni*, Eest*
Diagnosis	Autism, Autizm*, autism*, ASD, Autism Spectrum Disorder, Asperger*, Autizmo Spektro Sutrikim*, Autism Spectrum traucēj*, Autismi spektri hair*, Child Autism, Vaik* autism*, Bērnu Autism, Lapse Autism, ivairiapu* raid* sutrik*, Iespiedies attīstības traucējumi, Läbivad arengu häire
Language	Lithuanian, Latvian, Estonian and English

2.2.2 The Study Screening Process

A two-stage process was used to scan the targeted databases. Firstly, the titles and abstracts of studies were reviewed to identify relevant studies consisting of searched constructs. The remaining articles were carefully read and full text analysis was performed. If the full text of the article was not available online, the author or university library was contacted for a personal copy. If a copy was not obtained after that, the article was excluded from the review. The remaining articles were reported in the results section of this scoping review (*Figure 1*).

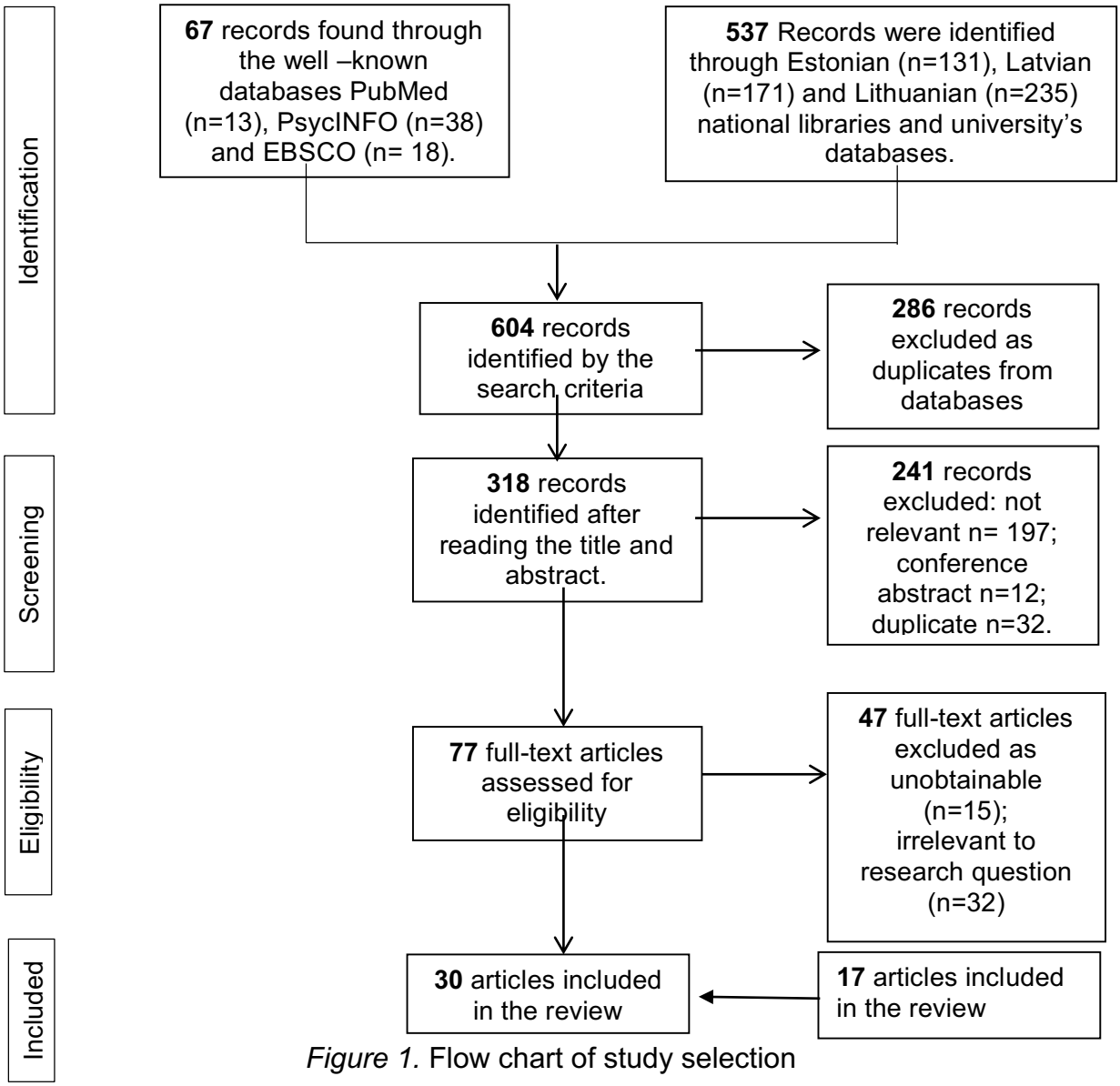


Figure 1. Flow chart of study selection

2.2.3 Inter-rater Reliability of Reviewers

All papers were reviewed by two reviewers: A. Prasauskiene and R. Buivydaite. The reviewers coded the papers based on agreed categories provided in Table 4. Then reviewers met and compared their results. If disagreements occurred, they revisited paper and discussed until the consensus was reached. There was disagreement on 5 extracted papers out of 47. However, a kappa score was not extracted because of the complexity of the data presented in the papers.

2.2.4 Procedure of Text Analysis

Each paper was read and the main findings of the paper were put in the Excel spreadsheet, then the papers were grouped according to their topic. After thorough analysis of the grouped papers, the main findings emerged and were reported in the discussion section.

2.3 Results

The total of 47 articles were fully reviewed and evaluated in this scoping review. The results revealed that most of the research on ASD started after 2005, as only 3 studies were found on ASD before that time. Most of the studies, *N*=27 were found in Lithuanian databases, *N*=9 studies in Estonian and *N*=11 studies in Latvian. Of the fifteen unobtainable studies, fourteen were from Latvia and one from Estonia. Majority of which consisted of Bachelor (*N*=6) or Master (*N*=8) thesis and *N*=1 journal article. Of the types of publications, 45% were journal articles mainly published in local journals of medicine, health, and education. The remaining 55% were theses (Bachelor, Masters, and Doctoral) submitted in final years of studies. Research methods used in the studies were mainly cross-sectional (46%) comparing parents of

children with ASD and parents of TD children, or comparing children with ASD to other children (TD or with developmental disorder), only a few studies addressed questions of treatment and intervention for ASD. Half of studies (51%) used parents of children with ASD or professionals as their primary participants, and only one third of the participants in the studies were children. Only one study used adults with ASD as research participants (*Table 3*).

Table 3. Demographic variables of the studies analysed

Characteristics	Lithuania	Latvia	Estonia
Publication year (*N*)			
2005<	3	0	0
2005 – 2010	2	1	1
2011 – 2014	12	4	6
2015- 31st March 2016	3	0	2
31st of March 2016 – 31st August of 2016	7	6	0
Publication type (*N*)			
Journal Article	18	3	0
Bachelor Thesis	0	5	5
Master Thesis	6	2	4
Doctoral Thesis	3	1	0
Research type (*N*)			
Case Study	3	1	3
Cross-sectional	13	6	3
Intervention	1	0	1
Qualitative (interviews)	6	1	1
Quasi-experimental	0	1	1
Systematic review	1	1	1
Mixed-methods	2	1	0
Epidemiological study	1	0	0
Participants of the study (*N*)			
Children with ASD	8	3	5
Adults with ASD	0	4	0
Parents of children with ASD	15	1	2
Professionals working with ASD people	0	1	0
Mixed: Parents & Professionals	3	1	1

This, scoping review revealed that research on ASD is limited. Areas studied in the Baltic States were education, medicine, parenting, ASD in adulthood, treatments, and epidemiology, however, the quality of research in these areas was poor (*Table 4*).

Table 4. Results of scoping review

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Lesinskienė (2000) [1]	Lithuania	epidemiological	Thesis	Population study	CARS	97 children with ASD	The epidemiological studies revealed that in 1999, Vilnius district, the prevalence of autism was 11.8:10,000 (0.12%). Out of 97 children, 38 were diagnosed with moderate autism and 59 severe autism.
Lesinskienė and Pūras (2001) [2]	Lithuania	cross-sectional	Thesis	Stakeholder Experience	Questionnaire developed by authors	39 grandparents of children with ASD	Grandmothers perceived their grandchild in a more positive caring manner than the grandfathers. Grandparents perceived that their grandchildren would be better in special boarding schools.
Lesinskiene (2002) [3]	Lithuania	cross-sectional	Thesis	Sensory-Motor Assessment	free drawings	26 children with AS	All children showed good abilities in drawing. Pictures had some common traits and were distinctly original, reflecting peculiarities of the syndrome's features.
Lesinskienė, Vilūnaitė, and Packevičiūtė (2002) [4]	Lithuania	cross-sectional	Journal Article	Gastrointestinal/ Physiological assessment	Questionnaire developed by the authors	75 mothers of children (with ASD N=25 & TD N=50)	Low appetite, narrow range of assortment of preferable dishes, digestive autonomic nervous system reactions were significantly more common in the ASD group. The sleep of the ASD children was significantly more often disruptive. Tallness and weight of the ASD children was delayed.
Lesinskienė et al. (2002) [5]	Lithuania	cross-sectional	Journal Article	Service Delivery/ Systems of Care	Questionnaire developed by the authors	111 mothers of children (with ASD N=37 & TD N=74)	Adaptation difficulties in medical services were very prominent, especially at the inpatient departments (unpredictable and impulsive behaviour, anxiety, decrease of appetite, sleep disturbances). Possibilities of home visit of the nurses are underestimated and could provide more useful and constructive help to the families.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Matonytė (2015) [6]	Lithuania	cross-sectional	Master Thesis	Stakeholder experiences	PSI	220 mothers of children (TD N=108, with CA N=84, with DD N=41)	The results showed that maternal stress is higher in mothers whose children are with developmental disabilities than mothers who are raising typically developing children and those suffering from chronic allergic diseases.
Ivoškuvienė and Urbutytė (2008) [7]	Lithuania	cross-sectional	Journal Article	Stakeholder Experiences	CARS	34 parents of children with ASD	Parents generally know behaviour features and communication ways of their children with ASD. Also, mothers in the process of upbringing usually use the ways of praise and encouragement, and fathers are more often inclined to punish the child.
Astrauskienė (2008) [8]	Lithuania	cross-sectional	Master Thesis	Language development/ communication	DISC	90 parents of children (with ASD N=42 & TD N=48)	Children with ASD had lower verbal and social skills as well as poorer communication and behavioural capacities compared with typically developing.
Kevere et al. (2009) [9]	Latvia	cross-sectional	Journal Article	Biomarkers	Measurement of Hcy	91 children (with SCZD N=37 & with ASD N=54)	Correlation among diagnosis, severity of disease and level of Hcy was r=−0.401, p<.001. It was found out that the level of Hcy was the highest in 14 schizophrenic patients with acute condition and adverse course of disease.
Priede (2009) [10]	Latvia	mixed -methods	Bachelor Thesis	Intervention Non-pharmologic	Observation in group work; Questionnaire group work & Interview	17 participants (children with ASD N=8, parents of children with ASD N=8, Portage specialist N=1)	Social skills improve in case children with ASD attend group work lessons regularly and for a long period of time.
Ivonytė, Kavaliauskienė, and Sąlyga (2009) [11]	Lithuania	cross-sectional	Journal Article	Intervention Non-pharmologic	SS by Ivoškuvienė & Balčiūnaitė	28 children with ASD	The results of the research demonstrated that occupational therapy influenced the development of their self-independence skills. The intervention group's common self-independence skill's average was 73.5, the control group children's score was 65.9.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Mickevičienė, Šinkariova, and Perminas (2009) [12]	Lithuania	cross-sectional	Journal Article	Stakeholder Experiences	CDS	240 parents of children (with ASD N=120 &TD N=120)	The results showed that depression in mothers and fathers with autistic children did not differ. Both parents of an autistic child had a higher depression than both parents of normally developing children (p=.001).
Karen (2010)[13]	Estonia	cross-sectional	Master Thesis	Language development/ communication	PEP-3	172 children (TD N=132, with ID N=32 & with ASD N=17)	There was a statistically significant difference among the typically developed children and special needs children in the test results. Children with intellectual disability scored the lowest in the domain of the use of speech and children with ASD on the behaviour rating scale.
Kobolt (2010) [14]	Estonia	case study	Master Thesis	Language development/ communication & behavioural assessment	PEP - R & Interview	10 children with PDD	The results showed that PEP-3 test developmental subtests results were similar to the maladaptive behaviour subtests results. Positively and strongly were connected all the PEP-3 test composites with caregiver report subtests included behaviour.
Demčenko (2010) [15]	Latvia	cross-sectional	Bachelor Thesis	Stakeholder experiences	PSIn & MGQ	70 mothers of children (with ASD N=35 & TD N=35)	Mothers whose children have ASD displayed higher indicators in both levels of stress and feeling of guilt compared with mothers of typically developing children.
Ustilaitė and Cvetkova (2011) [16]	Lithuania	qualitative	Journal Article	Stakeholder experiences	Semi-structured Interviews	11 parents of children with (CP N=1, ASD N=3, DS N=6, ID=1)	Positive experiences of parents raising disabled children: 1) feelings: emotional bond 2) inner parent's growth: changed perception of life 3) family relationship: common goals in family 4) spiritual resources: less worry about material wealth.
Ustilaite, Kuginyte - Arlauskiene, and Cvetkova (2011) [17]	Lithuania	qualitative	Journal Article	Stakeholder experiences	Semi-structured Interviews	8 parents of children with DD	Child disability supposes the change of parental expectations that create fear about the future of the family, problems of reconciliation with the fact of a disability; however certain families are mobilized by such a situation.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Vaičekauskaitė (2011) [18]	Lithuania	qualitative	Journal Article	Intervention Non-pharmologic	Structured Interview & DAT intervention	10 mothers of children (CP N=2, AS N=2, DS N=2, ASD N=2 & ID N=2).	Dolphin Assisted Therapy sessions helped families to face and identify their needs more precisely, moreover families felt empowered and motivated.
Tupits (2012) [19]	Estonia	quasi-experimental	Bachelor Thesis	Intervention Non-pharmologic	TEACCH	23 participants (children with ASD N=12, parents of children with ASD N= 8 & teachers N=3).	Results showed no statistical difference between dictate and reading exercise between research and controls groups. However, students' behaviour improved, they became more independent and motivated.
Medvedeva (2012) [20]	Latvia	quasi-experimental	Master Thesis	Intervention Non-pharmologic	LDI & MIS	17 children with ASD	The results of this study suggest that body imitation skills as well as imitation with objects correlate with expressive language in children with autism.
Dekšeniece (2012) [21]	Latvia	case study	Bachelor Thesis	Language development/ communication	Pictograms	3 boys with ASD	Pictograms help children with autism perceive the contents of ethical teaching and communicate with surrounding people.
Tamošūnienė et al. (2012)[22]	Lithuania	case-control study	Journal Article	Behavioural Screening	PEDI & questionnaire developed for this study	66 children (with ASD N=33 & TD N=33)	Comparison with control group showed that 91% (N=30) of children with ASD developed self-help skills later than their peers ($p<0.05$). The most prominent delay was determined in the areas of toilet skills and personal hygiene skills.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Žaromskytė (2012) [23]	Lithuania	qualitative	Master Thesis	Stakeholder experiences	Interviews	76 participants (parents of children with ASD N=7, professionals N=7, education specialists N=60, children with ASD N=2)	According to the parents, the socialisation of their children is limited by the frequent anger attacks. The parents emphasise that in the course of raising of the ASD child, they need help from relatives and family members. The educational specialists considered that parents had to be interested in new educational trends. Both specialists and parents sought for collaboration implementing the educational goals set.
Sejuniene (2012) [24]	Lithuania	cross-sectional	Master Thesis	Service Delivery/ Systems of Care	Online Questionnaire	204 participants (speech therapists N=107, parents N=42, teachers N=19, paediatricians N=5, psychologists N=13 and other N=18)	Paediatricians have a lack of knowledge about autism and the methods of education for children with ASD, but they should be the first to find out autistic traits. The majority of teachers write individual programs for children with ASD, but generally they work at the same time with whole class children. Parents and teachers want that the children with ASD be educated individually.
Petrulyte et al. (2012) [25]	Lithuania	cross-sectional	Journal Article	Gastrointestinal	Questionnaire developed by the authors	44 parents of children with DD: severe & moderate feeding problems N=17, mild feeding problems N=19 & no feeding difficulties N=8.	Parents 'confidence during the feeding process was lower in both study groups than in the control group. Satisfaction during feeding was experienced by 63% of parents in the mild feeding difficulties group and 5% of parents in the group of moderate/ severe feeding difficulty group.
Jegorova-Marcenkiene et al. (2012) [26]	Lithuania	cross-sectional	Journal Article	Stakeholder experiences	EPDS	104 mothers (children with DD N=14, with PDS N=12, with LD N=5 & with MDD N=2)	33 (31.7%) of the mothers had an increased risk of depression. Statistically, these mothers were more likely to blame themselves when affairs were turning bad and they had the idea of self-harming more often than the mothers who didn't have signs of depression (p<.05).

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Petjarv (2013) [27]	Estonia	intervention	Bachelor Thesis	Intervention Non-pharmologic	Physiotherapy	14 boys with ASD	Physical activity improved the physical conditions and reduce maladaptive behaviours in children with ASD.
Terje (2013) [28]	Estonia	case study	Master Thesis	Education	Interview, PEP-R & IDP	1 boy with ASD	IDP team reached the following conclusions: it is necessary to structure the group room according to different activities; it is wise to visualise the daily schedule with the help of pictograms.
Loonum and Veldemann (2013) [29]	Estonia	cross-sectional	Bachelor Thesis	Gastrointestinal	6 open questions	41 parents of children with ASD	61% of parents had used one or more dietary intervention in the treatment of their autistic child. The most popular dietary intervention was the gluten-free and casein-free diet.
Bauze, Piekuse, et al. (2013) [30]	Latvia	cross-sectional	Journal Article	Biomarkers	Anthropometric measures	169 patients with ASD	According to anthropometric parameters, patients with ASD were found to be taller in height (p<.001); however, no significant differences in weight and head circumference were observed. Seizures were significantly more frequent in patients with severe mental retardation (p=.003).
Pentjuss et al. (2013) [31]	Latvia	cross-sectional	Journal Article	Molecular genetics	genetic analysis	235 human mitochodrics	It is found that deletion of SUCLG2 gene reduces the maximal production of ATP by 50% with wide flux variability range for most of the reactions.
Vaičekauskaitė and Acienė (2013) [32]	Lithuania	intervention	Journal Article	Intervention Non-pharmologic	SSC, PSI & BDC	8 children with ASD	The qigong massage statistically significantly improved speaking, sleeping, attention, concentration, communication for children with ASD and reduced aggression and tantrums.
Oie (2014) [33]	Estonia	literature review	Bachelor Thesis	Gastrointestinal	Nutrition tests	N/A	This study reflected that nutritional problems in autism differ from those resulting from dietary deficiencies. Suggestions for parents is to not use glutamine and regulate exercise activity for their children with autism

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Marii-Heleen (2014) [34]	Estonia	cross-sectional	Master Thesis	Stakeholder experiences	COPE, BDI & NEO	156 mothers of children (with ASD N=31, with DiA N=41, with AsT N=36 & TD N=48)	Results showed that mothers of chronically ill children had much higher BDI score (*M*=12.96, *SD*=10.03) than mothers of healthy children (*M*=7.59, *SD*=6.57). All five personality factors had significant and meaningful correlation with coping strategies.
Bauze et al. (2014) [35]	Latvia	cross-sectional	Doctoral Thesis	Clinical genetics	genetic analysis	169 patients with ASD	A statistically significant correlation was found between autism spectrum disorders and the SNP rs11212733 (*p*=0.008), which was localized in the 11q22.3 locus between DDX10 and EXPH5 genes.
Sarmite (2014) [36]	Latvia	qualitative	Bachelor Thesis	Education	Interview	4 professionals	The role of the multidisciplinary team and the basic principles of therapy work with ASD children found to be important in educating children with ASD.
Kreivinienė and Vaičekauskaitė (2014) [37]	Lithuania	systematic review	Journal Article	Intervention Non-pharmologic	Meta - analysis	N/A	Complementary and Alternative Medicine has a huge potential to help for families of children with disabilities.
Adomėnienė and Jurevičiūtė (2014) [38]	Lithuania	case study	Journal Article	Education	IDP	1 boy with ASD	A composed suitable educational content, which corresponds child faculties and potential capacities, influences developmental changes even for children with severe complex disabilities.
Serapinaitė (2014) [39]	Lithuania	mixed - methods	Master Thesis	Stakeholder experiences	Interviews & Questionnaires developed by authors	87 participants (teachers N=37, parents of children with ASD N=23, children with ASD N=23)	Children with ASD experience difficulty at school, they preferred to be alone, had substantial difficulty in expressing themselves. Parents stated that their biggest challenge is tantrums and behavioural problems, as also the unsupportive environment for such children.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Jurkštas and Pukelis (2014) [40]	Lithuania	qualitative	Journal Article	Stakeholder experiences	Semi-structured interviews	6 mothers of children with (DS N=5 & ASD N=1)	Key points that positively influenced mothers perception on their children: acceptance of help; efforts of parents or caregivers; the gift and efforts of a child with disabilities; fruits of nurturing a person with disabilities.
Labanauskaitė et al. (2014) [41]	Lithuania	cross-sectional	Journal Article	Intervention Non-pharmologic	BBS Berg Balance Scale, Dynamometry, Squat test & Sit up test	10 children with ASD	Balance, muscle strength and endurance of children with ASD were significantly lower than those in healthy children. Physical therapy significantly improved physical capacity of ASD children, but the level of healthy children was not reached.
Elis (2015) [42]	Estonia	case study	Bachelor Thesis	Education	Mathematical calculations methods	1 boy with ASD	pre- tests and post test results showed that using a “number-row” the student was able to perform calculations right 100% of the time and without the “number- row” in 17% of instances.
Zvingule (2015) [43]	Latvia	cross-sectional	Master Thesis	Adult Outcome: Vocational	AASQ, RSA & AAS	211 participants (ASD adults N=110 &TD adults N=101)	Results indicate that ASD correlates significantly with resilience, anxiety and depression. There is significant difference between resilience, anxiety and depression for unemployed with ASD compared with healthy adults. Unemployed with ASD had higher depression and anxiety with low resilience.
Vilkelienė and Kondrotienė (2015) [44]	Lithuania	case study	Journal Article	Intervention Non-pharmologic	Music Therapy	2 children with ASD (1 boy & 1 girl)	Music activities revealed interpersonal relations between young autistic adolescent and pedagogues through more active eye contact; young autistic adolescents started more actively communicating with gestures and body language.

Reference first author & date	Country	Research method	Publication type	Topic of Research	Tools used	Number of participants	Main Findings
Ustilaitė et al. (2015) [45]	Lithuania	qualitative	Journal Article	Stakeholder experiences	Interviews	12 parents of children with (CP N=1, ASD N=1, DS N=6, ID N=2)	Family counselling, the communication and cooperation of the family with various specialists and other families having similar experience is a prerequisite guaranteeing a better quality of life for children with disability and their parents.
Baškienė (2015) [46]	Lithuania	mixed - methods	Master Thesis	Service Delivery/ Systems of Care	Interviews & Questionnaires developed by authors	77 participants (parents of children with ASD N=7 & social workers N=70)	The most appropriate place to provide social services for a family having a child with ASD is a child day care centre. The main roles played by the social workers are informant, consultant, and educator. The most important aspects of organised activities are social interaction and the development of social skills through the playing.
Lelde (2016)[47]	Latvia	literature review	Master Thesis	Intervention Non-pharmologic	Pedagogical Methods for Socialization	N/A	The process of socialisation of children with ASD aged 7-10 can be successful if on the first hand the children are going to be observed continuously in order to choose the most appropriate methods what can improve the socialisation abilities of children.

Note: Legend of Table 4.***Questionnaires***: AASQ - Adult Autism Spectrum Quotient; AAS - Achenbach Adult Self Report; BBS - Berg Balance Scale; BDC - Bunse Developmental Checklist; BDI - Beck Depression Inventory; CARS – Childhood Autism Rating Scale; CDS - Cung's Depression Scale; COPE - Coping Inventory; DAT - Dolphin Assisted Therapy; EPDS - Edinburgh Postnatal Depression Scale; IDP - Individual Development Plan; LDI - Language Development Inventory; MIS - Motor Imitation Scale; MGQ - Maternal Guilt Questionnaire; NEO – Personality Inventory; PEP-R – Psycho-educational Profile Revised; PEP3 - Psycho-educational Profile Third Edition; PEDI - Paediatric Evaluation of Disability Inventory; PSI – Parental Stress Index; PSIn - Parenting Stress Inventory; RSA - Resilience Scale of Adults; SSC - Sense and Self-Regulation Checklist; SS - Self-independence scheme; TEACCH - Treatment and Education of Autistic and Communication related handicapped Children. ***Diagnosis***: AS – Asperger's syndrome; ASD – Autism spectrum disorder; AsT – Asthma; CA – Chronic allergies; CP – Cerebral palsy; DiA – Diabetes; DD – Developmental disorder; DS – Down Syndrome; Hcy – Hyperhomocysteinemia; ID – Intellectual disability; LD – Language disorder; PDD – Pervasive Developmental Disorder; MDD – Motor Development disorder; SCZD – Schizophrenia; TD – Typically developing.

2.3.1 Epidemiology

This review revealed that the epidemiology of the ASD in this region is still not clear as only one study attempted to estimate the prevalence across three Baltic States. It was conducted in 1999 in Lithuania. During this study, 6018 school children in 14 randomly selected secondary schools and 252 classes in Vilnius district were recruited for the study (Lesinskienė and Pūras 2001). Out of 133 children found with a diagnosis of ASD, there were 36 cases of Asperger's, 38 cases of moderate ASD and 59 cases of severe ASD. The research was conducted 17 years ago and requires updated results with the wider Lithuanian population. No epidemiological studies were found in Latvia or Estonia. Therefore, prevalence of ASD across the Baltic countries remains unaddressed (Querdenker and Meirhofer 2014).

2.3.2 ASD and Education

Different measurements were used to assess children with ASD. There were questionnaires designed by the researchers to measure individual accomplishments and social behaviours of children with ASD in a school setting. Also, prior validation or psychometric properties of the designed questionnaires were not presented (Astrauskienė 2008; Terje 2013; Priede 2009). Psycho-Educational Profile (PEP) and Paediatric Evaluation of Disability Inventory (PEDI) tests were used to evaluate the children's independence skills. These tools were not validated in these populations (there were fewer studies assessing the children's behaviour or well-being) (Kobolt 2010; Karen 2010; Tamošūnienė et al. 2012).

The characteristics of ASD were studied in parallel with schooling experiences Lack of integration of children with ASD to mainstream schools

was investigated too. The questionnaires were used to evaluate the child's abilities when undertaking group work (Priede 2009) individual programs (Terje 2013; Adomėnienė and Jurevičiūtė 2014), mathematical lessons (Elis 2015), and socialization programs (Lelde 2016). The review revealed that children learn social norms more effectively in regular schools than special schools (Astrauskienė 2008; Ivonytė, Kavaliauskienė, and Sąlyga 2009; Priede 2009; Karen 2010; Lelde 2016; Žaromskytė 2012; Baškienė 2015). Other studies claimed that adapted or special programs are less stressful for the child and more productive in process (Dekšeniece 2012; Medvedeva 2012; Pociute 2012; Tamošūnienė et al. 2012; Terje 2013; Adomėnienė and Jurevičiūtė 2014; Sarmite 2014; Vilkelienė and Kondrotienė 2015). Other developmental problems of children with ASD were not studied in the Baltic countries. There is still a need for more elaborate studies on understanding the relevant educational practices for children with ASD in schools and teachers' experiences of working with these children.

2.3.3 Medical Research

There were two genetic studies that concentrated on possible genetic causes of ASD (Pentjuss et al. 2013; Bauze et al. 2014) and two studies concentrated on biological differences in children with ASD (Kevere et al. 2009; Bauze, Kevere, et al. 2013). One study compared frequency of hyperhomocysteinemia between patients of schizophrenia and ASD with the results revealing that hyperhomocysteinemia is more common in ASD than schizophrenia (Bauze et al. 2014). However the study did not use typically developing individuals as controls. According to Guo et al. (2009), hyperhomocysteinemia is a congenital condition with an abnormally high level

of homocysteine in the blood. The homocysteine is responsible for the vitamin B_6, B_9 and B_{12} production in the body (Miller et al. 1994). The other study concentrated on anthropometric parameters and found that children with ASD were taller in height compared to TD (Bauze, Kevere, et al. 2013). Four studies underlined a lack of studies concerning biomarkers of ASD across Baltic countries.

The review also highlighted interest in research on diets and digestion for children with ASD in the Baltic States. The study by Lesinskienė, Vilūnaitė, and Packevičiūtė (2002) showed that children with ASD suffer from more digestion problems compared to TD, which was highly correlated with poor sleep. Moreover, studies by Loonum and Veldemann (2013) as also by Oie (2014) found that diet interventions like glutamine- or casein- free diets are common practices among parents of children with ASD. The above findings showed that dietary treatments are used to influence the child's development and behaviour, which is a common finding in Western research (Emond et al. 2010; Whiteley et al. 2010).

The review found limited studies on the experience among medical services concerning children with ASD. The studies revealed a lack of knowledge about Autism among emergency doctors (Lesinskienė et al. 2002) and general practitioners (Pociute 2012). In addition, it highlighted the need to provide adapted medical services and home visits for families with children with ASD (Lesinskienė et al. 2002). These above-mentioned studies revealed that medical personnel in Baltic countries require more teaching on ASD and its characteristics as well as the need to draw their attention to alternative ways of delivering treatment for these children.

2.3.4 Parenting

I found that there is interest in research on parent's mental health based on levels of stress, depression, and anxiety. Results highlighted that parents of children with ASD experienced statistically higher levels of stress, depression, and anxiety compared with control groups (Matonytė 2015; Mickevičienė, Šinkariova, and Perminas 2009; Demčenko 2010; Stina 2013; Marii-Heleen 2014). In cross – sectional studies that compared parents of children with ASD with parents of typically developing children, stress or depression were more common in those with children with ASD and this correlated with the children's behavioural difficulties. These findings are supported by previous research findings (Sharp, Burrell, and Jaquess 2014; Hamlyn-Wright, Draghi-Lorenz, and Ellis 2007).

Another area highlighted in review findings was parenting qualities and skills while raising child with ASD (Ivoškuvienė and Urbutytė 2008; Ustilaitė and Cvetkova 2011; Ustilaite, Kuginyte -Arlauskiene, and Cvetkova 2011; Žaromskytė 2012; Pociute 2012; Serapinaitė 2014; Jurkštas and Pukelis 2014; Ustilaitė et al. 2015). A study by Ivoškuvienė and Urbutytė (2008) found that mothers use positive affirmation, while fathers use punishment and criticism in parenting their child. Research by Lesinskienė, Vilūnaitė, and Packevičiūtė (2002) evaluated the grandparents' perception of their grandchild with ASD and revealed that grandmothers are more positive towards their grandchild than grandfathers. In addition, research showed the parents experience difficulty in raising children with ASD and require higher levels of support from society (Ustilaite, Kuginyte -Arlauskiene, and Cvetkova 2011; Žaromskytė 2012; Serapinaitė 2014; Jurkštas and Pukelis 2014) and professionals

(Pociute 2012; Ustilaitė et al. 2015; Baškienė 2015). Despite difficulties in parenting children with ASD, there were two studies that highlighted on positive aspects of raising children with ASD (Ustilaitė and Cvetkova 2011; Labanauskaitė et al. 2014).

These findings require further research on possible external factors of stress, depression, or anxiety among parents of children with ASD as causation is yet to be determined. There is a lack of studies on coping or protective mechanisms that could be useful in addressing high levels of stress, anxiety or depression in parents of children with ASD.

2.3.5 Autistic Adults

There was only one study of adults with ASD (Zvingule 2015), which attempted to define mental health and resilience factors in the population of adults with ASD. Results indicated that unemployed adults with ASD were more anxious and depressed compared to unemployed healthy controls. Also, adults with ASD had lower levels of resilience compared with controls. This scoping review showed that there is a large gap of research about education, work, relationships, personal development, or support for adults with ASD.

2.3.6 Treatments and Interventions

I found studies on various alternative therapies and interventions used across three countries such as: art (drawing) (Lesinskiene 2002), homeopathic medicine (Vaičekauskaitė, Kreivinienė, and Tilvikas 2014), body imitation (Medvedeva 2012), qigong massage (Vaičekauskaitė and Acienė 2013), dolphin therapy (Kreivinienė and Vaičekauskaitė 2014), occupational health (Elis 2015), and music therapy (Ustilaitė et al. 2015). Results of most therapies showed a statistically significant change in the child's behaviour, physical

health, and self-independence and social skills. It is important to state that homeopathic medicine was mainly researched as a potential “cure” for ASD symptoms. This could be attributed to the societal perception that ASD is an illness that can and should be “cured” rather than treated, and alternative medicine is seen as more acceptable than traditional medicine (Mikulėnaitė and Ulevičiūtė 2004).

Interventions used in these Baltic countries were TEACCH (Tupits 2012), pictograms (Dekšeniece 2012), and physiotherapy (Ivonytė, Kavaliauskienė, and Sąlyga 2009; Stina 2013). Study results showed that there was no significant difference between the intervention group and control group in reading and dictating when using TEACCH. The study that used pictograms found improvement in the communication skills of children with ASD. Physiotherapy resulted in advanced self-independence skills among children with ASD. Findings about the TEACCH program in the review do not support wider findings on this intervention, which include significant improvement in communication and social behaviours (Panerai, Ferrante, and Zingale 2002; Virues-Ortega, Julio, and Pastor-Barriuso 2013). It is important to highlight that there is no data on the usage of medical treatments that are available in Baltic States.

2.4 Discussion

This review has mapped the existing research on ASD across Baltic countries and also revealed the issues related to ASD that exist in this region. The review found that there is a lack of epidemiological studies. Therefore, it is hard to determine ASD prevalence in the Baltic States. Also, the lack of epidemiological studies limits the understanding of ASD’s burden on individual

countries and hinders the development of governmental policies to address the ASD related issues such as adapted schooling programmes for ASD children. This is a common issue highlighted by similar systematic reviews on ASD research conducted in Africa, East Asia and South America. The researchers encouraged future studies to close the knowledge gap on ASD prevalence and concentrate the research on treatment and interventions (Alnemary 2017; Hossain et al. 2017; Franz et al. 2017).

In Baltic countries, the most developments in research were made on parental experiences and the education of ASD individuals. In contrast, the systematic review across Arabic countries demonstrated that the biological underpinnings of ASD was the most common research area N=49/132 (34.5%), with fewer studies addressing treatment/interventions N=20/132 (14.1%) or parental experiences N=12/132 (8.5%). Assessing the publications in Baltic region showed high disparity of research outputs. Nevertheless the investment in meeting the needs of individuals with ASD and their families is more advanced in Baltic countries compared to other countries in Middle East or Africa where such research is low (Hossain et al. 2017; Alnemary 2017; Franz et al. 2017).

The review found a lack of peer-reviewed publications; half of the studies were university theses. The issue with University theses is that they are inaccessible by the general public or the wider research community, because access is given only to members associated with specific University libraries. This lack of access complicated the development of research as it is difficult to identify the existing knowledge on ASD and the geographic distribution thereof. The lack of peer-reviewed and reachable publications in

the Baltic States promotes difficulty in creating change. It is especially difficult for families to advocate for the need and ask the government for support, when evidence is not visible.

In comparison, South American and Arabic systematic reviews on ASD research have produced high volumes of peer-evaluated publications. For example, across Arabic countries 6% (0.23 articles/million population) of the global output of ASD research (3.65 articles/million population) is produced, while in Brazil alone it's 2% (0.07 articles/million population). This allows for more constructive change and access for different stakeholders to demand change. Nevertheless, it is important to underline that for example in Brazil and Arabic countries there is more need to acknowledge the mental health difficulties which puts constraints on ASD research. These constraints include a general lack of funding and infrastructure such as staff, administrative arrangements, and legal frameworks. In contrast, in Baltic countries, staff and administrative arrangements are present, but poorly developed (Ruškus and Gudavičius 2018).

Finally, the existing studies tended to have small samples and use cases to describe ASD in education, medicine, and family studies. The lack of bigger cohorts makes it difficult to refer to causation or predictors of ASD and impede generalisability of the results. Also, there is a lack of longitudinal data that could provide information of the life-long effects of ASD, which another common gap in ASD research across different regions of the world (Hossain et al. 2017; Alnemary 2017; Franz et al. 2017).

2.5 Strengths and Limitations

This scoping review is a first analysis of the situation of ASD in Baltic countries. This paper revealed the deficiencies in the research areas and lack of services around ASD in Lithuania, Latvia and Estonia. The limitations of this review were the restricted access to the papers that are published, and the language barrier as some theses were published in the language that the authors of this review do not speak (Estonian and Latvian).

2.6 Implications

This review revealed that ASD is a severely under-researched area in the Baltic region. The social aspects of ASD (education experience and parenting) are the most intensively researched areas across three countries, while the medical aspects (treatments, interventions, and services) are severely behind the current research in the rest of the world. For future research, it is important to consider studying the lives of adults with ASD across the Baltic States. Biological research is of great importance in advancing the knowledge of ASD symptomology, however, the priorities of Baltic countries should be set by the interests of the stakeholders (parents or professionals), as this is more valuable research as a basis for improving treatment and support for ASD, rather than simply satisfying researchers' curiosities. Therefore, the primary aim should be to assess existing interventions by validating and adapting them to the Baltic countries' populations. The next chapter is driven to understand the stakeholder experiences, especially in terms of parental stress. It has been demonstrated that parental stress is higher in the ASD group, however this has not been further explored in the Lithuanian cohort. Before embarking on parental stress

research, I was keen to understand the existing instrument of parental stress and evaluate them on psychometric properties (validity and reliability), responsiveness and cultural sensitivity. Choosing adequate instruments is pivotal for the production of high quality research. Therefore, I used systematic review to meticulously analyse the instruments of parental stress that are used in ASD research and assess which one would be the best fit for the Lithuanian population.

Chapter 3. Systematic Review: on Tools of Parental Stress in Neurodevelopmental Disorders

3. Background

The previous chapter has demonstrated gaps in research when it comes to ASD in Lithuania. One of the findings was a lack of research on parental experiences in raising ASD children. In order to fill in the gap I decide to evaluate the best existing tool for measuring parental stress that would be appropriate to use in an Eastern European context.

A variety of tools are used to measure parental stress in clinical and research areas (Deater-Deckard 2004; Yirmiya and Shaked 2005). They vary by the scales of the questionnaire used and the parent/patient groups that are examined. It is still unclear which tools are robust and which is most appropriate for its cultural context. There are no gold standards for the measure of parental stress, with which to compare tests of parental stress (Bonis 2016; Deater-Deckard 2004; Uhrskov 2013). Therefore, it is difficult to compare results of studies that research the same construct but use different questionnaires to measure it. In particular, external validation is problematic as there is still controversy about the influence or even causes of parental stress (Pisula 2011b). In addition, culture may greatly influence how people comprehend and define parental stress (Deater-Deckard 2004; Uhrskov 2013). However, few studies report about parental stress measured across different cultures. This might be partially the result of the limited number of psychological measures developed and validated for different countries (Tsang, Royse, and Terkawi 2017). Finally, there is variation in how professionals organise and interpret the scales of analysis that are used.

3.1 The Aims of the Study

We conducted a systematic review of the tools used to measure parental stress in parents of children with ASD using the PRISMA guidelines (http://www.prisma-statement.org/). The research questions of the review concern the instruments for measuring stress in parents of children with ASD:

- which have the best psychometric properties (i.e. validity and reliability)?
- which can measure changes in parental stress (i.e. responsiveness)?
- which are culturally sensitive and can be used appropriately in different cultures (i.e. variety in race, education, gender)?

3.2 Methods

There are two major diagnostic classification systems for mental and behaviour disorders in current use: The Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association, and the International Classification of Diseases (ICD) published by the World Health Organization. Each includes the neurodevelopmental disorders affecting movement, speech, language, and specific academic learning; and in addition, autism spectrum disorder (ASD) (in ICD-10 known as pervasive developmental disorders). The autism spectrum disorder definition used in this study was based on the two manuals.

3.2.1 Data Sources and Search Strategy

A three-step search strategy identified the published scientific articles to be included in this systematic review. Firstly, the review questions were broken into search elements: parental stress, disorders studied, instrument,

validity, reliability, cultural sensitivity, outcomes, participants, key words, and language (*Table 5, see next page*). Secondly, we included studies published from 1996 to 31st October 2018 to coincide with the publications of current international classifications: DSM–IV and ICD–10. Search elements yielded a number of papers around the area of interest using these databases: PubMed (1996 – 31/10/2018), PsycINFO (1996 – 31/10/2018), and EMBASE (1996 – 31/10/2018). Each search consisted of primary and secondary searches. The key components of the search were parental stress, age group, and tool name. The third step was to evaluate titles and abstracts based on inclusion and exclusion criteria. The study designs chosen were interventions, observational studies, and mixed-design. Furthermore, if multiple articles were published from the same study, the most comprehensive paper was used to avoid duplication. The final papers for the review were chosen after reading through the full text.

Table 5. The search strategy of the review

Topic	Key Words	Results PubMed	Results PsycINFO	Results EMBASE
Primary search				
	Autism; parent*	4816	25217	9053
	Autism; stress*	1964	10 163	4190
	Autism; parent* stress	630	2389	494
Secondary search	Autism; parent* experience	409	5316	43
	Autism; child*; stress	374	5125	2371
	Autism; parent*stress; symptom severity	155	409	23
	Autism; parent*stress; management	68	567	58
	Autism; parent*stress; coping strateg*	50	416	21
	Autism; parent* stress; support	378	3430	155
	Autism; parent* stress; resource	39	4231	43
	Autism; parent* stress; challenging behav*	274	708	2
	Autism; parent* stress; diagnosis	212	4279	129
	Autism; parent*stress; validity	17	978	22
	Autism; parent*stress; reliability	10	450	7
	Autism; parent* stress; responsiven*	13	0	13
	Autism; parent* stress; cultur*	24	0	5
	Pervasive developmental disorder; parent* stress	484	1291	24
	Pervasive developmental disorder; parent* experience	306	1476	2
	Pervasive developmental disorder; child*; stress	998	2493	96
	Pervasive developmental disorder; parent*stress; symptom severity	18	2	1
	Pervasive developmental disorder; parent*stress; management	60	15	1
	Pervasive developmental disorder; parent*stress; coping strateg*	43	6	2
	Pervasive developmental disorder; parent* stress; support	320	22	6
	Pervasive developmental disorder; parent* stress; resource	22	225	1
	Pervasive developmental disorder; parent* stress; challenging behav*	276	11	0
	Pervasive developmental disorder; parent* stress; diagnosis	182	183	9
	Pervasive developmental disorder; parent*stress; validity	15	42	0

Topic	Key Words	Results PubMed	Results PsycINFO	Results EMBASE
	Pervasive developmental disorder; parent*stress; reliability	8	29	0
	Pervasive developmental disorder; parent* stress; responsiven*	10	0	0
	Pervasive developmental disorder; parent* stress; cultur*	18	0	2
	Asperger's; parent* experience	6	1569	0
	Asperger's; child*; stress	28	2519	35
	Asperger's; parent*stress; symptom severity	0	2	0
	Asperger's; parent*stress; management	1	32	0
	Asperger's; parent*stress; coping strategies	3	16	0
	Asperger's; parent* stress; support	9	5106	2
	Asperger's; parent* stress; resource	1	1326	0
	Asperger's; parent* stress; challenging behav*	0	1358	0
	Asperger's; parent* stress; diagnosis	5	315	2
	Asperger's; parent*stress; validity	1	2194	0
	Asperger's; parent*stress; reliability	0	18	0
	Asperger's; parent* stress; responsiven*	0	1326	0
	Asperger's; parent* stress; cultur*	0	1120	0

3.2.2 Inclusion Criteria

Studies were included in the review if they met the following inclusion criteria:

- the participants of the study were parents of children diagnosed with Autism Spectrum Disorder (classical autism, child autism, pervasive developmental disorder, pervasive developmental disorder non-specified, Asperger's);
- all studies in which at least 50% of children included had ASD clinical diagnosis, according to ICD-10 or DSM-IV criteria;
- studies used standardised questionnaires meaning they were written and administered identically to all respondents and records are in a uniform manner (Lavrakas 2008);
- psychometrics of the questionnaire were presented for the given sample;
- studies were in English, French, Russian or Lithuanian, languages understood by the authors.

3.2.3 Exclusion Criteria

Studies were excluded if they had one of the following criteria:

- the research reported general stress questionnaires to measure parental stress, since general stress is influenced by a variety of factors and is not parent specific;
- they reported parents of adults with ASD;
- if the sample consisted of children below the age of 2 years because a definitive diagnosis for ASD is rarely given before this age (Bölte 2014; Johnson et al. 2015; Yirmiya and Shaked 2005);

- a qualitative design was used e.g. interviews, focus groups, case studies, as questionnaires are used mainly with quantitative methods;
- they were not research papers (i.e. book);
- the outcomes measured were biophysical (i.e. medical investigations) or experimental tasks (i.e. reaction time).

3.2.4 Evaluation Criteria

The online abstracts were reviewed; those that met the above-mentioned criteria were further screened using the full text of the records and the final selections were obtained. Inclusion criteria and analyses of the data were specified a priori and documented in a protocol and registered in PROSPERO database (Nr.116176).

The selected articles were evaluated on these criteria:

- *Reliability*. Test-retest, split half and inter-rater reliability are usually presented in correlation analysis using general standards: 0–0.2 signifies poor agreement; 0.3–0.4 signifies fair agreement; 0.5–0.6 is moderate agreement; 0.7–0.8 strong agreement; above 0.8 indicates perfect agreement (Carmines and Zeller 1979; Litwin 1995). The results of the scale were compared with accepted standards in research. Another method is internal consistency, which is usually reported by Cronbach's alpha. Low alpha levels are 0.6–0.7, acceptable are 0.7–0.8, good are 0.8–0.9 and excellent are >0.9 (Hair et al. 2014). Test-retest determines if the measurement consistently produces the same results between different time points or conditions. The test-retest reliability is evaluated using correlations across different time points or

conditions. Another method is split-half reliability when you split tests into two parts and then both parts are given to a participant at the same time. The scores from both parts of the test are correlated (Hair et al. 2014).

- *Validity*. We looked for construct and criterion validity. Construct validity determines if the scale is measuring the construct it was designed to measure (DeVellis 2012). Construct validity is determined using correlations or regression models between the scale of the studies or psychological standards. Criterion validity indicates to which extent a tool is related to an outcome and its measurement (DeVellis 2012). The Criterion validity is measured using the mean differences between known groups and magnitude (absolute or relative) based on priori hypothesis.
- *Responsiveness*. Responsiveness indicates if the scales are capable of detecting change after intervention. The measure would only detect change in the context of an effective intervention. In other words, a tool that measures parental stress at different points in time is counted successful if they are able to detect the change of the outcome. The best way to evaluate responsiveness is through change of scores in the construct measured over time, i.e. longitudinal studies (Olive and Franco 2007).
- *Cultural sensitivity*. According to the American Psychological Association ethics code, culturally sensitive instruments are required to be established in the group for which the measure is intended (Knapp and Vandecreek 2003). To avoid test bias, participants have to take

tests in their preferred language and be motivated to respond accurately (Tran 2009). Items of the test must be appropriate and of equal difficulty for individuals of the same age, regardless of their ethnic background. Measures should be evaluated cross-culturally, use translation equivalence (index of accuracy of the translation), and have the same conceptual equivalence across different cultures (Tran 2009).

- *Clinical Range*. This shows the ability of instruments to differentiate between clinical and non-clinical samples. This identifies the content of the sample and provides information about the differences between groups. In general, parental stress scores above the 85th percentile in identifying participants who are experiencing clinical levels of parental stress. This is the reason it is thought that the questionnaire can detect stress in parents beyond manageable or coping point (Deater-Deckard 2004).

3.2.5 Data Extraction and Data Items

For data extraction, every paper was read and data from the papers was entered into an Excel (Microsoft, USA) spreadsheet to synthesize it. There was a total of 630 studies found whose abstracts included the constructs of parental stress and autism (*Figure 2*). Data synthesis was conducted in three stages. Firstly, articles were read and those that had the required criteria (reliability, validity and cultural sensitivity) were recorded. Secondly, remaining articles were put in the spreadsheet using the first author, year of publishing, country of research, sample size, questionnaire used, study design, and key findings.

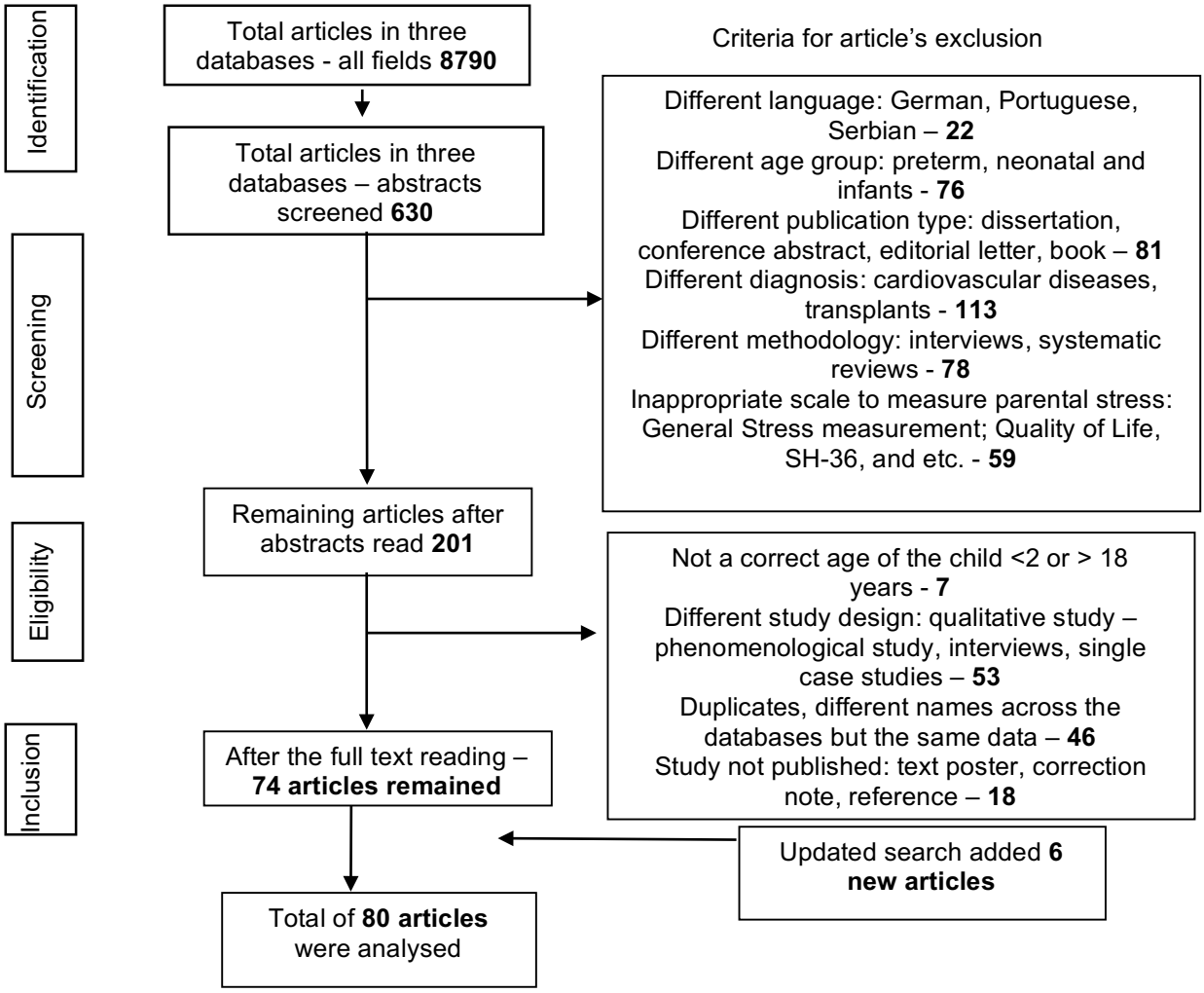


Figure 2. Flowchart of systematic review, data extraction

We reported the total scores of the parental stress instrument as well as the statistical analysis performed using the scores of the test. For example, if it was a cross-sectional study between mothers and fathers of children with ASD, then investigators reported the means and standard deviations of the parental stress for mothers and fathers and the results of the statistical test including p–values.

3.2.5 Inter-rater Reliability of Reviewers

All papers were reviewed by R. Buivydaite (RB), and 10% of the papers were reviewed by C. Newton (CN) for data extraction based on the pre-piloted

data extraction form. Then, reviewers met to discuss the results. If there were inconsistencies between RB & CN, they were resolved through discussion and review of the paper. Given the large between-study heterogeneity in the exposure and outcome of interest, as well as in the population studied and statistics being used, a meta-analysis was considered to be inappropriate and a narrative synthesis of aggregated and individual study findings was conducted (Borenstein 2009).

3.2.6 Risk of Bias

Only studies with languages that the researchers could speak were included. The choice of the databases was made based on the topic covered, thus, smaller databases were not checked. As a result, researchers could have missed papers due to limiting the languages and databases used. The most common tool used to assess the risk bias is Cochrane risk of bias, however it is used for randomised control trials, which was not relevant for the data extracted in this systematic review.

3.3 Results

8790 abstracts were identified during the initial screening, of which 201 were selected for full text review. After reading the full text of the records, 124 were excluded because they did not meet the inclusion criteria: age range (<2 or >18 years) *N*=7, study design (qualitative, case studies and etc.) *N*=53, publication type (text poster, correction note, reference) *N*=18, duplicates *N*=46. Overall, 80 articles were chosen for analysis and review.

3.3.1 Demographics

Most of the studies were conducted in North America (*N*=37) and Western Europe (*N*=24), with fewer studies from Eastern Europe (*N*=1), Asia

(*N*=7), the Middle East (*N*=5), and Australia (*N*=6). There were no studies identified from Latin America (including papers in Spanish) or Africa. The most common research methods used were cross-sectional (*N*=64), intervention (*N*=13), and longitudinal (*N*=3) studies. In 14 studies the primary purpose was to study children with ASD and screening parental stress was a secondary aim, while in 66 papers, parental stress was the primary focus. The mothers were the main participants in 22 studies. The remaining studies looked at both parents (*N*=46), however, the majority of respondents were mothers and only 35% of articles included fathers. The key outcomes studied and compared were: parent psychopathology (anxiety, depression & stress) (*N*=18), ASD characteristics (behavioural issues, communication challenges & etc., *N*=67), support and resources (*N*=21), and external factors (*N*=11) (*Table 6*). There is significantly less research on external factors (support, resources, bullying, stigma, etc.) of parental stress.

Table 6. Demographics of the articles reviewed

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Silva (2012) [1]	APSI	USA	Cross – sectional	One - time testing	274 children (ASD 107, DD 28, TD 139)	ASD (y) (M=3.85, Range 2-6), DD (y) (M=2.64, Range 2-5), TD (y) (M=3.98, Range 3-6)	ASD, DD, TD	ASD (M=22.9, SD=10.4), DD (M=11.8, SD=6.7) & TD (M=5.4, SD=5.2)	50.4% ASD, 23.6% DD & 7.1% TD were clinically stressed
Dunn (2001) [2]	PSI	USA	Cross – sectional	One - time testing	58 parents (mothers 39 & fathers 19)	Total (y) M=7.47, SD=3.31	ASD	N/R	No
Baker-Ericzen (2005) [3]	PSI	USA	Intervention	8 (m)	60 parents (ASD 37 & TD 23)	ASD (m) (M=28.35, SD=5.2), TD (m) (M=24.35, SD=5.03)	ASD & TD	N/R	59% ASD & 18% TD were clinically stressed
Dale 2006 [4]	PSI	United Kingdom	Cross – sectional	One - time testing	16 mothers	Total (y) Range 3 - 11	ASD	sample M=272.9, SD=38.9	50% of mothers were clinically stressed
Hoffman (2009) [5]	PSI	USA	Cross – sectional	One - time testing	446 mothers (ASD 104 & TD 342)	ASD (y) (M=8.61, SD = 2.77), TD (y) (M=8.03, SD=3.61)	ASD & TD	ASD (M=147.9, SD=25.7) & TD (M=94.8, SD=21.7)	No
Mori (2009) [6]	PSI	Japan	Cross – sectional	One - time testing	193 parents (ASD 163 & Asperger's 30)	Total (y) M=7.39, SD=2.77	ASD & Asperger's	Autism (M=92.1, SD=17.8) & Asperger's (M=101.5, SD=21.2)	No
Rao (2009) [7]	PSI & SIPA	USA	Cross – sectional	One - time testing	29 parents (ASD 15 & TD 14)	Total (y) M=10.6, Range 8-15	ASD & TD	ASD (M=266.7, SD=43.9) & TD (M=198.7, SD=46.1)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Quintero (2010) [8]	PSI	USA	Cross – sectional	One - time testing	43 mothers (ASD 20 & TD 23)	ASD (y) (M=4.35, SD=1.2), TD (y) (M=3.72, SD=0.71)	ASD & TD	ASD (M=215.5, SD=34.5) & TD (M=206.3, SD=50.0)	No
Ekas (2011) [9]	PSI	USA	Cross – sectional	One - time testing	119 mothers	Total (y) M=10.17, SD=4.28, Range 2-18	ASD	Sample M=24.8, SD=6.0	No
Fava (2011) [10]	PSI	Italy	Intervention	6 (m)	22 parents (IG 12 & CG 10)	IG(m) (M=52, SD=19.5), CG(m) (M=43.7, SD=26.9)	ASD	CG baseline (M=92, SD=13.1), 6(m) (M=94.3, SD=9.7) & IG baseline (M=88.7, SD=2.3), 6 (m) (M=81.0, SD=12.1)	67% IG group & 44% CG were clinically stressed
Gika (2012) [11]	PSS & PSI	Greece	Intervention	6 (w)	11 mothers	Total (y) Mdn=7.5, Range 4.5-17	ASD	Baseline Mdn=100, IQR=22-48; 6 (w) Mdn=77, IQR=51-114	No
Peters - Scheffer (2012) [12]	PSI - Dutch version	Netherlands	Longitudinal study	2 (y)	205 mothers (ASD 104 & IntD 101)	N/R	ASD & IntD	Baseline M=81.6, SD=26.7; T1 6 (m) M=85.0, SD=29.2; T2 1 (y) M=80.65, SD=25.9; T3 1.5 (y) M=83.1, SD=27.8; T4 2 (y) M=85.0, SD=28.1	36% ASD & 45% ID were clinically stressed
Welterlin (2012) [13]	PSI	USA	Intervention	12 (w)	12 families (IG 6 & CG 6)	Total (y) Range 2-3	ASD	IG baseline (M=254.1, SD=48.5), 12 (w) (M=242.4, SD=41.5) & CG baseline (M=244.5, SD=32.8), 12 (w) (M=256.2, SD=70.0)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Ichikawa (2013) [14]	PSI	Japan	Intervention	6 (m)	11 parents (IG 5, CG 6)	IG (m) (M=64, Range 60-66), CG (m) (M=62, Range 60-70)	ASD	Baseline IG (M=226.2, SD=31.5) & CG (M=198.2, SD=26.8); 6 (m) IG (M=213.0, SD=34.8) & CG (M=204.3, SD=36.3)	No
Zamora (2014) [15]	PSI	USA	Cross – sectional	One - time testing	116 children (girls 27 & boys 89)	Total (y) M=5.36, SD=3.34	ASD	Sample M=87.8, SD=23.1; Boy (M=86.6, SD=21.5) & Girl (M=92.0, SD=28.0)	No
Kerns (2015) [16]	PSI & SIPA	USA	Cross – sectional	One - time testing	59 children	Total (y) M=10.56, SD=2.75, Range 7-17	ASD	ASD Anxiety (M=0.4, SD=0.3) ASD Non-Anxiety (M=0.6, SD=0.3)	No
May (2015) [17]	PSI subscale	Australia	Cross – sectional	One - time testing	152 parents (mothers 80 & fathers 72)	N/R	ASD	Mothers (M=280, SD=43) & Fathers (M=276, SD=40)	No
Yun Gong (2015) [18]	PSI	China	Cross – sectional	One - time testing	332 parents (ASD 188 & TD 144)	Total (m) M=77.73, Range 23-144	ASD & TD	ASD (M=311.2, SD=7.9) & TD (M=246.1, SD=41.3)	ASD 91.9% & TD 42.6% were clinically stressed
Pastor-Cerezuela (2016) [19]	PSI	Spain	Cross – sectional	One - time testing	84 families (ASD 42 & TD 42)	Total (y) Range 5-8; ASD (m) (M=77.60), TD (m) (M=81.50)	ASD & TD	ASD (M=131.9, SD=27.8) & TD (M=112.1, SD=22.2)	No
Argumedes (2018) [20]	PSI	Canada	Intervention	3 (m)	47 parents (mothers 32 & fathers 15)	N/R	ASD	N/R	52% of total sample were clinically stressed

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Schiltz (2018) [21]	PSI	USA	Cross – sectional	One - time testing	77 parents (mothers 59 & fathers 15)	Total (y) M=13.58, SD=1.46	ASD	Sample M=212.8, SD=40.2	No
Kuhn (2006) [22]	PSI - SF	USA	Cross – sectional	One - time testing	170 mothers	Total (y) M=6.5, Range 2.4-10.8	ASD	Sample M=95, SD=23.1	No
Lecavalier (2006) [23]	PSI - SF	USA	Longitudinal study	2(y)	293 parents (mothers 252 & fathers 41)	Total (y) M=9.0, SD=3.4, Range 3-18	ASD	Baseline (M=95, SD=22.9), 2 (y) (M=94.4, SD=21.0)	58% of sample were clinically stressed
Davis (2008) [24]	PSI - SF	USA	Cross – sectional	One - time testing	108 parents (fathers 54 & mothers 54)	N/R	ASD	mothers (M=81.9, SD=21) & fathers (M=79.6, SD=19.3)	93% mothers & 28% fathers were clinically stressed
Brobst (2009) [25]	PSI - SF	USA	Cross – sectional	One - time testing	90 parents (ASD 25 dyads & TD 20 dyads)	ASD (y) (M=6.64, SD=2.66), TD (y) (M=6.80, SD=3.19)	ASD & TD	ASD mothers (M=101.7, SD=23.5) & fathers (M=92.8, SD=24.2); TD mothers (M=66.0, SD=16.2) & fathers (M=66.1, SD=16.1)	No
Lee (2009) [26]	PSI - SF	USA	Cross – sectional	One - time testing	135 parents (ASD 89 & TD 46)	ASD (y) (M=9.5, SD=2.0), TD (y) (M=9.7, SD=2.1)	ASD &TD	TD (M=192.5, SD=36.4) & ASD (M=226.3, SD=42.3)	No
Georgiades (2011) [27]	PSI - SF	Canada	Cross – sectional	One - time testing	335 children (2 (y) - 123, 3 (y) - 143, 4 (y) - 69)	Total (m) M=39.8, SD=9.0	ASD	N/R	No
Hall (2012) [28]	PSI - SF	USA	Cross – sectional	One - time testing	73 parents (mothers 50 & fathers 23)	Total (y) M=8, SD=4	ASD	Sample M=99.9, SD=23.2, mothers (M=102.8, SD=23.3) & fathers (M=92.2, SD=22.2)	62.7% of parents were clinically stressed

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Strauss (2012) [29]	PSI - SF	Italy	Intervention	6 (m)	44 children (IG 22 & CG 20)	IG (m) (M=55.67, SD=17.63) CG (m) (M=41.94, SD=13.07)	PDDS-NoS & ASD	Baseline IG (M=89.1, SD=26.0) & CG (M=91.7, SD=9.6); 6 (m) IG (M=91.6, SD=21.0) & CG (M=78.5, SD=17.4).	80% IG & 65% CG were clinically stressed
Wang (2013) [30]	PSI - SF	China	Cross – sectional	One - time testing	150 mothers	Total (y) M=5.15, SD=1.72	ASD	Sample M=105.09, SD=18.35	No
Dardas (2014) [31]	PSI - SF Arabic version	Jordan	Cross – sectional	One - time testing	184 parents (mothers 114 & fathers 70)	Total (y) M=6.3, SD=3, Range 2-12	ASD	Mothers (M=116.9, SD=22.5) & fathers (M=118.6, SD=22.6)	No
D'Elia (2014) [32]	PSI - SF Italian version	Italy	Intervention	2 (y)	30 children (IG 15 & CG 15)	IG (y) (M=4.1, SD=1.2), CG (y) (M=4.1, SD=1.3)	ASD	Baseline IG (M=84, SD=14) & CG (M=83, SD=12); T1 6 (m) IG (M=70, SD=14) & CG (M=68, SD=30); T2 1 (y) IG (M=74, SD=14) & CG (M=80, SD=17); T3 2(y) IG (M=58, SD=36) & CG (M=62, SD=30)	No
Feinberg (2014) [33]	PSI - SF	USA	Intervention	3 (m)	122 mothers (IG 59 & CG 63)	IG (m) (M=34, SD=10) CG (m) (M=34, SD=12)	ASD	Baseline IG (M=92.6, SD=20.1) & CG (M=97.0, SD=24.3), 3 (m) IG (M=85.5, SD=19.6) & CG (M=94.2, SD=25.6)	28% CG & 30% IG were clinically stressed

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
McStay (2014) [34]	PSI - SF Dutch version	Netherlands	Cross – sectional	One - time testing	204 parents (ASD 150 & TD 54)	ASD (y) (M=13.23, SD=2.98, Range 6.4-18.8), TD (y) (M=11.72, SD=2.77, Range 6-16.8)	ASD & TD	ASD (M=30.0, SD=9.4) & TD (M=20.7, SD=8.6)	No
Neece (2014) [35]	PSI - SF distress subscale	USA	Intervention	6 (m)	46 parents (IG 21 & CG 25)	Total (y) Range 2.4-5	DD (ASD 84%)	Baseline IG (M=35.2) & CG (M=38.3); 9 (m) IG (M=31.7) & CG (M=37.6)	No
Ozturk (2014) [36]	PSI - SF	Italy	Cross – sectional	One - time testing	90 parents (mothers 45 & fathers 45)	Total (m) M=87.5, SD=40.9	ASD	Mothers (M=74.9, SD=21.8) & fathers (M=74.2, SD=24.2)	49% mothers & 51% fathers were clinically stressed
Rivard (2014) [37]	PSI - SF	Canada	Cross – sectional	One - time testing	236 parents (118 parent dyads)	Total (y) M=4, SD=0.61, Range 2.9-5.1	ASD	Mothers (M=118.4, SD=20.2) & fathers (M=112.4, SD=21.2)	60.6% fathers & 54.1% mothers were clinically stressed
Samadi (2014) [38]	PSI - SF	United Kingdom	Cross – sectional	One - time testing	236 parents (ASD 121 & ID 115)	ASD (y) M=8.3, ID (y) M=12.6	ASD & ID	ID (M=102.5, SD=21.8) & ASD (M=117.6, SD=17.4)	No
Zaidman - Zait (2014) [39]	PSI - SF	USA	Cross – sectional	One - time testing	184 mothers	Total (m) M= 36.4, SD=6.6, Range 24-47	ASD	Baseline (M=2.4, SD=0.8), T2 (M=2.6, SD=0.8), T3 (M=2.5, SD=1.1)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Valicenti-McDermott (2014) [40]	PSI - SF	USA	Cross – sectional	One - time testing	100 parents (ASD 50 & DD 50)	ASD (y) (M=8.8, SD=3) DD (y) (M=9.2, SD=3)	ASD & DD	ASD (M=89, SD=24) & DD (M=72, SD=29)	50% ASD & 30% DD were clinically stressed
Dardas (2015) [41]	PSI - SF Arabic version	Jordan	Cross – sectional	One - time testing	101 fathers	Total (y) M=5.9, SD=3.2, Range 2-13	ASD	M=94.4, SD=19.3	No
Giovagnoli (2015) [42]	PSI - SF	Italy	Cross – sectional	One - time testing	312 parents (ASD 190 & TD 122)	ASD (m) (M=42.9, SD=9.2) TD (m) (M=42.4, SD=14.6)	ASD & TD	ASD (M=65.6, SD=29.4) & TD (M=31.1, SD=25.6)	50% ASD & 18% TD were clinically stressed
Izadi-Mazidi (2015) [43]	PSI - SF	Iran	Intervention	7 (w)	16 mothers	Total (y) M=7.5, SD=2.2	ASD	Baseline (M=1.2, SD=11.4) & 7 (w) (M=1.2, SD=10.1)	No
Minnes (2015) [44]	PSI - SF distress subscale	Canada	Cross – sectional	One - time testing	115 mothers (ASD 80, DD 40, DS 19, GD 16)	Total (y) M=4.9, SD=0.8, Range 3-6.9	ASD, DD, DS & GD	Sample M=2.74, SD=0.9	No
Postorino (2015) [45]	PSI - SF	Italy	Cross – sectional	One - time testing	60 children	Total (y) M=3.55, SD=0.9, Range 2-5.4	ASD	Baseline girls (M=73.2, SD=28.7) & boys (M=72.1, SD=24.1); T1 2 (y) girls (M=68, SD=24.4) & boys (M=63.9, SD=32.6)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Postorino (2015) [46]	PSI - SF	Italy	Cross – sectional	One - time testing	158 children (FS 79 & Non-FS 79)	Total (y) M=7.16, SD=2.05, Range 3-12	ASD (FS & Non-FS)	ASD FS (M=73.9, SD=25.3) ASD NoFS (M=54.4, SD=31.7)	No
Valicenti - McDermont (2015) [47]	PSI - SF	USA	Cross – sectional	One - time testing	100 parents (ASD 50 & DD 50)	ASD (y) (M=8.8, SD=3) DD (y) (M=9.2, SD=3)	ASD	ASD (M=89, SD=24) & DD (M=72, SD=29)	ASD 45% & DD 22% were clinically stressed
Craig (2016) [48]	PSI - SF	Italy	Cross – sectional	One - time testing	186 children (SpLD 60, LD 34, ASD 45 & ADHD 47)	SpLD (y) (M=10.3, SD=2.1), LD (M=4.8, SD=1.2), ADHD (M=9.3, SD=2.1), ASD (M=8.3, SD=3.6), TD (M=8.3 SD=2.5)	LD, SpLD, ASD, ADHD	Mothers SpLD (M=89.1, SD=7.3); LD (M=87.5, SD=10.5); ADHD (M=95.5, SD=4.1); ASD (M=96.7, SD=6.8); TD (M=62.8, SD=1.9) & fathers SpLD (M=88.3, SD=7.9); LD (M=82.3, SD=5.3); ADHD (M=97.4, SD=4.1); ASD (M=96.5, SD=5.6); TD (M=62.0, SD=2.3)	Mothers SpLD 55%, LD 70%, ADHD 91%, ASD 93%, TD 75%. Fathers SpLD 30%, LD 26%, ADHD 93%, ASD 87%, TD 45% were clinically stressed
Derguy (2016) [49]	PSI - SF French version	France	Cross – sectional	One - time testing	115 parents (mothers 73 & fathers 42)	Total (y) M=6.3, SD=2.3, Range 3-10	ASD	Sample M=101.6, SD=20.9	70% of parents (42 % mothers & 27% fathers) were clinically stressed

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Keenan (2016) [50]	PSI - SF	Australia	Cross – sectional	One - time testing	58 parents (ASD 24 & TD 24)	ASD (y) Range 7.2-14, TD (y) Range 7.2-12.9	ASD & TD	ASD (M=104.9, SD=19.2) & TD (M=63.9, SD=17.6)	No
Levin (2016) [51]	PSI - SF	Israel	Cross – sectional	One - time testing	65 parents (ASD 34 & TD 31)	Total (m) M=36.23, SD=5.75, Range 25-48	ASD & TD	ASD (M=89.9, SD=22.9) TD (M=58.8, SD=16.6)	No
Marshall (2016) [52]	PSI - SF	Australia	Cross – sectional	One - time testing	68 children (ASD 33 & NMC 35)	ASD (m) (M=52.1, SD=11.2), NMC (m) (M=48.7, SD=11.5)	ASD & (NMC)	ASD (M=87.4, SD=17.5) & NMC (M=60.1, SD=30.1)	69% ASD & 31% NMC were clinically stressed
Almogbel (2017) [53]	PSI - SF	USA	Cross – sectional	One - time testing	149 parents (ASD 93, ADHD 21 & DD 35)	Total (y) M=11.1, SD=4.5, Range 12-18	ASD, ADHD, DD	PSI - SF score <85 percentile (M=67, SD=13.9) & PSI - SF score >85 (M=109.4, SD=14.8)	70.6% of the sample were clinically stressed
Shawler (2017) [54]	PSI -SF	USA	Cross – sectional	One - time testing	130 parents (mothers 115 & fathers 15)	Total (y) M=8.57, SD=2.36, Range 3-11	ASD	Sample M=83.98, SD=18.7	37% of parents were clinically stressed
Telman (2017) [55]	PSI -SF Dutch version	Netherlands	Cross – sectional	One - time testing	228 children (AD 63, ASD 39, ADHD-C 62, ADHD-I 64 & TD 42)	AD (y) (M=11.73, SD=0.33), ASD (M=12.49, SD=0.57) ADHD-C (M=10.60, SD=0.33) ADHD-I (M=11.58, SD=0.38) TD (M=12.71, SD=0.39)	AD, ASD, ADHD & TD	AD mothers (M=54.7, SD=23.3), fathers (M=53.2, SD=23.6); ASD mothers (M=72.7, SD=23.0), fathers (M=75.6, SD=25.9); ADHD - C mothers (M=74.1, SD=21.2), fathers (M=64.5, SD=22.7); ADHD - I mothers (M=59.2, SD=21.0), fathers (M=51.8, SD=19.7); TD mothers (M=43.5, SD=19.5); fathers (M=39.9, SD=17.7)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Thullen (2017) [56]	PSI - SF	USA	Cross – sectional	One - time testing	112 mothers	Total (y) M=9.5, SD=2.5, Range 4-13	ASD	Sample M=96.6, SD=23.2	No
Zaidman - Zait (2017) [57]	PSI - SF distress subscale	Canada	Longitudinal study	2 (y)	283 mothers	Total (m) M=38.9, SD=8.6	ASD	N/R	No
Iadarola (2018) [58]	PSI -SF	USA	Intervention	24 (w)	180 children	Total (y) M=4.2, SD=1.1, Range 3-7	ASD	Parent training (PT) baseline (M=106.2, SD=19.0), 12 (w) (M=96.5, SD=20.7) 24 (w) (M=91.4, SD=19.6); Parent education (PEP) baseline (M=103.5, SD=17.9), 12 (w) (M=96.9, SD=17.6), 24 (w) (M=93.9, SD=19.4);	No
Lu (2018) [59]	PSI -SF	China	Cross – sectional	One - time testing	479 parents (mothers 277 & fathers 202)	Total (y) M=6.68, SD=3.79, Range 3-18	ASD	Sample M=100.4, SD=22.7	No
Hamlyn -Wright (2007) [60]	PSS	United Kingdom	Cross – sectional	One - time testing	619 parents (TD 131 ASD 265 & DS 223)	ASD (y) (M=13.51, SD=7.65), DS (y) (M=12.35, SD=7.43), TD (y) (M=12.35, SD=4.47),	ASD, DS & TD	TD (M=29.3, SD=9.1), ASD (M=45.7, SD=8.6) & DS (M=37.2, SD=10.4)	No
Firth (2013) [61]	PSS	Australia	Cross – sectional	One - time testing	109 mothers	Total (y) M=7.89, SD=2.43, Range 4-12	ASD	Sample (M=52.1, SD=11.0)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Tellegen (2014) [62]	PSS	Australia	Intervention	6 (m)	64 parents (IG 35 & CG 29)	IG (y) (M=5.66, SD=2.18) CG (y) (M=5.69, SD=2.12)	ASD	Baseline IG (M=42.7, SD=9.3) CG (M=43.8, SD=9.2), 6 (m) IG (M=42.4, SD=8.0) CG (M=44.2, SD=10.4)	No
Lovisotto (2015) [63]	PSS	Australia	Cross – sectional	One - time testing	45 parents (mothers 36 & fathers 9)	N/R	ASD	Sample M=52, SD=11.6; ABA M=16.03, EIC M=27.4, CG M=25.7	No
Hsiao (2018) [64]	PSS	USA	Cross – sectional	One - time testing	236 parents (mothers 203 & fathers 33)	Total (y) Range 5-18	ASD	Sample M=2.5, SD=0.6	No
Estes (2009) [65]	QRS	USA	Cross – sectional	One - time testing	73 mothers (ASD 51 & DD 22)	ASD (m) (M=43.88, SD=4.26) DD (y) (M=43.32, SD=4.44)	ASD & DD	ASD (M=2.3, SD=0.4) & DD (M=2.0, SD=0.4)	No
Makrygianni (2010) [66]	QRS	Greece	Cross – sectional	One - time testing	86 children	Total (m) M=79.6, SD=37.3	ASD	Sample M=26.4, SD=10.5	No
Wang (2011) [67]	QRS	China	Cross – sectional	One - time testing	340 parents (mothers 216 & fathers 124)	Total (y) M=11, SD=4.17	ASD	Sample Mdn=0.55, IQR=0.9-1.2	No
Estes (2013) [68]	QRS	USA	Cross – sectional	One - time testing	96 mothers (ASD 46, DD 25, TD 25)	ASD (m) (M=23.33, SD=3.85), DD (m) (M=22.36, SD=3.53), TD (m) (M=22.6, SD=3.11)	ASD, DD & TD	ASD (M=2.1, SD=0.3), DD (M=1.92, SD=0.3) & TD (M=1.7, SD=0.3)	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Jones (2013) [69]	QRS	USA	Cross – sectional	One - time testing	161 couples	Total (y) M=10.5, SD=2.93	ASD	Mothers (M=10.6, SD=5.2) & fathers (M=8.1, SD=5.1)	No
Padden (2017) [70]	QRS	United Kingdom	Cross – sectional	One - time testing	76 parents (ASD 38 & TD 38)	Total (y) M=7.34, SD=3.40	ASD & TD	ASD (M=32.1, SD=8.4) & TD (M=21.2, SD=5.6)	No
Reed (2017) [71]	QRS	United Kingdom	Cross – sectional	One - time testing	122 mothers	Total (y) M=11.48, SD=6.20, Range 2-44	ASD	Autism (M=31.5, SD=9.1), Asperger's (M=27.4, SD=10.3), Multiple (M=33.1, SD=9.0)	No
Hastings (2003) [72]	QRS - SF	United Kingdom	Cross – sectional	One - time testing	36 parents (fathers 18 & mothers 18)	Total (y) M=11.8, SD=2.6, Range 8-17	ASD	mothers (M=10.2, SD=5.6) & fathers (M=8.8, SD=5.2)	No
Honey (2005) [73]	QRS - SF	United Kingdom	Cross – sectional	One - time testing	217 parents (mothers 174 & fathers 43)	Total (y) Range 2-6	ASD	mothers (M=10.7, SD=7.1) & fathers (M=9.9, SD=5.9)	No
Osborne (2008) [74]	QRS - SF	United Kingdom	Cross – sectional	One - time testing	65 children	Total (y) Range 2.6-4	ASD	CG lower stress (M=23.4, SD=5.3), higher stress (M=33.3, SD=4.7) & IG lower stress (M=25.1, SD=4.4), higher stress (M=32.5, SD=4.1)	No
Dabrowska (2010) [75]	QRS - SF	Poland	Cross – sectional	One - time testing	162 parents (ASD 51, DS 54 & TD 57)	ASD (y) (M=4.7, SD=1.34), DS (y) (M=4.3, SD=1.48), TD (y) (M=4.9, SD=1.42)	ASD, DS & TD	N/R	No

Reference first author & date	Country	Research method	Length of the study	Parental stress instrument used	Number of participants	Children Age	Disorders	M, SD or Mdn , IQR of parental stress scores	Cut-off points
Griffith (2010) [76]	QRS - SF	USA	Cross – sectional	One - time testing	57 mothers (ASD 19 & DS 19 & ID 19)	ASD (y) (M=10.16, SD=3.86), DS (y) (M=9.98, SD=4.04), ID (y) (M=9.84, SD=4.18)	ASD & DS & ID	ASD (M=8.64, SD=3.7), DS (M=3.48, SD=2.87) & ID (M=3.9, SD=3.3)	No
Siman - Tov (2011) [77]	QRS - SF	Israel	Cross – sectional	One - time testing	176 parents (mothers 88 & fathers 88)	Total (y) M=10.3, SD=3.1, Range 6-16	PDD	N/R	No
Xue (2014) [78]	QRS - SF	Singapore	Cross – sectional	One - time testing	65 parents (mothers 46 & fathers 19)	Total (y) M=6.9, SD=2.1, Range 3.2-11.8	ASD	Sample M=12.5, SD=6.8	No
Reed (2016) [79]	QRS - SF	United Kingdom	Cross – sectional	One - time testing	93 mothers (Low QRS 39 & High QRS 54)	Total (y) M=10.49, SD=4.12, Range 3-18	ASD	QRS Low (M=18.5, SD=6.7) & QRS High (M=35.2, SD=4.6)	58% were clinically stressed
Tomeny (2017) [80]	QRS - SF	USA	Cross – sectional	One - time testing	111 mothers	Total (y) M=11.98, SD=3.31, Range 3-17	ASD	N/R	No

Note: Legend of Table 6 & 7. ***Abbreviations*****:** y - Years; m - Months; w - Weeks. ***Disorders:*** ASD – Autism Spectrum disorder; AD – Attention deficit; ADHD – Attention Deficit Hyperactivity disorder; ADHD–C – ADHD-combined type; ADHD-I – ADHD - inattentive subtype; LD – Learning Disability; ID – Intellectual disability; SpLD – Specific Learning difficulty; DD – Developmental disability; GD – Genetic disorders; TD – Typically developing; NCH – Nonmedical complex history; FS – Food selectivity group; Non-FS – Non-Food Selectivity group. ***Questionnaires***: PSI – Parental stress index; PSI SF – Parental stress index short form; SIPA – Stress Index for Parents of Adolescence; PSS – Parental Stress Scale; QRS – Questionnaire of Resources and Stress; QRS SF – Questionnaire on Resources and Stress short form; APSI – Autism Parental Stress Index. ***Parametric*****:** M – mean; SD – standard deviation; Med – median; Z – z score; OR – odds ratio; N/R – not reported; N/A – not applicable. ***Groups*****:** IG – intervention group; CG – control group.

3.3.2 Reliability & Validity

To evaluate reliability of the tests used in studies, the reviewers obtained information on test-retest, inter-rater, or internal consistency. The reliability and validity were reported by more than half of the studies (*M*=52, 65%). Six studies reported test-retest reliability with alphas varying from 0.68-0.97. One study reported split half-alpha 0.8 & 0.85 and one study reported on internal reliability with depression alpha 0.80 and anxiety 0.85. However, internal consistency of the test was the main method to report the tests' reliability (*N*=45). Four studies that used this parametric reported alpha above 0.7 (Hamlyn-Wright, Draghi-Lorenz, and Ellis 2007; Lu et al. 2018; Rivard et al. 2014; Tomeny 2017), seventeen studies had internal consistency above 0.8 (Dabrowska and Pisula 2010; Davis and Carter 2008b; Ekas, Lickenbrock, and Whitman 2010b; Estes et al. 2013; Firth and Dryer 2013; Honey, Hastings, and McConachie 2005a; Izadi-Mazidi, Riahi, and Khajeddin 2015; Jones et al. 2013; Kerns et al. 2015; McStay et al. 2014b; Neece 2014; Ozturk, Riccadonna, and Venuti 2014; Silva and Schalock 2012a; Tellegen and Sanders 2014; Wang et al. 2013a; Xue, Ooh, and Magiati 2014; Zaidman-Zait et al. 2014), and twenty-nine reported alphas above 0.9 (Argumedes, Lanovaz, and Larivée 2018; Brobst, Clopton, and Hendrick 2009; Craig et al. 2016; Dardas and Ahmad 2014; Dardas and Ahmad 2015; Derguy et al. 2016; Dunn et al. 2001a; Gika et al. 2012; Griffith et al. 2010; Hall and Graff 2012a; Lecavalier, Leone, and Wiltz 2006; Lee et al. 2009; Levin and Scher 2016b; Lovisotto, Caltabiano, and Hajhashemi 2016; May et al. 2015; Minnes, Perry, and Weiss 2015; Padden and James 2017a; Pastor-Cerezuela et al. 2015; Quintero and McIntyre 2010; Samadi, McConkey, and Bunting 2014; Schiltz et

al. 2018; Shawler and Sullivan 2017; Siman-Tov and Kaniel 2011; Strauss et al. 2012; Telman et al. 2017a; Thullen and Bonsall 2017; Valicenti-Mcdermott et al. 2015; Zaidman-Zait et al. 2017). Twenty–eight out of fifty-two reported reliability of the PSI–Short Form (PSI-SF), nine used PSI, five used PSS, nine used QRS scale, and one used APSI. Twenty-two studies did not report reliability.

In order to check validity, we used construct or criterion validity (convergent) for this systematic review. Correlations above 0.3 are considered clinically significant. The results revealed that forty- four out of eighty studies checked the construct validity for the scale and correlated the stress scores with well-established child and parental outcome measures, and thirty-one used convergent validity with established stress questionnaires (Brobst, Clopton, and Hendrick 2009; Davis and Carter 2008b; Honey, Hastings, and McConachie 2005a).

3.3.3 Responsiveness

18 studies provided reliable data on scale responsiveness and reported the change of parental stress over-time. However, the power of the scale was reported only by five studies (Baker-Ericzen, Brookman-Frazee, and Stahmer 2005; Fava and Strauss 2011; Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014; Marshall et al. 2016; Reed et al. 2017), even though fourteen studies used intervention design.

3.3.4 Cultural Sensitivity

Fifteen studies reported the parental test scores in diverse ethnic samples. PSI was used in three (Baker-Ericzen, Brookman-Frazee, and Stahmer 2005; Gong et al. 2015; Hoffman et al. 2009); PSI – SF in nine

(Dardas and Ahmad 2014; Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014; Izadi-Mazidi, Riahi, and Khajeddin 2015; Kuhn and Carter 2010; Lu et al. 2018; Samadi, McConkey, and Bunting 2014; Valicenti-Mcdermott et al. 2015; Wang et al. 2013a); QRS in two (Estes, Olson, et al. 2009; Xue, Ooh, and Magiati 2014) and PSS in one (Hsiao 2018) ethnically diverse sample.

In addition, fifty studies reported the educational background of the sample. Out of those studies, thirty-six reported that the sample consisted of 50% or more University and College graduates. Thus, parental tests were used with academically achieved participants. PSI was used in seven studies (Argumedes, Lanovaz, and Larivée 2018; Ekas, Lickenbrock, and Whitman 2010b; Hoffman et al. 2009; Ichikawa et al. 2013; Mori et al. 2009; Quintero and McIntyre 2010; Welterlin et al. 2012), PSI–SF in seventeen studies (Almogbel, Goyal, and Sansgiry 2017; Brobst, Clopton, and Hendrick 2009; Dardas and Ahmad 2015; Davis and Carter 2008b; Hall and Graff 2012a; Iadarola et al. 2018; Izadi-Mazidi, Riahi, and Khajeddin 2015; Kuhn and Carter 2010; Lee et al. 2009; Lu et al. 2018; McStay et al. 2014b; Shawler and Sullivan 2017; Thullen and Bonsall 2017; Valicenti-McDermott et al. 2014; Valicenti-Mcdermott et al. 2015; Zaidman-Zait et al. 2017), PSS in three studies (Hamlyn-Wright, Draghi-Lorenz, and Ellis 2007; Hsiao 2018; Tellegen and Sanders 2014), and QRS in nine studies (Dabrowska and Pisula 2010; Estes, Olson, et al. 2009; Estes et al. 2013; Honey, Hastings, and McConachie 2005b; Jones et al. 2013; Siman-Tov and Kaniel 2011; Tomeny 2017; Wang, Michaels, and Day 2011; Xue, Ooh, and Magiati 2014).

Most studies revealed that the average parent age is 36 years, with SD 5.5 years, showing that both younger (below >30 years) and older (above <50

years) are not extensively researched. The results have shown that there were 32 studies that explored parental stress in the mid-30s, of which eight used PSI, seventeen used PSI–SF, two used PSS, and five used QRS. There were only 13 studies that looked at parental stress in mid-40s population, out of which three used PSI, six used PSI-SF, two used PSS, and three used QRS (*Table 7).*

3.3.5 Clinical Range

Twenty-three studies used reported clinically significant scores for parental stress. They clearly differentiated between low and high levels of parental stress. Cut-off points were reported in six studies of PSI (Baker-Ericzen, Brookman-Frazee, and Stahmer 2005; Dale, Jahoda, and Knott 2006; Fava and Strauss 2011; Gong et al. 2015; Mori et al. 2009; Peters-Scheffer et al. 2012); sixteen of PSI-SF (Almogbel, Goyal, and Sansgiry 2017; Craig et al. 2016; Davis and Carter 2008b; Derguy et al. 2016; Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014; Giovagnoli, Postorino, Fatta, Sanges, et al. 2015; Hall and Graff 2012a; Lecavalier, Leone, and Wiltz 2006; Ozturk, Riccadonna, and Venuti 2014; Reed et al. 2017; Rivard et al. 2014; Shawler and Sullivan 2017; Strauss et al. 2012; Valicenti-McDermott et al. 2014; Valicenti-Mcdermott et al. 2015); one in QRS (Marshall et al. 2016); and one in the APSI (Silva and Schalock 2012a).

Table 7. The variables used to evaluate the articles

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Dunn (2001) [1]	PSI	Cronbach's α=0.95 of total score,	test - retest ranged from α 0.69 - 0.96	N/R	N/R	Correlated with locus of control test	N/R	N/R	81% Caucasian, 8% African American, 8% Hispanic & 3% others	Sample M=36.8	33%
Hastings (2003) [2]	QRS - SF	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.25 between fathers & mothers	N/R	M=41.2 mothers & M=43.4 fathers	28%
Baker-Ericzen (2005) [3]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's d maternal stress pre=1.57 & post=1.37; paternal stress pre=1.26 & post=0.87	71% Caucasian, 5% Latino, 10% Asian & 14% Mixed	M=32.6 mothers & M=34.57 fathers	43% fathers & 33% mothers
Honey (2005) [4]	QRS - SF	Kuder-Richardson coefficient mothers α=0.85 & fathers α=0.88	N/R	N/R	N/R	convergent validity between mother's and father's stress scores t(42)=1.34, p=.19	N/R	Cohen's d =0.12 between fathers & mothers	N/R	M=34.9 mothers & M=36.1 fathers	60%
Dale 2006 [5]	PSI	N/R	N/R	N/R	N/R	Correlated with depression scale	N/R	N/R	100% Caucasian	Sample M=36	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Kuhn (2006) [6]	PSI - SF	N/R	N/R	N/R	N/R	Correlated with parent psychological tests	N/R	Cohen's *d* =0.39, *p*<.001 between groups high v. low ASD	88% Caucasian & 12% ethnic minority	Sample M=37	50%
Lecavalier (2006) [7]	PSI - SF	Cronbach's α=0.93 of total score	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Cohen's *d* =0.03, *p*>.05 between time points: baseline & 2 (y)	93% Caucasian	Sample M=39.9	48%
Hamlyn - Wright (2007) [8]	PSS	Cronbach's α=0.76 of total score	N/R	N/R	N/R	Correlated with depression, anxiety scale	N/R	N/R	N/R	DD M=43.4, ASD M=43.9, DS M=42.4	55.7% (DD), 38.5% (ASD), 33.2% (DS)
Davis (2008) [9]	PSI - SF	Cronbach's mothers α=0.84 - 0.90 & fathers α=0.84 - 0.92	N/R	N/R	N/R	Convergent validity between mother's and father's stress scores, p<.10	N/R	Cohen's *d* =0.11 between mothers & fathers	87% Caucasian	M=36.5 mothers & M=37.9 fathers	63% of mothers & 70% of fathers
Osborne (2008) [10]	QRS - SF	Kuder - Richardson coefficient of total score α=0.89	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Brobst (2009) [11]	PSI - SF	Cronbach's α=0.95 of total score	N/R	N/R	N/R	Convergent validity between groups stress F(2,90)=45.7, p<.001, η2=0.5; between couple F(1,45)=1.07, p>.05, η2=0.03	N/R	N/R	98% Caucasian	ASD mothers M=38.5, fathers M=40.1 & Non-DD mothers M=35.1, fathers M=36.2	64%
Estes (2009) [12]	QRS	N/R	N/R	N/R	N/R	correlated with child outcome measures	N/R	Cohen's d =0.75 between ASD & DD	70% Caucasian in ASD & 62% in DD	M=35.99 ASD & M=36.23 DD	54% ASD & 36% DD
Hoffman (2009) [13]	PSI	N/R	N/R	N/R	N/R	correlated with child outcome measures	N/R	Cohen's *d* =2.2, between ASD & TD	40% Caucasian ASD & 38% in TD	M=37.52 ASD & M=34.9 TD	67% ASD & 75 % TD
Lee (2009) [14]	PSI - SF	Cronbach's α=0.92 of total score	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.85 between ASD & TD	96% Caucasian ASD & 93% in TD	M=42.2 ASD & M=38.5 TD	50% ASD & 64% TD
Mori (2009) [15]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.48 between Autism & Asperger's	N/R	Asperger's M=39.2 mothers, M=42.4 fathers; Autism M=38.1 mothers, M=40.8 fathers	57% Asperger's & 59% Autism

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Rao (2009) [16]	PSI & SIPA	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's d = 1.51 between Asperger's & TD	94% Caucasian	M=42.5 Asperger's & M=41.6 TD	N/R
Dabrowska (2010) [17]	QRS - SF	Kuder-Richardson of total score α=0.81	N/R	N/R	N/R	N/R	N/R	N/R	N/R	ASD M=30.7 mothers, M=34.4 fathers; DS M=32.8 mothers, M=34.9 fathers; TD M=31 mothers M=34.6 fathers	75%
Ekas (2010) [18]	PSI	Cronbach's α=0.89 of total score	N/R	N/R	N/R	Correlated with support, depression scales	N/R	N/R	95% Caucasian	Sample M=40.1	75%
Griffith (2010) [19]	QRS - SF	Kuder - Richardson coefficient of total score α=0.91	N/R	N/R	N/R	N/R	N/R	Cohen's d ASD & DS *d* =1.56, *p*<.001; ASD & ID *d* =1.37 *p*<.001; DS & ID *d*=- 0.13 *p*>.05	N/R	M=36.6 ASD, M=43.7 DS, M=38.8 ID	39%
Makrygianni (2010) [20]	QRS	N/R	N/R	N/R	N/R	correlated with child outcome measures	N/R	N/R	N/R	N/R	48%

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Quintero (2010) [21]	PSI	Cronbach's α=0.92 ASD; α=0.97 TD of total scores	N/R	N/R	N/R	correlated with child outcome measures & depression scale	N/R	Cohen's *d* =0.21, *p*>.05 between ASD & TD	92% Caucasian	M=36.4 ASD & M=36.6 TD	59% ASD & 77% TD
Fava (2011) [22]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.88, IG group between time points: baseline & 6 (m)	N/R	N/R	N/R
Georgiades (2011) [23]	PSI - SF	N/R	N/R	N/R	N/R	correlated with child outcome measures	N/R	N/R	72% Caucasian	N/R	N/R
Siman - Tov (2011) [24]	QRS - SF	Kuder-Richardson total score α=0.94	N/R	N/R	N/R	correlated with child outcome measures & marriage and parent's mental health scale	N/R	N/R	N/R	Sample M=35.4	71%
Wang (2011) [25]	QRS	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	M=38.7 mothers & M=40.3 fathers	60%
Gika (2012) [26]	PSS & PSI	PSI test -retest T1 α=0.97 & T2 α=0.95 of total scores	N/R	N/R	N/R	N/R	N/R	N/R	N/R	Mdn=44, IQR=36-50	0%

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Hall (2012) [27]	PSI - SF	Cronbach's α=0.93 of total score, test-retest reliability α=0.84	N/R	N/R	N/R	correlated with child outcome measures & coping scale	N/R	Cohen's *d* =0.46, *p*>.05 between mothers & fathers	84% Caucasian	Sample M=40.1	56%
Peters - Scheffer (2012) [28]	PSI - Dutch version	N/R	N/R	N/R	N/R	correlated with child outcome measures	N/R	N/R	N/R	N/R	N/R
Silva (2012) [29]	APSI	Cronbach's α=0.83 of total score	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R
Strauss (2012) [30]	PSI - SF	Cronbach's α=0.91 T1 & α=0.95 T2 of total score	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R
Welterlin (2012) [31]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	IG time points baseline & 12 (w) t(11)=1.3, p=.02, Cohen's d =-0.3; CG t(11)= -0.7, p=.05, Cohen's d=0.2	90% Caucasian	N/R	90%
Estes (2013) [32]	QRS	Cronbach's α=0.85 of total score	split - half r=0.85 and 0.89	N/R	N/R	correlated with child outcome measures	stability r=0.8	ASD v. DD t(94)= -2.1, p<.05 Cohen's d=0.6; ASD v. TD t(94)=-4.6, p<.001 Cohen's d=1.3	N/R	M=34.9 ASD, M=36.7 DD, M=34.7 TD	*84%*

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Firth (2013) [33]	PSS	Cronbach's α=0.86 of total score	N/R	N/R	N/R	correlated with child outcome measures & depression, anxiety scale	N/R	N/R	N/R	N/R	N/R
Ichikawa (2013) [34]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	IG & CG mean differences - 18.1 (95%CI 55.8-19.5), Cohen's d=0.58	N/R	Sample M=39.0	68%
Jones (2013) [35]	QRS	Kuder-Richardson total score of mothers α=0.88 & fathers α=0.87	N/R	N/R	N/R	Correlated with parent & child demographic measures	N/R	Cohen's d =0.48 between mothers & fathers parental stress score	95% Caucasian	M=41.6 mothers & M=44.0 fathers	50%
Wang (2013) [36]	PSI - SF	Cronbach's α=0.89 of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	100% Chinese	Sample M=32.39	35%
Dardas (2014) [37]	PSI - SF Arabic version	Cronbach's α=0.92 of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	100% Jordanians	N/R	53%
D'Elia (2014) [38]	PSI - SF Italian version	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Feinberg (2014) [39]	PSI - SF	N/R	N/R	N/R	N/R	N/R	N/R	between time points baseline & 3(m): mean differences 8.6 (95% CI - 17.2 to - 0.30), p=.04	35% Caucasian, 24% Black, 32% Latina & 9 % Asian	M=32 IG & M=35 CG	13%
McStay (2014) [40]	PSI - SF Dutch version	Cronbach's α=0.86 ASD & α=0.87 TD of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	Cohen's *d* =1.03 between ASD & TD	N/R	N/R	84%
Neece (2014) [41]	PSI - SF distress subscale	Cronbach's α=0.83 of total score	N/R	N/R	N/R	N/R	N/R	Cohen's d baseline - IG and CG d=0.2, after 9 (m) d=0.7	N/R	M=34.2 IG & M=36.4 CG	N/R
Ozturk (2014) [42]	PSI - SF	Cronbach's α=0.84 - 0.92 mothers & α=0.81 - 0.91 fathers	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	Cohen's *d* =0.03 between mothers & fathers	N/R	M=40.7 mothers & M=44.1 fathers	N/R
Rivard (2014) [43]	PSI - SF	Cronbach's for mothers α=0.73–0.86, for fathers α=0.77–0.87	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	Cohen's d =0.29, t(117)=-3.8, p<.001 between mothers & fathers	N/R	N/R	36%

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Samadi (2014) [44]	PSI - SF	Cronbach's α=0.92 of total score	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	Cohen's *d* =0.77 between ASD & ID	71% Iranians	40< years old - 45% of sample >40 years old - 65% of sample	32%
Tellegen (2014) [45]	PSS	Cronbach's α=0.88 of total score	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.2, *p*<.01 between IG & CG	90% Caucasian	M=36.8 IG & M=38.0 CG	51%
Xue (2014) [46]	QRS - SF	Kuder-Richardson total score α=0.89	N/R	N/R	N/R	The QRS test not validated for Chinese population, correlation between child outcome measures	N/R	N/R	76.9% Chinese, 7.7% Malay, 3.1% Indian & 12.3% Others	M=37.9 mothers & M=42.2 fathers	50%
Zamora (2014) [47]	PSI	N/R	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Child gender: boys & girls Cohen's *d*=0.2	N/R	N/R	N/R
Zaidman - Zait (2014) [48]	PSI - SF	N/R	T1 α=0.82, T3 α=0.83, T4 α=0.88 of total score	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Valicenti-McDermott (2014) [49]	PSI - SF	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d* =0.63 between ASD & DD	N/R	Sample M=38	57%
Dardas (2015) [50]	PSI - SF Arabic version	Cronbach's α=0.92 of total score	N/R	N/R	N/R	Correlated with quality of life scales	N/R		N/R	Sample M=39.3	90%
Giovagnoli (2015) [51]	PSI - SF	N/R	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Cohen's *d*=0.63 between ASD & TD, *p*<.001	N/R	ASD mothers M=37.7, fathers M=41 & TD mothers M=37.6, fathers M=40.6	33% ASD & 58% TD
Izadi-Mazidi (2015) [52]	PSI - SF	Cronbach's α=0.80 of total score	test-retest reliability 7 (w) α= 0.75	N/R	N/R	N/R	N/R	Cohen's d=0.1 between different time points: baseline & 7(w)	100% Iranians	Sample M=37.7	57%
Kerns (2015) [53]	PSI & SIPA	Cronbach's α=0.85 of total PSI & α=0.90 of total SIPA	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	Cohen's d=0.66, p=.039 between ASD Anxiety & ASD Non-Anxiety	N/R	N/R	N/R
May (2015) [54]	PSI subscale	Cronbach's for mothers α=0.94 & for fathers α=0.91	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	Cohen's d=0.09 between mothers & fathers	N/R	M=39 mothers & M=42 fathers	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Minnes (2015) [55]	PSI - SF distress subscale	Cronbach's α=0.91, subscale of PSI	N/R	N/R	N/R	Correlated with child & parent outcome measures		N/R	N/R	M=35.3	N/R
Postorino (2015) [56]	PSI - SF	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R	N/R
Postorino (2015) [57]	PSI - SF	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d*=0.68 between FS & NoFs	N/R	N/R	N/R
Valicenti - McDermont (2015) [58]	PSI - SF	Cronbach's α=0.92 of total score	N/R	N/R	N/R	N/R	N/R	Cohen's *d*=0.63, *p*<0.05 between ASD & DD	12 % Caucasian, 51 % Hispanic, 31 % Black, 6 % Other	Sample M=38	54%
Yun (2015) [59]	PSI	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d*=2.2, *p*<.001 between ASD & TD	100% Chinese	M=37.1 fathers & M=34.3 mothers	N/R
Craig (2016) [60]	PSI - SF	Cronbach's for mothers α=0.91, for fathers α=0.88	N/R	N/R	N/R	Correlated with child outcome measures	N/R	N/R	N/R	M=40.5 mothers & M=41.9 mothers	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Derguy (2016) [61]	PSI - SF French version	Cronbach's α=0.92 of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	N/R	M=42.7 mothers & M=44.9 fathers	N/R
Keenan (2016) [62]	PSI - SF	N/R	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	Cohen's d=2.2, p<.01 between ASD & TD	N/R	N/R	N/R
Levin (2016) [63]	PSI - SF	Cronbach's α=0.95 of total score	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Cohen's *d*=1.6, *p*<.001 between ASD & TD	N/R	M=32 ASD & M=33.6 TD	N/R
Lovisotto (2016) [64]	PSS	Cronbach's α=0.91 of total score	N/R	N/R	N/R	Correlated with parent outcome measures & marriage quality	N/R	N/R	N/R	Sample M=39.7	44%
Marshall (2016) [65]	PSI - SF	N/R	N/R	N/R	N/R	N/R	N/R	Cohen's *d*=1.1, *p*<.001 between ASD & NMC	N/R	N/R	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Pastor-Cerezuela (2016) [66]	PSI	Cronbach's child domain α = 0.93 & parent domain α = 0.92	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	Cohen's d=0.38 p=.005 between ASD & TD	N/R	M = 38.9 ASD & M = 39.6 TD	35%
Reed (2016) [67]	QRS - SF	N/R	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Cohen's *d*=2.9, *p*<.001 between high & low score	85% Caucasian, 10% Asian & 5% Black	Sample M=43.3	N/R
Almogbel (2017) [68]	PSI - SF	Cronbach's α=0.8 of total score	N/R	N/R	N/R	Correlated with child outcome measures	N/R	Cohen's *d*=2.9, *p*<.001 between high & low score	85% Caucasian, 6% Black & 9% Others	Sample M=45.7	97%
Padden (2017) [69]	QRS	Cronbach's α=0.91 of subscale	N/R	internal reliability between anxiety α=85 & depression α=0.80 subscales	N/R	N/R	N/R	Cohen's d=1.51, p<.001 between ASD & TD	N/R	M=41.1 mothers & M=42.2 fathers	N/R
Reed (2017) [70]	QRS	Kuder-Richardson total score α = 0.97	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	N/R	N/R	Sample M=41.5	N/R

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Shawler (2017) [71]	PSI -SF	Cronbach's α=0.91 of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	91% Caucasians	Sample M=39.8	94%
Telman (2017) [72]	PSI -SF Dutch version	Cronbach's α=0.94 for mothers, α=0.95 for fathers	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	N/R	77% Caucasians	M=44.9 mothers & M=47.0 fathers	N/R
Tomeny (2017) [73]	QRS - SF	Kuder-Richardson total score α=0.74	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	94% Caucasian	Sample M=44.1	65%
Thullen (2017) [74]	PSI - SF	Cronbach's α=0.94 of total score	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	93% Caucasian, 5% Latino, 1% Black & 1% Asian	Sample M=39.9	92%
Zaidman - Zait (2017) [75]	PSI - SF distress subscale	Cronbach's α=0.90 of PSI subscale	N/R	N/R	N/R	Correlated with child & parent outcome measures	N/R	N/R	74% Caucasian	Sample M=35.4	65%
Argumedes (2018) [76]	PSI	Cronbach's α=0.95 for total score	test - retest α=0.68 - 0.90	N/R	N/R	Correlated with child outcome measures	N/R	N/R	N/R	N/R	50%

Papers	Parental stress tool	Internal consistency	Test-retest	Inter-rater	Construct	Criterion (Convergent & Concurrent)	Stability	Change	Ethnicity	Age (y)	Education (% of college/university degree)
Hsiao (2018) [77]	PSS	N/R	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	N/R	65% Caucasian, 6% Black, 5% Asian, 11% Latino & 13% Others	N/R	62%
Iadarola (2018) [78]	PSI -SF	N/R	N/R	N/R	N/R	N/R	N/R	N/R	78% Caucasian, 8% Black, 4% Asian & 10% Others	M=35.4 mothers & fathers M=38.5	65%
Lu (2018) [79]	PSI -SF	Cronbach's α = 0.79 of total score	N/R	N/R	N/R	N/R	N/R	N/R	100% Chinese	Sample M=36.6	77%
Schlitz (2018) [80]	SIPA	Cronbach's α = 0.95 of total score	N/R	N/R	N/R	Correlated with parent outcome measures	N/R	N/R	88% Caucasian	Sample M=46.6	N/R

Note: Legend of Table 6 & 7. ***Abbreviations*****:** y - Years; m - Months; w - Weeks. ***Disorders:*** ASD – Autism Spectrum disorder; AD – Attention deficit; ADHD – Attention Deficit Hyperactivity disorder; ADHD–C – ADHD-combined type; ADHD-I – ADHD - inattentive subtype; LD – Learning Disability; ID – Intellectual disability; SpLD – Specific Learning difficulty; DD – Developmental disability; GD – Genetic disorders; TD – Typically developing; NCH – Nonmedical complex history; FS – Food selectivity group; Non-FS – Non-Food Selectivity group. ***Questionnaires***: PSI – Parental stress index; PSI SF – Parental stress index short form; SIPA – Stress Index for Parents of Adolescence; PSS – Parental Stress Scale; QRS – Questionnaire of Resources and Stress; QRS SF – Questionnaire on Resources and Stress short form; APSI – Autism Parental Stress Index. ***Parametric*****:** M – mean; SD – standard deviation; Med – median; Z – z score; OR – odds ratio; N/R – not reported; N/A – not applicable. ***Groups*****:** IG – intervention group; CG – control group.

3.4 Discussion

The results have shown that PSI scale was found to have sufficient reliability (both internal consistency and test-retest) and validity (between 0.2-0.7 with other scales). Most of the studies used PSI for longitudinal measurement of stress. The scale was able to detect change between the scores. When it comes to cultural sensitivity, PSI was mostly used in samples with higher education, middle age parents from Caucasian background. The shortened version of PSI has demonstrated high levels of reliability and validity. It was correlated with different scales with high correlation scores (alpha above .80). When it comes to cultural sensitivity, it was mostly used in Caucasian samples with middle age groups and highly educated parents. The QRS scale had lower reliability and validity compared to PSI and its short form (alpha on average .70-.80). The scale was not used in interventions so its responsiveness was not evaluated. The cultural sensitivity of the scale was more diverse, the average age was between 35-50 years and there was 48-64% that had a university degree compared to 64-89% in PSI and PSI-SF scales. The QRS short form has shown a better reliability and validity compared to QRS (alpha between .81-.94) and construct and convergent validity (r between .35-.80 with other scales). The responsiveness was not evaluated as it was not used in interventions. The cultural sensitivity was more diverse as the age group was between 30 to 50 years and less than 50% participants had a university degree. The PSS had medium reliability (alpha between .76-.86) with construct and convergent validity with other scales (r between .2-.4). The age range was higher, between 40 to 44 years, and around 50% of participants had a university degree.

The results show that the most common parental stress test used for parents of children with ASD was PSI, particularly PSI-SF. These tests appear to be reliable and valid, with a definition of the clinical range of parental stress. The main type of validity assessed was construct validity, and more than half of studies used well-established tests and correlated parental stress with other outcome measures. However, the convergent validity was poor for the majority of studies reported. The effect sizes of parental stress were reported in half of the studies, demonstrating that all four questionnaires were well-designed for responsiveness. Instruments were mostly used in cross-sectional type research and less in interventions or treatments, raising difficulty in assessing the power of these tests. In addition, the questionnaires such as PSI or PSI–SF lacked cultural sensitivity and appear to be less applicable in samples of ethnically diverse and academically able participants. Meanwhile, PSS or QRS were more commonly reported in different cultures and ethnic backgrounds (i.e. Middle East or Asian countries). It is important to mention that there were no studies found on parental stress in South America or Africa demonstrating a lack of diversity in research; therefore, complicating the assessment of the cultural sensitivity tests. There might be couple reasons for lack of studies in these regions, to name a few: socioeconomic factors, language barrier or culture. Both PSS and QRS tests had good reliability; however, the validity and the tests' ability to differentiate between clinical cases was less clear. APSI reported high reliability and validity, however it was only reported and used in one ASD study.

3.4.1 Validity

The systematic review revealed that construct validity was mainly reported in these studies with medium to high correlations with outcome measures. Only three studies reported convergent validity, which used the PSI-SF test. The PSI-SF was compared to general stress scales and it demonstrated medium to high convergent validity. Results that showed medium validity of parental stress as tests were not consistent at discriminating parents across a broad range of stress. The lack of reports about validity is explained by the fact that there is no gold standard for measuring parental stress; therefore, there are few appropriate tests with which to validate instruments against (Deater-Deckard 2004; Yirmiya and Shaked 2005; Uhrskov 2013; Zaidman-Zait et al. 2010). In addition, there were no studies that attempted to establish criterion validity. Overall, none of the instruments could be determined to provide consistent results of good validity.

3.4.2 Reliability

We found that only half of the studies reported reliability scores, mostly measuring Cronbach's alpha. Although internal consistency provides information on the compatibility of the items in the scale, it does not provide information about repeatability and test consistency over time. As a result, there was little reliance on statistical approaches when reporting data, which was collected at a single time point. Seven studies reported test-retest reliability with alphas varying from 0.68–0.97 for PSI-SF (N=5) and QRS (N=2). This small number of test–retest studies can be explained because it requires more investment in data collection and resources (Uhrskov 2013). Mostly, authors who did not report reliability or validity of the instruments, but relied on

the psychometrics from prior studies, particularly for the PSI and PSI-SF questionnaires. Few studies had test development as a primary objective. Nevertheless, collecting data at different times and across multiple samples increases test robustness. Currently PSI and PSI-SF are the instruments with substantial evidence on reliability and validity in assessing parental stress in ASD studies.

3.4.3 Clinical Range

The cut-off for clinical significant stress was determined by assessment of cases and the severity of psychological impact. This review demonstrates that 50% of parents from ASD groups and only 10% of parents in the control group had clinically significant stress. Studies that compared mothers and fathers of children with ASD showed that 44% of mothers and 51% of fathers were clinically stressed. However, the clinical stress in parents varied from 2% to 78% in the studies. Parental stress index (PSI) and its short form (PSI-SF) were scales that had clear statistical guidance for detection of clinical stress compared to PSS and QRS. Researchers that used QRS and PSS defined clinical cut-offs for their specific studies and did not have standardised methods from the instrument. This creates heterogeneity in the research and it becomes difficult to interpret clinical range across different studies.

3.4.4 Responsiveness

There were 42 papers that assessed the responsiveness of scale and measured effect size from low to high across parental stress instruments. Only 5 studies reported the power of the scales when using interventions. The instruments were administered to parents of children with ASD both at the baseline and at the follow-up. Changes in the scores were observed in the

intervention group and control group. The scores after intervention were significantly different at the follow-up between these groups. However, eight studies that used interventions or testing over a period of time did not provide the statistics of parental stress scores. Researchers seeking to evaluate interventions should provide evidence regarding the amount of change that these scales are able to detect.

Another important consideration when selecting an instrument is the age of the children with ASD. Since parental stress changes to accommodate the different children's needs and problems at different ages, parenting adapts to the age of the children and differs from one age group to another (Deater-Deckard 2004; Yirmiya and Shaked 2005). Studies that used PSI and PSI-SF were used for parents with children between the ages of 0 to 13 years old, but PSS and QRS were used across a wider age spectrum. For example, the same scale used for parents of toddlers as well as parents of teenagers. Thus, PSS and QRS may be less robust in detecting parental stress among parents of older children compared to PSI and its short form.

3.4.5 Cultural Sensitivity

Parental stress may vary with the cultural environment. Cultural framework is important as it determines the support parents are provided, while highlighting stigma and unacceptable behaviour associated with rearing children with these disorders (Tran 2009). Moreover, parents can perceive behaviours differently due to their culture. Therefore, it is crucial that tests are adapted to the appropriate groups to capture the parental stress construct in different cultures. Results show that there are no studies from South America or Africa. This indicates the cultural biases that parental stress questionnaires

might encounter. Nevertheless, the PSS instrument was more comprehensible in different cultures (Middle East & Asia), while the relevance to the target population was better address by PSI and PSI-SF. This was determined by ethnic diversity, as well as parent age and education degree, as suggest by APA ethics code (Tran 2009). The results show that the majority of samples consisted of people of Caucasian ethnicity with college or university degrees. Also most of the studies did not adjust for population demographics. This limits the testing of cultural sensitivity of the test due to the samples on which these instruments were used. This review shows that when it comes to cultural sensitivity, researchers have made complex choices based on what is available to them.

3.5 Limitations

We tried to provide a broad assessment of existing parental stress tools. However, the review was limited to a specific age group as families with adult children were not included. We limited ourselves to the younger population as parents experience different challenges through the child's development until adulthood. This review is limited to French, English, Russian, and Lithuanian as these are languages spoken by the authors.

3.6 Strengths

This is the first study to critically evaluate the existing tools to measure parental stress in parents of ASD children. This study is characterised by methodological rigor, data search, and data extraction. Research on the psychometric tools to measure parental stress and its relevance to the ASD sub-group was limited. Thus, this systematic review has demonstrated strengths and limitations of existing tools. The future research needs to

address these limitations by investigating further cultural sensitivity and responsiveness of the parental stress tools.

3.7 Conclusion

In summary, there are different considerations when it comes to choosing an instrument to measure parental stress and it is mainly dictated by the aims of the research and the context in which it is performed. The PSI and PSI-SF are the most reliable, whilst the PSS and QRS are more widely used across different cultures. Nevertheless, all tests lack data on their power and convergent validity. Future work should focus on the evaluation of appropriateness of scale and certain instruments' capacity to measure parental stress construct at different times and/or ages and across different parent groups. New instruments could be developed, but the development of such tests should consider stages provided in this review to create a valid and reliable instrument.

Chapter 4. Parental Stress in Lithuanian Parents Raising Children with ASD

4. Background

In the previous chapter, I have explored which parental stress measure is best for ASD cohort. I have found that Parental Stress Index (PSI) and its short form were the most robust tool with the highest psychometric standards. I have found that PSI short form was adapted to Lithuanian parents raising children with neurodevelopmental disorder (Matonyte 2015). Therefore, I have chosen to use it for this study.

There is substantial evidence showing that parental stress is higher in parents of children with ASD. High levels of parental stress can have debilitating consequences on the individual - exhaustion, insomnia, feeling hopeless etc. - and on the family. Stress is contagious. Weitlauf et al. (2014) has shown that highly stressed parents have relationship challenges with their partners compared to less stressed parents. In addition, studies have informed that parents tend to exhibit negative behaviours and focus inwardly when stressed; this can be detrimental to the development of healthy bonds between parents and children (Neece and Baker 2008; Baker-Ericzen, Brookman-Frazee, and Stahmer 2005; Keenan et al. 2016; Goodman and Glenwick 2012). Stress has not only psychological but also biological consequences. The study has demonstrated that parenting stress in early childhood has been linked to epigenetic changes that are triggered by the environment, as the key segments of the DNA are “deactivated” and kids are susceptible to higher risk for stress-related problems(Essex et al. 2013). There are several factors determining the increase in parenting stress: child characteristics, support

networks (spouse and surroundings), and society's perception. Due to the potential negative effects of parental stress, it was important to understand the levels of stress in the Lithuanian sample in order to understand what factors contribute the most to the experience at the high levels. As well to find potential methods to prevent/reduce stress. This is the first time parental stress is explored among parents raising children with ASD in Lithuania.

In this chapter, I explore the levels of parental stress, relationship satisfaction, and experienced stigma based on the current research these are the contributing factors for parental stress. I used cross-sectional methods and compared parents of children with Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), and Typically Developing (TD) in regard to the above-mentioned variables.

4.1 Aims of the Chapter

I investigated:

- levels of parental stress among parents of children with ASD, Cerebral Palsy or Typically Developing;
- relationship satisfaction in these three groups of parents;
- levels of experienced stigma in these three groups of parents;
- the relationship between parental stress, couple satisfaction and stigma variables;
- the difference in parental stress, couple satisfaction and stigma between mothers and fathers of children with ASD;
- using a linear mixed effect model to find explanatory variables (parent self-report and medical data) contributing to the parental stress.

4.2. Methods and Materials

4.2.1 Participants

Participants were Lithuanian parents of children from three groups i.e., those of children with ASD, CP and TD. The children's ages ranged from 2 to 18 years as the diagnosis of ASD is rarely made before 2 years of age in Lithuania. The age of 18 years was chosen as it is the age children become adults by law in Lithuania and funding from the government changes also the child is transferred to adult mental health services. The participants were recruited via hospitals where children received diagnosis, parents' associations, and charities for children with ASD and CP. Both ASD and CP group children had clinical diagnoses made by certificated teams of specialists (child neurologists, occupational therapists, speech and language therapists, child psychologists etc.) using the International Statistical Classification of Diseases and Related Health problems (ICD-10). However, some of the children's medical records were not obtained (*N=26*) and only parental reports of the disorder and its severity were collected. The parents of neurotypical children were contacted through the mainstream schools in urban (N=2) and rural areas (N=3).

4.2.2 Procedure

The charities, parent associations, special schools and hospital directors were contacted via phone or email for permission to conduct the research for the ASD and CP groups. If they agreed to participate, I met the staff and informed them about the research. Then staff approached the parents and informed them about participation in this research. If parents indicated that they were interested in taking part in the study, they were given a Participant

Information Sheet which contained my contact details and they could call me or email me. If the parent was in the hospital I met them on the ward and if it was through a charity & parent association I met them in a public place and provided them with the consent form and questionnaires. If it was done in school, the children brought the questionnaires home and returned them to me the next day. There were parents that refused to participate due to sensitivity of the data required after skimming through the questionnaires; their data was not obtained. There were no parents that stopped in the middle or refused to finish answering the questionnaire. Parents were not reimbursed for participating in the study.

I have obtained full written informed consent from each participant. The original copy of the consent form was given to the participants, and another signed copy was retained by me. The questionnaires took approximately 20-30 minutes to answer. After filling the questionnaire, parents were thanked for their participation and informed to get in touch if they have any questions or concerns (if met in person). Each participant was given a code. The data from the questionnaires was entered to password-secured document on a password-secured laptop, the demographic information was stored separately from the results with a different password. The paper versions of the questionnaires were stored in the Department of Psychiatry in University of Oxford. The demographic information was stored in a locked storage compartment separately from the questionnaire data.

For reliability purposes the clinical information of child's data was collected as a follow–up study for those parents that agreed to provide their child's clinical information. The researcher contacted the parents via phone

and explained the necessity of the follow-up study for the clinical data of the child in order to strengthen their report. If parents had any questions or concerns, they were answered by me. Then I asked for permission to access their child's medical data. If the parent disagreed no further information was pursued. If the parent agreed, the researcher sent the consent form via email to the parent and asked to sign and send a scanned copy back. This consent form was used to access the data in National Child's Rehabilitation Hospital. The hospital administrator retrieved individual's tests scores that were assessed: learning disability, hyperactivity, tantrums, independence and language development (for ASD and CP cases). Then, a comparative analysis was performed between the parent's report and child's clinical data obtained in the hospital. The data was added to a password protected file.

4.2.3 Instruments

Parental Stress Index

For parental stress I used the Parental Stress Index–Short form. This instrument was chosen because of the findings from the systematic review (*Chapter 3*). The reliability from the previous research in Italy (D'Elia et al. 2014a; Strauss et al. 2012), the Netherlands (McStay et al. 2014a; Peters-Scheffer et al. 2012; Telman et al. 2017b), Norway (Suren et al. 2012), Spain (Miranda, Tárraga, et al. 2015; Ribeiro et al. 2014), Jordan (Dardas and Ahmad 2014), and the United States (Brossard-Racine et al. 2012; Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014) showed child subscale alpha 0.78-0.88 and Parent subscale alpha 0.75-0.87 while the total varied from 0.87-0.91. The form consists of 36 items and is based on the Likert scale. The answers varied from totally disagree (score=1) to totally agree (score=5). The

instrument provides clear cut-off points at the 85th percentile and has a defence score to detect biased answers. Defence scores are used to detect the results that report exceptionally low levels of stress that might indicate that parents are answering defensively and are not completely honest in their responses. The raw score below 10 points is treated as defensive. For this sample, internal reliability was *0.94*.

Couple Satisfaction Index

The questionnaire is created to measure satisfaction in one's relationship in married, cohabiting, and dating dyads. It consists of 32 item measures: one global item on a 7-point scale, 31 items on a 6-point Likert scale (Funk and Rogge 2007). The test was validated with a variety of measures including the Dyadic Adjustment Scale (DAS) *r=0.91*, the Locke–Wallace Marital Adjustment Test (LWMAT) *r=0.88*, and the Quality of Marriage Index (QMI) *r=0.94*. It was developed using item response theory (Graham, Diebels, and Barnow 2011). In this study, the internal reliability was *0.97*.

Family Interview Schedule Stigma Scale (FESS)

For measuring experienced stigma, the FESS was created by the World Health Organization (Sartorius and Janca 1996). The scale consisted of 15 items that measured self-stigma in caregivers of people with mental illness. The scale is divided into three categories: hiding patient's condition (kept secret), feeling embarrassed about the condition (shame) and avoidance of events due to condition (isolation). Items were scored on a "yes=1" and "no=0" basis. Items then were summed up for a total score. A higher total score indicated higher levels of experienced stigma. The internal reliability was *0.86*.

4.2.4 Ethical approval

The study was reviewed and approved by the Central University Research Ethics Committee Medical Sciences division at the University of Oxford (Nr. R45354 – RE001) and the Lithuanian Bioethics Committee (Nr. Dok24587). Permission was given for one year to collect the data and to collect clinical data if the parent's permission was obtained. I have done online course on data handling and ethics provided by University of Oxford (https://researchsupport.admin.ox.ac.uk/support/training/ethics).

4.2.5 Statistical Analysis

After the completion of the questionnaires, the data was entered into R *version 3.4.3* and analysed. Estimations of the total number of participants were based on the statistical power calculations using a two–tail statistical power of 0.80 and α=0.90, the number of participants for each group was 128. I decided to account for non-response & incomplete data on the questionnaires and recruited 140 participants per group, making a total of 420 participants. I used One-way ANOVA and non-parametric tests to explore independent variables: parental stress, relationship satisfaction, and experience of stigma. T-tests were used to compare mothers and fathers of children with ASD. Lastly, mixed non-linear effect modelling was used to investigate further parental stress.

4.3 Results

I distributed around 600 questionnaires and received 410 back (68%), out of which 377 were filled. The remaining 190 were either not returned, refused to fill the survey due to the sensitivity of the data required, filled it only partially or were not interested. Out of the 190 there were 72 parents from ASD

group, 51 parents from CP and 67 parents from TD. I was able to obtain demographic information of ASD and CP parents as they were mostly recruited through the hospital. The demographics obtained can be found in *table 8*, this has showed that missing data has differed in two variables: the sex of the child and relationship to the child. This is similar differences in the obtained data due to the differences in how the diagnosis is more detected in boys in ASD than in girls. In addition, the relationship to the child difference can be explained by the fact that more fathers refused to participate in this study. This is a common challenge reported by previous researchers that men are more reluctant to participate in research compared to women (Johnson et al. 2014). However the demographic information of the TD missing data was not obtained thus it is not possible to comment on it full representativeness of the sample.

Table 8. The demographics of the participants that refused to participate in the study.

Variable	ASD missing	ASD data obtained	CP missing 51	CP data obtained
Location (N, %)				
Urban	55 (76%)	99 (75%)	35 (69%)	71 (67%)
Rural	17 (24%)	34 (25%)	16 (31%)	35 (33%)
Child's Age (Mdn, IQR)	Mdn = 7, IQR=5	*Mdn*=7, *IQR*=4	Mdn=8, IQR=4	*Mdn*=7, *IQR*=8
Child's Sex (N, %)				
Boy	51 (71%)	107 (80%)	20 (39%)	56 (52%)
Girl	21 (29%)	26 (20%)	31 (60%)	50 (48%)
Relationship to the child (N, %)				
Mother	18 (25%)	90 (68%)	18 (35%)	77 (72%)
Father	54 (75%)	41 (30%)	33 (65%)	29 (28%)
Grandmother	0	2/ (2%)	0	0
Nationality (N, %)				
Lithuanian	69 (96%)	124 (93%)	47 (92%)	94 (89%)
Polish	0	2 (2%)	1 (2%)	4 (4%)
Russian	3 (4%)	7 (5%)	3 (6%)	8 (7%)
Other	0	0	0	0

Notes: *N* - number of participants; % - percentage of participants out of the total number; *Mdn* – Median; *IQR* – interquartile range;

This data set consists of 374 parents: Autism Spectrum Disorder (ASD) *N=133*, Cerebral Palsy (CP) *N=106* and Typically Developing (TD) *N=138*. The

median participant age was 37 and the participants described themselves as Lithuanians (91.5%), Russians (5.0%), Polish (2.9%) and Other (0.5%). The children were grouped by age from 0-5, 5-10, 10-15, and 15-18 years to make the numbers comparable. The demographic features of the three groups were examined. A chi square test of goodness-of-fit did find significant differences in the children's age $\chi 2$ (6) =117.72, p>.05 and child's sex $\chi 2$ (2)=26.37, p>.05, and partner's education $\chi 2$ (10)=18.14, p<.001 but not in parents' education $\chi 2$ (10)=15.30, p=.12, or parents' salary $\chi 2$ (10)=23.72, p=.08. The groups were similar on location, relationship to the child (similar proportions of fathers and mothers were in each group) and nationality. The differences in the children's age was found because the ASD diagnosis is rarely given after year two and cerebral palsy usually is diagnosed within the first two years of life. The difference in child's sex is based on the biases in diagnosing more boys with ASD than girls, compared to CP diagnosis (Hiller et al., 2015). The demographic information of the sample is presented in the *Table 9.* Additional responses to the questions are shown in (*Appendix A*).

Table 9. Demographical data of three parent groups: ASD, CP and TD

Variables		ASD	CP	Typical
Location *(N, %)*				
	Urban	99 (75%)	71 (67%)	106 (77%)
	Rural	34 (25%)	35 (33%)	32 (23%)
Child's age (*Mdn, IQR*)		*Mdn*=7, *IQR*=4	*Mdn*=7, *IQR*=8	*Mdn*=8.5, *IQR*=5.5
Child's age at the time of diagnosis in years *(M, SD)*		*M*=3.3, *SD*=1.5	*M*=1.3, *SD*=1.6	N/A
Child's Sex (*N, %*)				
	Boy	107 (80%)	56 (52%)	68 (49%)
	Girl	26 (20%)	50 (48%)	70 (51%)

Variables	ASD	CP	Typical
Relationship with child (*N, %)*	90 (68%)	77(72%)	95 (69%)
Mother	41 (30%)	29 (28%)	43 (31%)
Father	2/ (2%)	0	0
Grandmother			
School type (*N, %)*			
Special	100 (75%)	53 (50%)	1 (1%)
Regular	24 (18%)	24 (23%)	131 (95%)
No School	9 (7%)	29 (27%)	6 (4%)
Parent's age (Mdn, IQR)	*Mdn*=37, IQR=9	*Mdn*=37, *IQR=10*	*Mdn*=39, *IQR*=9
Total children in the family (*Mdn, IQR*)	*Mdn=2, IQR=1*	*Mdn=2, IQR=2*	*Mdn=2, IQR=1*
Nationality (*N, %*)			
Lithuanian	124 (93%)	94 (89%)	127 (92%)
Polish	2 (2%)	4 (4%)	5 (4%)
Russian	7 (5%)	8 (7%)	4 (3%)
Other	0	0	2 (1%)
Parent's marital status (*%*)			
Married	75%	74%	91%
Cohabitates	14%	8%	4%
Separated	N/A	1%	2%
Divorced	9%	7%	1%
Single	2%	6%	1%
Widow	N/A	4%	1%
Finances *per month* (*%)*			
0 -100 EUR	10%	8%	4%
101-201 EUR	20%	26%	14%
201-400 EUR	33%	42%	53%
401-600 EUR	23%	13%	17%
601-1000 EUR	11%	8%	6%
<1000 EUR	1%	2%	6%
not reported	2%	1%	N/A
Parent’s education (*N, %)*			
University	66 (49%)	44 (41%)	86 (62%)
College	23 (17%)	20 (19%)	19 (14%)
Professional	22 (16%)	22 (21%)	19 (14%)
High school	19 (14%)	14 (13%)	10 (6%)
Secondary	1 (1%)	5 (5%)	3 (3%)
Other	2 (3%)	1 (1%)	1 (1%)
Partner’s education (*N, %*)			
University	56 (42%)	24 (23%)	60 (43%)
College	20 (15%)	28 (26%)	27 (20%)
Professional	23 (17%)	22 (20%)	32 (23%)
High school	24 (18%)	21 (20%)	13 (10%)
Secondary	3 (3%)	4 (4%)	4 (3%)
Other	7 (5%)	7 (7%)	2 (1%)

Variables	ASD	CP	Typical
Total PSI *(M, SD)*	*M*=102.6, *SD*=19.5	*M*=92.0, *SD*=19.7	*M*=76.4, *SD*=16.6
Total CSI *(Mdn, IQR)*	*Mdn*=34, *IQR*=35	*Mdn*=132, *IQR*=40	*Mdn*=135, *IQR*=32
Total FESS *(Mdn, IQR)*	*Mdn*=5, *IQR*=7	*Mdn*=3.5, *IQR*=4	*Mdn*=1, *IQR*=1

Notes: *N* - number of participants; % - percentage of participants out of the total number; *Mdn* – Median; *IQR* – interquartile range; *M* – Mean; *SD* – Standard Deviation.

4.3.1 Distribution of Main Variables

Gaussian distribution was checked for all three variables: parental stress (PSI), relationship satisfaction (CSI) and experienced stigma (FESS). All three variables were not normally distributed Shapiro-Wilk test: parental stress p <.001; relationship satisfaction p < .001; stigma p < .001.Therefore, I performed folded transformations (PSI Total/(180 – PSI Total). The Shapiro-Wilk test revealed that after transformation the parental stress variable had Gaussian distribution, Shapiro–Wilk *p=0.17 (Figures 3 & 4).* The relationship satisfaction variable was positively skewed, even after folded and square root transformation (CSI Total + 1)/(161 – CSI Total) the distribution was not normally distributed *(Figures 5 & 6),* the Shapiro–Wilk test was *p<0.001*. The experienced stigma variable was negatively skewed, and after log and folded transformation (FESS Total+ 1)/(15 – FESS Total) the distribution did not have Gaussian form *(Figures 7 & 8)* with a Shapiro-Wilk test *p<0.001*.

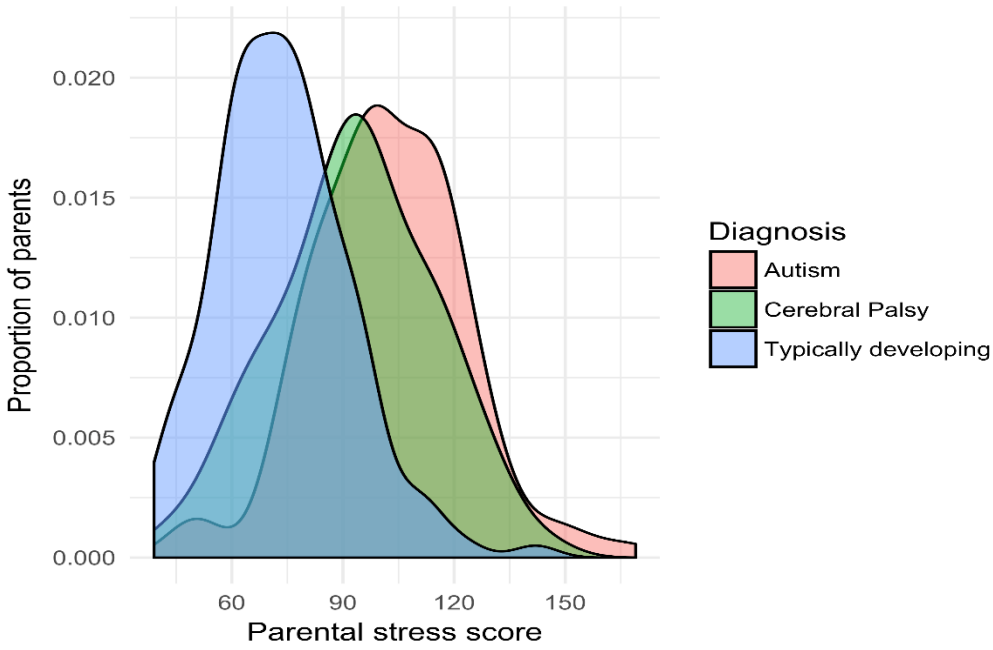


Figure 3. Parental stress scores distribution across the three groups of parents

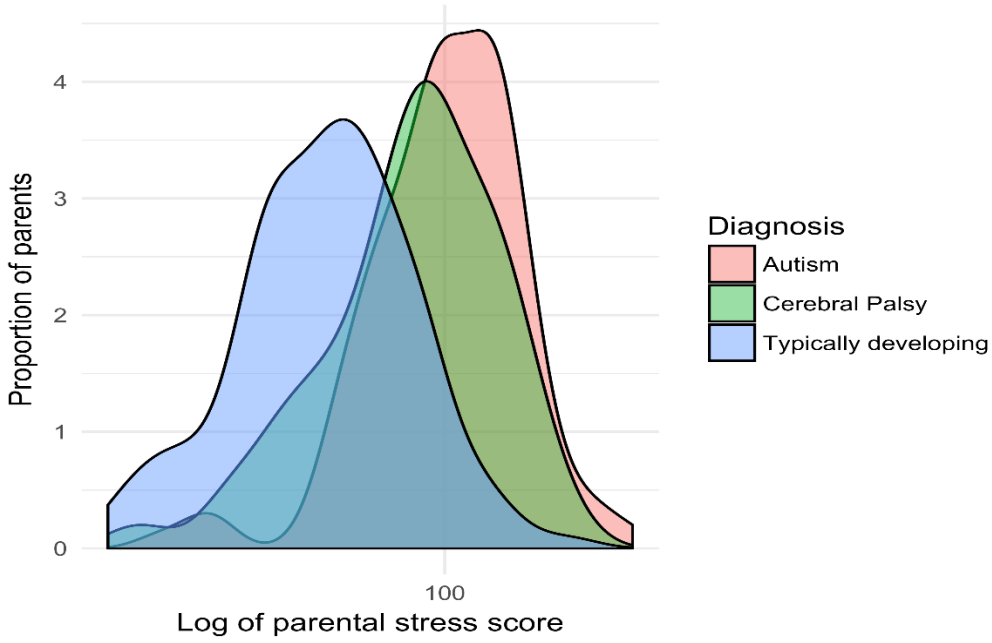


Figure 4. Parental stress distribution across the sample after Log transformation

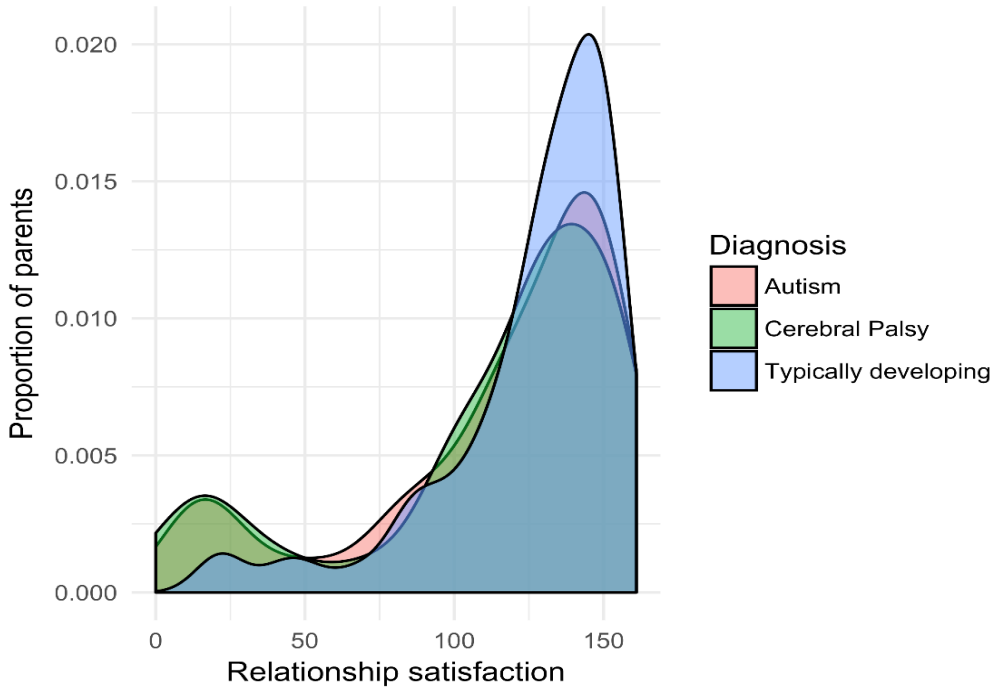


Figure 5. Relationship satisfaction distribution across the sample

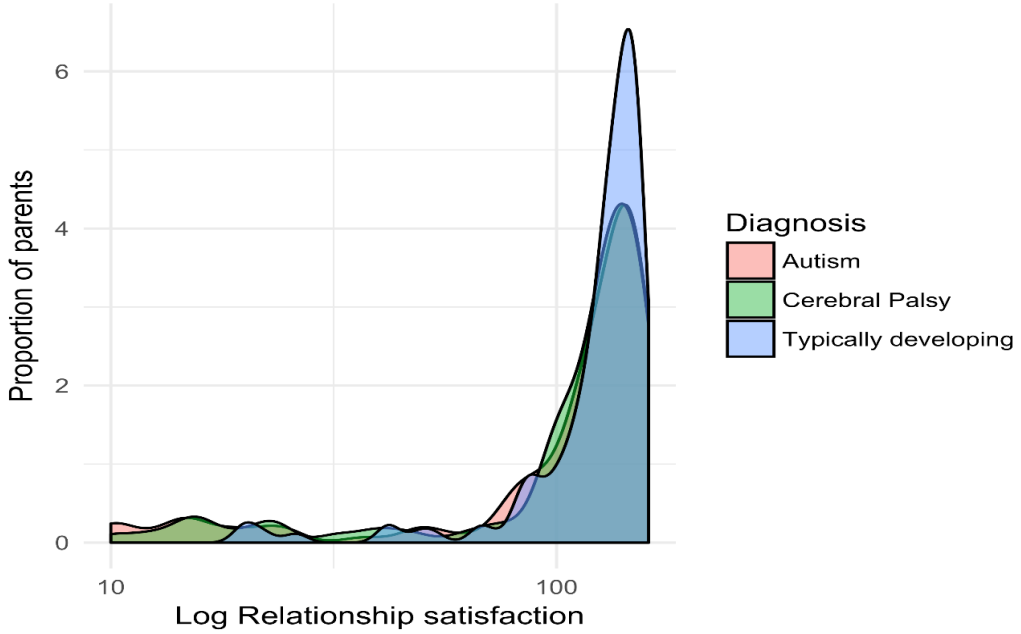


Figure 6. Relationship satisfaction distribution across the sample after folded transformation

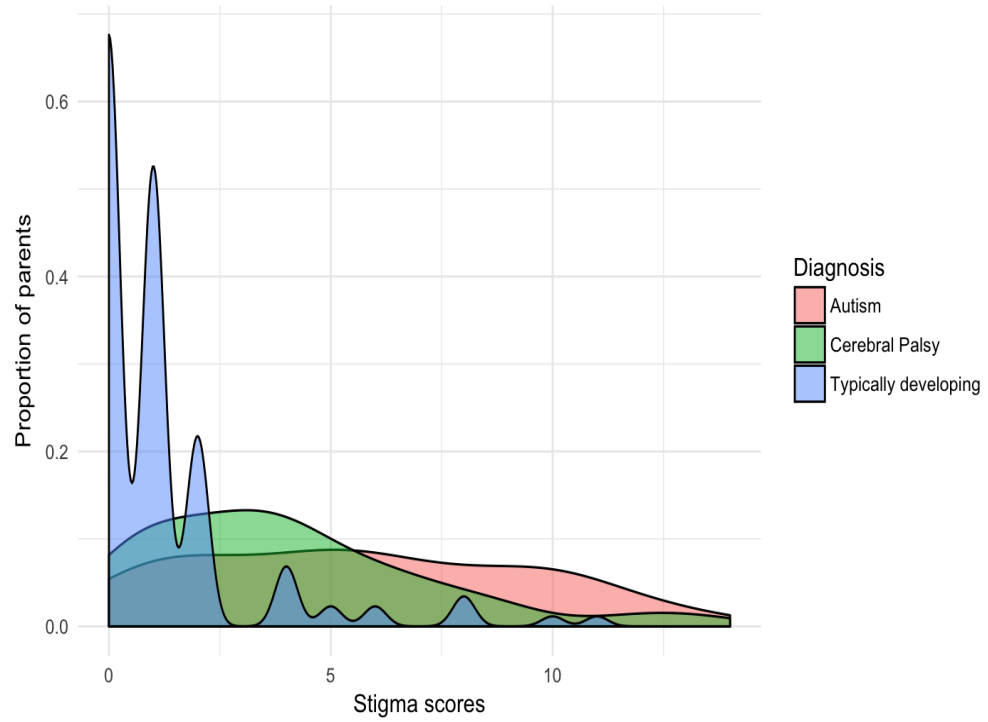


Figure 7. Experienced stigma distribution across the sample



Figure 8. Experienced stigma distribution after log and folded transformation

4.3.2 Results of the Parental Stress, Relationship Satisfaction and Experienced Stigma

Since the parental stress variable had a Gaussian distribution after the transformation, a One–Way ANOVA was performed. There was a statistically significant difference between groups *F (2,354) = 65.73*, *p<.05 (Figure 9).* A Bonferroni post-hoc test revealed that parental stress scores were significantly higher in parents of children with ASD (*M=10.11, SD=0.99, p<.001*) and parents of children with CP (*M=9.62, SD=1.11, p<.001*) compared to the parents of TD children (*M=8.69, SD=0.93, p<.001*). There was a statistically significant difference between parents of children with ASD and parents of children with CP (*p<.001*) in the levels of parental stress.

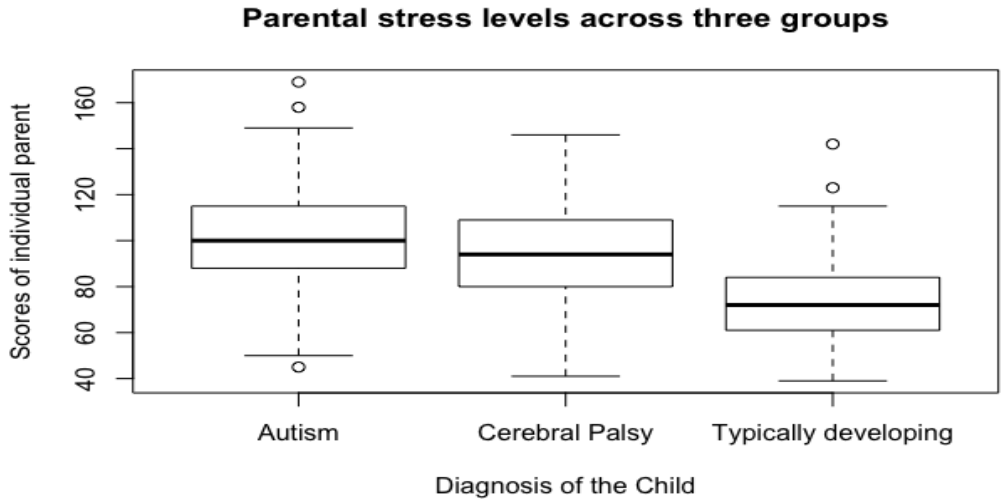


Figure 9. Boxplot of parental stress levels across three groups of parents, with 95% confidence intervals

In order to explore further the differences between two groups (ASD & CP) on parental stress, I performed t-tests on each question in the parental stress questionnaire. I have applied Bonferroni Correction and statistic significant was detected only if p <.00139 (.05/36 questions). The results revealed that there were significant differences among the groups between the questions. The CP group scored lower on questions 21, 22 from “Parent-child

interaction" subscales and questions 25, 30 and 36 from "Difficult child" subscale (*Table 10)*. The questions from the "Parent-Child Interaction" subscale indicated that parents saw their child as a disappointment, felt rejected by the child, and did not have a bond with them. This subscale identified a lack of warmth and interaction with the child by the parent. Thus, ASD parents reported more on such experiences compared with CP parents. Similarly, the questions from the "Difficult Child" subscale indicated that the parent was having a hard time gaining cooperation and managing the child's behaviour. It also shows how "easy" or "difficult" the parent perceived their child to be and on some questions ASD parents scored higher than CP parents (*Table 10).*

Table 10. Differences on parental stress questionnaire (PSI-SF) items between CP and ASD groups

The subset of the question	Question number	Means and standard deviations between the groups		Levine's test	T-test results
	Q15 "My child smiles less than expected"	M_A=1.9 *Mc*=1.7	SD_A=1.0 SD_C=0.9	*F*=0.4, *p*=0.6	*t*(237) = 1.9, *p*=.05
Sub-scale "Parent – Child interaction"	Q18 "My child does not learn as quickly as most children"	M_A=3.8 *Mc*=3.4	SD_A=1.1 SD_C=1.3	*F*=9.8, *p*=0.02	*t* (204)=2.5, *p*=.01
	Q20 "My child is not able to do as much as I expected"	M_A=2.6 *Mc*=2.3	SD_A=1.2 SD_C=1.2	*F*=0.1, *p*= 0.8	*t* (237)=2.3, *p*=.02
	Q21 "It takes time for my child to adjust to new things"	M_A=3.4 *Mc*=2.7	SD_A=1.0 SD_C=1.1	*F*=2.6, *p*=0.1	*t* (237) = 5.5, *p* <.0001
	Q22 "I am good/average/bad/ parent"	M_A=2.7 *Mc*=2.2	SD_A=1.1 SD_C=1.0	*F*=0.7, *p*=0.4	*t* (237)=3.2, *p*=.0001
	Q25 "My child cries more often than most children	M_A=3.6 *Mc*=2.9	SD_A=1.0 SD_C=1.1	*F*=3.7, *p*=0.06	*t* (237) = 4.5, *p*=.00001
	Q27 "I feel that my child is very moody"	M_A=3.1 *Mc*=2.8	SD_A=1.0 SD_C=1.2	*F*=5.1, *p*=0.02	*t* (212)=2.1, *p*=.04

The subset of the question	Question number	Means and standard deviations between the groups		Levine's test	T-test results
Sub-scale "Difficult Child"	Q28 "My child does things which bother me great deal"	M_A=3.2 Mc=2.7	SD_A=1.1 SD_C=1.3	F=6.9, p=0.01	t (204)=2.7, p=.008
	Q29 "My child reacts negatively when something happens that my child doesn't like"	M_A=4.1 Mc=3.7	SD_A=0.8 SD_C=1.0	F=10.9, p=0.01	t (193)=3.0, p=.003
	Q30 "My child gets upset over the smallest things"	M_A=3.2 Mc=2.8	SD_A=1.0 SD_C=1.2	F=0.3, p=0.6	t (237)=3.4, p=.0001
	Q32 "It is difficult to get my child to stop doing something…"	M_A=4.1 Mc=3.7	SD_A=0.9 SD_C=1.1	F=6.9, p=0.009	t (206)=2.9, p=.003
Sub-scale "Difficult Child	Q33 "My child does X things that annoy me"	M_A=2.0 Mc=1.6	SD_A=1.0 SD_C=1.0	F=0.1, p=0.7	t (237)=3.0, p=.003
	Q34 "My child is more problematic than I have expected…"	M_A=3.4 Mc=2.9	SD_A=1.0 SD_C=1.2	F=5.1, p=0.03	t (203)=3.0, p=.003
	Q36 "My child cries more than most of children"	M_A=3.5 Mc=2.8	SD_A=1.1 SD_C=1.3	F=5.9, p=0.02	t (206)=4.2, p=.00004

Notes: M_A - mean of the individual question for ASD group, SD_A – Standard Deviation of the individual question for ASD group; M_C - mean of the individual question for CP group, SD_C - Standard Deviation of the individual question for CP group.

After performing transformations, the relationship satisfaction variable remained positively skewed, therefore I have performed a non-parametric test. A Kruskal-Wallis H test showed that there was no statistically significant difference in relationship satisfaction scores between the different parental groups $\chi^2(2)=0.149, p=.928$, with median and interquartile range for ASD *Mdn=134, IQR=35*, for CP *Mdn=132, IQR=40*, and for TD *Mdn=135, IQR=32 (Figure10).*

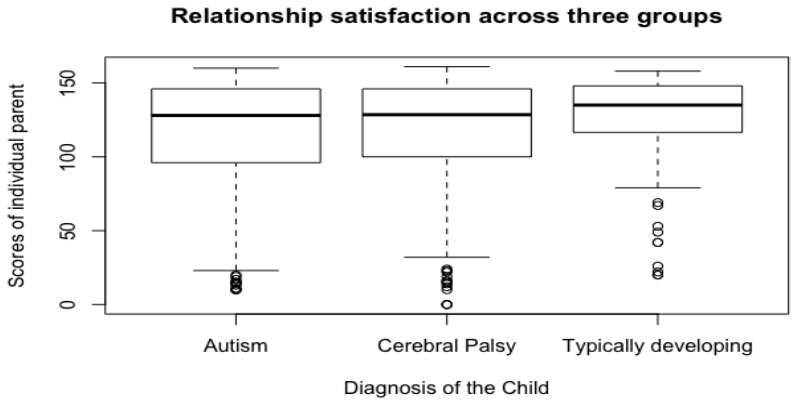


Figure 10. Box plot of relationship satisfaction scores across three groups of parents, with 95% confidence intervals

I have performed a non-parametric test for the experienced stigma variable because it was not normally distributed, despite various transformation techniques. A Kruskal-Wallis H test showed that there was a statistically significant difference in experience stigma scores between the different parental groups $\chi^2(2)=123.14$, $p<.001$, for ASD $Mdn=5.0$, $IQR=7$, CP $Mdn=3.5$, $IQR=4$, and TD $Mdn=1$, $IQR=1$. Post Hoc test of pairwise comparisons with adjusted p-values showed that there was significant difference between experience stigma levels between TD and CP ($p<.001$); between TD and ASD ($p<.001$); CP and ASD $p=.007$ *(Figure 11).*

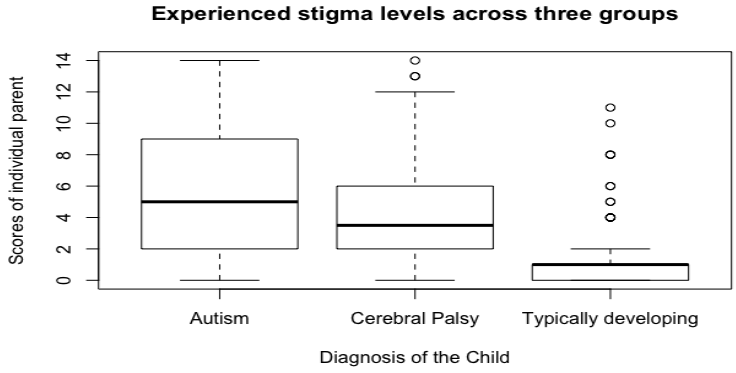


Figure 11. Box plot of experienced stigma scores across three groups of parents, with 95% confidence intervals

4.3.3 Comparison of Mothers and Fathers of Children with ASD

The parents of child with ASD were explored further. Fathers and mothers were compared on three main variables parental stress, relationship satisfaction and experienced stigma (*Table 11*).

Table 11. Mothers and fathers of child with ASD scores across main outcome variables

Parent	Parental stress (PSI-SF)	Relationship satisfaction (CSI)	Experienced Stigma (FESS)
Mother (*N, M, SD*)	*N=89, M=104.2, SD=21.9*	*N=78, M=119.9, SD=33.8*	*N=89, M=6.0, SD=3.8*
Father (*N*, *M, SD*)	*N=41, M=100.1, SD=14.3*	*N=40, M=133.9, SD=20.4*	*N=41, M=4.9, SD=3.6*

Notes: *N* – Number of participants; *M* – Mean; *SD* – Standard Deviation

There was no statistically significant difference between parental groups: as determined by the *t-test*, equal variance was assumed *p= .07, t (128) = .97, p=.33 (Figure 12).*

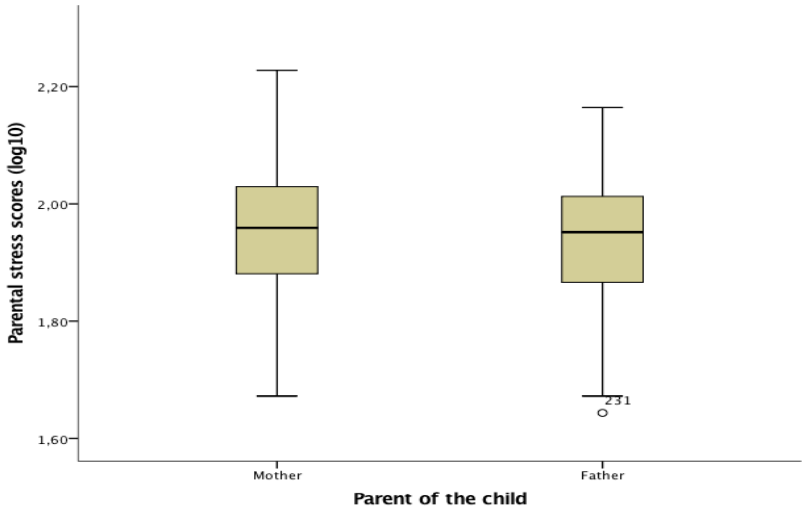


Figure 12. Boxplot of parental stress score between mothers and fathers of children with ASD, with 95% confidence intervals

A Mann-Witney U-test showed that there was a statistically significant difference in relationship satisfaction between the different parents (mothers *N=78*, fathers *N=40*) *U=1227, p=.059*, with a mean rank of relationship satisfaction score of mothers 55.2 and fathers 67.8 *(Figure 13).*

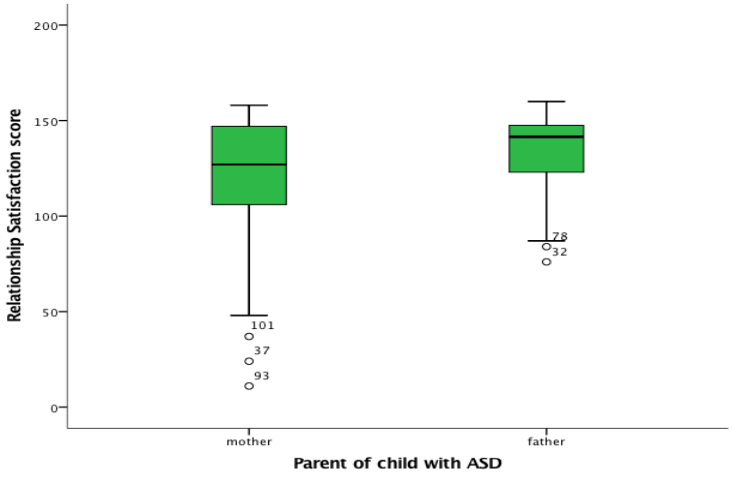


Figure 13. Boxplot of relationship satisfaction scores between mothers and fathers of children with ASD, with 95% confidence intervals

A Mann–Whitney U-test showed that there was no statistically significant difference in experience stigma scores between mothers (*N=89*) and fathers (*N=41*) *U=1497.5, p=.10*, with a mean rank of experience stigma score of mothers 69.2 and fathers 57.52 *(Figure 14).*

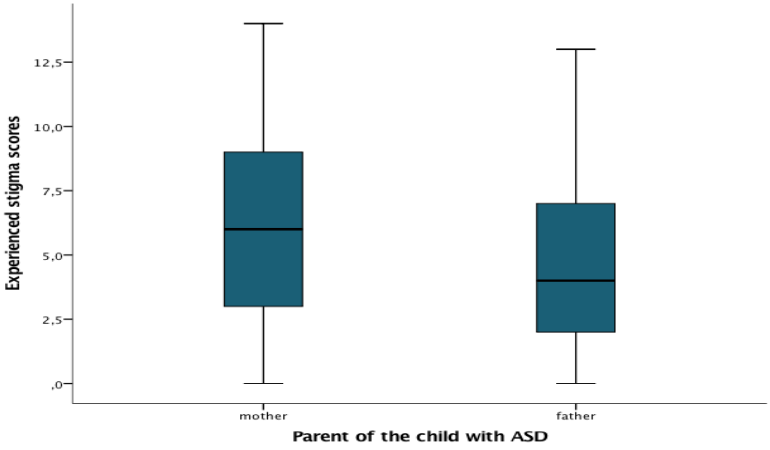


Figure 14. Boxplot of experienced stigma scores between mothers and fathers of children with ASD, with 95% confidence intervals

4.3.4 Clinical data

During the follow-up the clinical data was obtained. The consent was provided by 89 out of 133 parents (66%) in the ASD group and 86 out of 106 (81%) in the CP group. For some children, the data was not retrievable as the digital data is stored for 7 years and then it is deleted, so in the ASD cohort there were 10 children out of 49 with missing data and in CP there were 12 children out of 43 with missing data. Despite the low response and missing data, the results has showed that there was little discrepancy between parental reports and clinical data retrieved from the hospital. The learning disability discrepancy was 5% between parent reports and clinical evaluation; the language delays and communication discrepancy was 2% and hyperactivity discrepancy was 7%. The clinical data based on epilepsy was not verified as not all individuals were evaluated at the time of diagnosis. The epilepsy diagnosis is usually given by neurologist, separately, and is not part of the diagnostic tool. In addition, tantrums and anxiety data is not clinically verifiable because that is dependent on the psychological evaluation that is performed by observation and not a generalisable test score. However, the clinical data that was retrieved has shown that parent's reports were reliable when evaluating the child's clinical characteristics. However, using clinical results in analysis would have limited the findings because it was on time evaluation at the beginning of diagnosis, and on average the children in the ASD group were diagnosed *M=4, SD=3.5* years ago and the CP group were diagnosed *M=5.3, SD=6.3* years ago. Thus the validity of clinical data is questionable because the parents report was based on the current state of the child, while the clinical data was based on the evaluation at the time of diagnosis. Therefore, any

improvements or regressions that could appear in that time was not counted in. Due to the limitations mentioned above I decided to use parent's reports on the child's clinical characteristics instead.

4.3.5 Parental Stress Model

Before exploring the parental stress in detail, I have performed Pearson correlations among the main variables: relationship satisfaction, experienced stigma, and parental stress. Results have revealed that there was a significant correlation among all three variables *(Table 12).*

Table 12. Correlation matrix of the main outcome variables

	Parental stress (PSI-SF)	Relationship satisfaction (CSI)	Experienced stigma (FESS)
Parental stress (PSI-SF)	1		
Relationship satisfaction (CSI)	r=-0.30***	1	
Experienced stigma (FESS)	r=0.68***	r=-0.21***	1

*** p<.001

The clinical characteristics used in the model were based on the reports from parents and they are reported in *Appendix A*. Most of the clinical characteristics are a binary yes or no, answering if the child has a specific clinical characteristic like epilepsy. The severity was calculated based on the parent's response to child characteristics. If parents said yes to all the characteristics (epilepsy, learning difficulty, anxiety, tantrums, aggressiveness, attention problems or language deficit) or positively to at least 50%, they were counted as having a child with severe disorder.

In order to determine the explanatory factors of parental stress, I have created a model using non-linear mixed effects model in R software. Before creating the model, I have created various plots using *ggplot* and inspected

the interactions visually. Then, using the Parental stress variable, I started to create the model by adding the main explanatory variables: relationship satisfaction and experienced stigma. I continued on building the model by checking the significances of the added variables to the model. If the variable was significant it stayed in the model; if not, it was removed. Then, I performed ANOVA and compared model 1 with model 2 to check if the added new variables improved the model or not. Also, parents of the same child were accounted in the model and named as *ChildID*. In addition, I used the most likely probability method for the model. The final parental stress model AIC 2768.2, BIC 2311.41, loglike -1502.295, *p<.0001* (*Table 13).* The overall model of parental stress explained 58.8% of variance with variables: ASD severity and comorbidities explained 32.5% of variance, the child's age (3.8%), the number of children in the family (2.5%), relationship satisfaction (7.2%), and experienced stigma (12.8%).

Table 13. Degree of fit of individual variables to the final model

Variable	*β*	Stand. Error	t-value	p value
ASD Severity	99.67	5.12	t (237)=19.46	p<.001
Child Age	0.49	0.25	t (237)=1.98	p=.005
Number of children in the family	-1.12	0.86	t (237)=-1.29	p=.02
Epilepsy	-1.70	7.40	t (237)=-2.30	p=.07
Learning difficulty	6.72	2.65	t (237)=2.54	p=.01
Anxiety	11.15	2.43	t (237)=4.57	p<.001
Tantrums	3.72	2.50	t (237)=1.48	p=.014
Hyperactivity	5.51	2.42	t (237)=2.27	p=.02
Relationship satisfaction	-13.05	0.03	t (237)=-4.84	p<.01
Experienced stigma	-15.00	4.46	t (237)=-1.12	p<.001

Assumptions were checked for the final linear mixed effects model. In order to check the distribution of the residuals of the model for parental stress

variable, I used Box-Cox plot to check the residuals in the model. The residuals in the model were skewed (closer to 1) therefore I used the log transformation for the parental stress variable and the residuals were normally distributed (closer to 0) (*Figure 15 a & b*). After the residual transformation, the graph of the final model was produced *(Figure 16).*

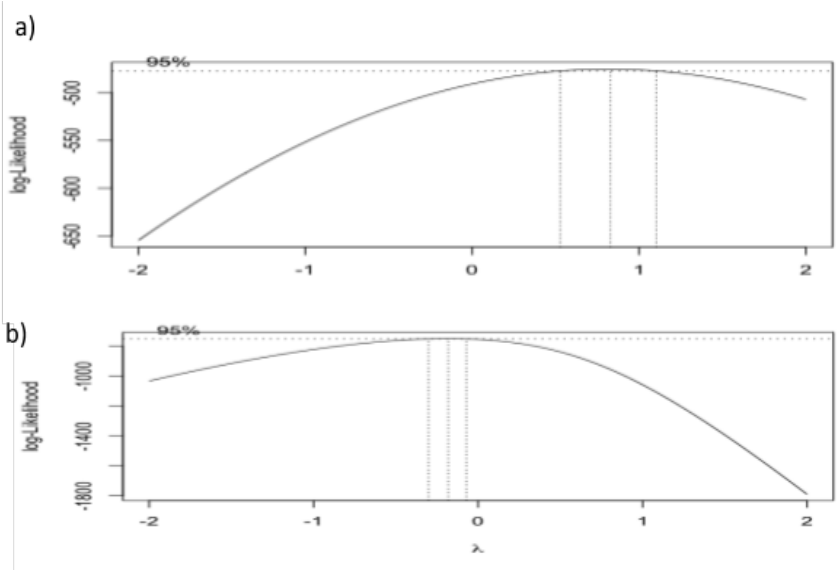


Figure 15. Box Cox plot for residual distribution of parental stress model before and after transformation.

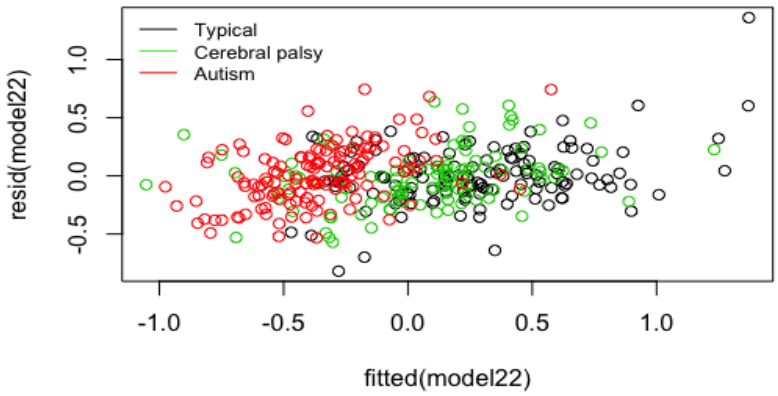


Figure 16. Fitted model against the residuals, distributed by diagnosis

4.4 Discussion

4.4.1 Parental Stress

The results have revealed that parental stress is significantly different across three parental groups, this supports the previous findings of the literature (Bluth et al. 2013a; Eisenhower, Baker, and Blacher 2005; Rutgers et al. 2007; Schieve et al. 2007a; Silva and Schalock 2012a). The parental stress in the ASD cohort was high for both mothers and fathers and 67% were at high levels of stress. Compared to the previous studies, Lithuanian parents raising ASD children scored higher on parental stress than parents in USA (Lecavalier, Leone, and Wiltz 2006; Hall et al. 2012; Valicenti-Mcdermott et al. 2015; Almogbel, Goyal, and Sansgiry 2017; Shawler and Sullivan 2017; Thullen and Bonsall 2017), Canada (Zaidman-Zait et al. 2017; Rivard et al. 2014), Italy (Giovagnoli, Postorino, Fatta, Sanges, et al. 2015; Ozturk, Riccadonna, and Venuti 2014), Netherlands (McStay et al. 2014b), United Kingdom (Samadi, McConkey, and Bunting 2014) and France (Derguy et al. 2016) based on the samples' median and standard deviation scores of PSI-SF scale. However, Lithuanian parents' scores were similar to those of parents raising ASD children in China (Lu et al. 2018; Wang et al. 2013b) and in Jordan (Dardas and Ahmad 2014). This is an interesting finding, as one would expect Lithuanian parents to score similarly to parents from other developed countries (i.e United Kingdom) but results demonstrated that Lithuanian parents are stressed in a similar level to parents from developing countries. This calls for further investigation, in order to understand the potential factors that might be contributing to such differences.

Current study also, showed that there were significant differences between ASD and CP groups on parental stress scores. These findings are supported in the previous research (Dabrowska and Pisula 2010; Davis and Carter 2008a; Phelps et al. 2009). However, the debate still exists on the potential explanations of such differences in parental stress. Thus, in this study, I explored the individual questions of the parental stress questionnaire (PSI-SF) among the two groups. I discovered that, on some questions, parents of children with ASD scored significantly higher than parents of children with CP. For example, in the sub-scale "Parent and Child interaction" that measures the parents' bond with, and hopes for, their child. Parents of children with ASD scored higher than parents of children with CP. These findings are consistent with symptomology of the ASD disorder, i.e. children with ASD prefer isolation and have difficulties in communication compared to those with CP who are more verbal and seek for the parental bond (Hamlyn-Wright, Draghi-Lorenz, and Ellis 2007; Mikulėnaitė and Ulevičiūtė 2004). Another significant difference between the two groups was in the "Difficult Child" subscale, which measured parents' ability to manage the child and their challenging behaviour. The difference between the ASD and CP groups can be explained by referring to the differences of disorder characteristics, children with ASD have more challenging behaviours (e.g. tantrums and hyperactivity) compared to children with CP (Suren et al. 2012). In addition, the "Parental Distress" subscale, which measures parental stress based on the personal characteristics and parent's mental health, was not significant. This shows that levels of stress of both groups are not due to their personal stress or mental-health difficulties.

There were no differences between mothers and fathers on the parental stress scores, which challenges findings in the existing literature on parental stress and parent's gender (Johnson and Simpson 2013; Jones et al. 2013; Knafl and Deatrick 2003; Smith et al. 2010). The study by Pisula and Porębowicz-Dörsmann (2017) informed that the severity of ASD's symptomology and parenting styles play a significant role in the experiences of parental stress. However, Esdaile and Greenwood (2003) study controlled for severity of ASD and did not find the difference among the parents, but informed that professional support was crucial in parental practices.

Another important aspect about parental stress is the difference between elevated and clinically stressed parents. In this study parents of children with ASD had an elevated stress level above the 85th percentile on average, however many did not have stress at the clinical level (above the 91st percentile). This may be explained by the fact that parents were recruited through parents' associations that provide support groups and care. The diagnosis was found to be significant covariate. The findings revealed that parents who received the diagnosis recently were more stressed then those parents who had received diagnosis years ago. This is supported by existing research which found that parental stress was highest among parents who had recently received the diagnosis (Moh and Magiati 2012; Siklos and Kerns 2007).

In addition, the Spearman correlation test revealed that support from the government and support from family/relatives was negatively and significantly correlated with parental stress (parental stress and government support $r=-0.3, p<.001$; parental stress and family $r=-0.13, p<.001$). This shows

the existing relationship between parental stress and support, for parents of children with ASD. Current research showed that social support (family and professional) helped reducing parental stress in the ASD population (Dunn et al. 2001a; Eremin 2011; Pisula 2011b).

4.4.2 Relationship Satisfaction

The results have shown that there was no difference in the relationship satisfaction among the three groups of parents. This was not consistent with the existing results in the literature which claim that relationship satisfaction is lower among couples raising children with ASD (Hartley et al. 2010; Higgins, Bailey, and Pearce 2005). However, some researchers stated that having a special needs child strengthened the parents' relationship and provided common goals for the couple i.e. assuring the child's future, health or education (Havens 2005; Park et al. 2012). Therefore, this could explain the high scores of relationship satisfaction in the ASD group.

In addition, a negative correlation was found between the experienced stigma and relationship satisfaction in this sample. It explained the role of the community in the relationship development. The study Sim et al. (2016) highlighted that acceptance of the community correlated with relationship satisfaction.

However, the comparison between mothers and fathers shows that there are significant differences in how mothers and fathers perceive their relationship. It seems that mothers rated the relationship lower compared to fathers. This could be based on the differences in parenting styles and the amount of time spent with the child. Smith et al. (2010) showed the importance of having a mutual agreement on the management of the child from both

parents. Also, the study identified mutual involvement in the child's day–to–day life as significant factor for relationship satisfaction with partner.

4.4.3 Experienced Stigma

The findings have revealed that there was a significant difference between the groups on the experienced stigma levels, which confirms the previous findings in the literature (Serapinaitė 2014; Corrigan and Watson 2007; Eremin 2011; Krajewski, Burazeri, and Brand 2013; Pisula 2011a; Pratto, Sidanius, and Levin 2006). The most interesting difference can be seen between the CP and ASD groups: parents of children with ASD experienced higher and more significant levels of stress suggesting that physically visible differences (CP) can reduce experienced stigma levels compared with invisible ones (ASD). This confirms the findings of previous research which state that there was a difference in perception among visible and invisible disability in general population (Serapinaitė 2014; Corrigan and Miller 2004; Eremin 2011; Puras et al. 2004b; Dobryninas and Gaidys 2003).

It was found that there were no differences between mothers and fathers on the experienced stigma scores. This can be put down to both parents accepted stigma in the similar way or used similar coping strategies to manage the experiences of stigma. In order to understand better, it is important to measure coping strategies that parents employ when exposed to stigmatizing environments.

4.4.4 The Parental Stress Model

The parental stress was modelled using the explanatory variables. The findings revealed that ASD characteristics were major predictors of parental stress. This confirms the existing findings in the literature (Davis and Carter

2008a; Estes, Munson, et al. 2009; Pisula and Porębowicz-Dörsmann 2017; Lecavalier, Leone, and Wiltz 2005; Georgiades et al. 2011; Wang et al. 2013b; McStay et al. 2014b; Rivard et al. 2014; Giovagnoli, Postorino, Fatta, Sanges, et al. 2015; Valicenti-Mcdermott et al. 2015). However, this study also considered comorbidities (epilepsy, learning difficulty, anxiety, problematic behaviour, and hyperactivity) and found that they have a significant role in parental stress. This is something that was not explored in great detail before (Ashwood et al. 2015).

The model accounted 32.5% of variance of ASD characteristics, severity and comorbidities, while in previous studies ASD characteristics accounted for: Levin and Scher (2016a) – 39%, Wang et al. (2013a) – 9.4%, Giovagnoli, Postorino, Fatta, Veronica, et al. (2015) – 28%, Schiltz et al. (2018) – 47.8% of parental stress. It is crucial to consider child ASD symptomology and comorbidities when addressing parental stress and designing interventions.

The model improved significantly when relationship satisfaction and experienced stigma were added. These variables inform further about parental stress, as studies confirm that the relationships within the family and outside the family can significantly reduce parental stress (Hall and Graff 2011; Tehee, Honan, and Hevey 2009; Hsiao 2018; Lovisotto, Caltabiano, and Hajhashemi 2016; Hall and Graff 2012b; Siman-Tov and Kaniel 2011). It is debated that support is one of protective factors against parental stress (Ekas, Lickenbrock, and Whitman 2010a; Lu et al. 2018; Zaidman-Zait et al. 2017). However, it is important to mention that governmental, family, and friend support did not yield significant change in the model, which challenges the previous findings in

literature. Therefore, for future work it is important to evaluate what the protective factors are against parental stress in the Lithuanian population when raising a child with ASD.

4.5 Strengths and Limitations

This is a novel study which investigated parental stress in parents raising children with ASD, CP, and TD in Lithuania. It examined the role of experienced stigma and parental stress in Lithuania; a transitioning country (Buivydaite, Newton, and Prasauskiene 2017; Serapinaitė 2014). Parental stress was assessed with an internationally accredited tool (PSI-SF), which was validated and adapted to the local population (Matonytė 2015). Associations between parental stress, relationship satisfaction, and experienced stigma were accounted for as potential confounders and further investigated. The parental stress variable was selected based on evidence from the literature. It was further explained by creating a mixed effect model and using exploratory variables to build the model.

For future reference it would be important to investigate the coping strategies and parenting wellbeing as potential variables predicting parental stress among Lithuanian parents with ASD children. Previous studies have demonstrated the dynamics between those variables and parental stress (Havens 2005; Schiltz et al. 2018; Gong et al. 2015; Ozturk, Riccadonna, and Venuti 2014; Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014). The diagnoses reported in this study were evaluated by a clinician using standardised neuropsychological batteries and long-term observations, however some children's medical records were not obtained and they were excluded from the data analysis.

The number of subjects in the CP group was lower than estimated by power calculations. It was labour intensive to find these parents, as there were no parental associations in Lithuania that would help with the recruitment process for the CP group and recruited parents were hesitant to participate in the study. The majority of data of CP was excluded because questionnaires were partially filled.

Also, it is important to note that only 46% of totally invited fathers and 54% of mothers responded to the survey. Thus, the experience of parenting cannot be generalised to parents who did not participate, either because they were unwilling or because they were not living with the child(ren).

4.6 Implications

There is a need to further explore parental stress in a mental health context in Lithuania. The findings revealed that there is a relationship between parental stress and experienced stigma. Therefore, it suggested studying more the directionality between these two variables, and improving the outcomes of families that experience higher levels of stress. Parenting programmes should be initiated to address the parental needs and problems associated with raising a child with ASD in Lithuania. The control of risk factors and causes of parental stress in families of children with ASD may reduce the burden of caring for such children.

Future longitudinal studies are however required to understand the direction of causality in the association between parental stress and experienced stigma. Also, there should be interventions designed to address the effects of parental stress on the parents and family as a whole.

4.7 Conclusion

This chapter has shown the complexity of parental stress in families of children with ASD and the importance of support for the family as well the understanding of the underlying symptomology of the disorder. Parental stress model has showed that child characteristics, the amount of children, the child's age, relationship satisfaction and experience of stigma contributed to parental stress in Lithuanian cohort. In order to understand what specific aspects of each variable were most stressful, I decided to interview parents about the findings of the model and if they were actually relevant in their daily parental stress experiences. I was interested in creating a parental stress definition specific to Lithuanian cohort. In the next chapter, parental stress is explored further using qualitative methodology.

Chapter 5. Grounded Theory of Parental Stress among Lithuanian Parents

5. Background

The disagreement of the main predictors of parental stress among parents of children with ASD raises difficulty in creating interventions and support programmes for parents. In Chapter 4, I explored potential explanatory variables for parental stress among Lithuanian parents. I have found that ASD characteristics (e.g. tantrums) internal relationships (e.g. couple's relationship satisfaction) and external relationships (e.g. experiences of stigma) were the factors contributing to parental stress. In order to test the validity of the model, I decided to use a qualitative method to explore in more detail parental stress and its predictors among the parents of an ASD child in a Lithuanian context. Especially, I tried to create the ways that would allow to understand parental stress between high and low parental stress groups and the relevance of the above-mentioned factors in day to day lives of families raising children with ASD.

5.1 Aims of the Chapter

This chapter aimed to:

- investigate in-depth parental experiences while raising a child with ASD in Lithuania;
- explore parental stress using grounded theory;
- expand further on the parental stress theoretical framework and potential explanatory variables.

5.2 Methods

Grounded theory is a qualitative approach developed by Glaser and Strauss (2006) that centralises on family studies. It has two major streams: 'objectivist and constructivist' (Taghipour 2014). The objectivist method claims it is possible to obtain objective truth and the truth waits to be discovered through the existing data in the world (Taghipour 2014). The constructivist method opposes such a notion and states that there is no objective truth and it is all relative to each person's experience. As a result, truth is constructed through interactions in the world and not discovered (Taghipour 2014). Also, these two types of grounded theory use different theoretical perspectives: the objectivist approach uses positivism which employs quantitative approaches, while the constructivist approach uses interpretation to explain a person's experiences in a meaningful manner (Taghipour 2014; Denzin and Lincoln 2011).

The purpose of grounded theory is to develop a theory for a process from the participant's data where the process is explained (Creswell and Poth 2018; Willig 2008). It is an appropriate method when there are no available models of a process, or the available models are incomplete or describe samples other than the one that interests the researcher (Creswell and Poth 2018; Willig 2008). It is appropriate to use this method in this sample because - as shown in the introduction - this study fits the two above mentioned criteria. Even though there are models of parental stress in parents of children with ASD, the existing models are incomplete or even contradict one another and there are no models describing parental stress among parents of children with ASD in a transitional (post-soviet) context. The current model in Chapter 4 has

not been validated and using grounded theory will serve as part of validation process for the parental stress model in Lithuanian families.

Unlike other qualitative methods (content or phenomenological analysis), grounded theory is more explanatory and less descriptive (Denzin and Lincoln 2011; Banister 1994). Therefore, for this study I decided to use grounded theory and try to explain parental stress in Lithuanian parents raising children with ASD, instead of describing the experiences therein. I also tried to develop a framework for this process that later can be tested on larger scale (Denzin and Lincoln 2011).

5.2.1 Participants

The study was conducted in rural and urban areas of Lithuania. The participants were recruited through the database from previous study *(Chapter 4)*, namely the parents that scored high (above 85th percentile) and parents who scored low (below 70th percentile) on the parental stress questionnaire. Only parental dyads were invited in this study, in order to interview both mothers and fathers of children with ASD. This was chosen because relationship satisfaction was one of variables in the model. Thus, it was important to understand further the perspective of parents on their relationships. Therefore, interviewing dyads would allow to see the same relationships from both father's and mother's perspectives.

5.2.2 Procedure

The data collection started in January 2017 and finished in April 2017. Data was transcribed and professionally translated within three months (March – May, 2017). Data was analysed from June – August 2017, using the NVIVO (QSR International Pty Ltd. Version 10, 2012). I contacted the families that

agreed to participate in the follow-up studies and signed consent forms in study for chapter 4. I contacted the parents and informed them about the study. There were parents that disagreed to participate due to the sensitivity of the study, lack of time or interest, and due to financial constraints. The parents that agreed to be interviewed were informed about the study with an information sheet. After reading the information sheet and asking questions, willing participants signed the consent form. Due to the personal (and potentially distress-provoking) nature of the interview, especially with regard to the parents from the "high parental stress" group, information on counselling services was provided. The parents were interviewed individually in public places, this was due to Lithuanian ethics regulations, which require to interview people in public places and not at their homes due to security reasons. Therefore, interviews were performed in public places such as libraries, parks or restaurants. Each parent was met individually and the same questions were asked to both fathers and mothers. The interview was conducted in Lithuanian and audio recorded with the permission of the parent, who signed the informed consent form. The semi-structured interviews took around 1 – 1.5 hours for each participant. All interviews were transcribed electronically during the data collection. The data collection stopped when data saturation was reached, which was based on transcriptions from the interviews and finding elaborate responses to questions asked during the interview.

5.2.3 Data Analysis

I read the transcriptions while listening to the original audio to double check the reliability of transcriptions. This was the first stage of familiarisation with the data. After the transcription, a professional interpreter translated the

interviews from Lithuanian into English, trying to respect the original verbal expressions related to the discursive context from which they were elicited. Certain Lithuanian phrases and idioms don't have literal, direct translations, however, the best approximation in English was chosen. The translation was performed alongside the original text. Non-verbal utterances, hesitations and pauses are omitted in a dry transcription. After this, I read all the translated transcripts, this was the second stage of familiarisation. After that, interviews were uploaded to the NVIVO 10 program and analysed.

The interviews were consistent with the methodology of the questions used to explore the elements of the parental stress experienced by the participants (Creswell and Poth 2018; Denzin and Lincoln 2011). Parents were asked to talk about 7 different domains: i) characteristics of child with ASD; ii) family dynamics; iii) ASD; iv) marital relationships; v) support; vi) society's perceptions; vii) advice to other parents *(Appendix B).* In the child characteristics domain, parents explored the abilities and personality of their child with ASD. In family dynamics, parents reported the relationship between the siblings (if applicable), their own relationship with the child and the daily routine of the family. In the ASD domain, parents spoke about the process of receiving the diagnosis, the acceptance of the diagnosis, the perception of the child's future and the coping strategies for daily stressors. Further in the interview, parents talked about their marital relationship; whether there were any changes and what methods they used to cope as a couple. After that, the parents spoke of the support that they receive from the government, their relatives, and their friends. In addition, parents also shared about the experiences of being in public and provided advice that they would give to

themselves (if they could) or to other parents who had just received the ASD diagnosis.

The interviews were transcribed, coded and analysed using the grounded theory framework (Glaser and Strauss 2006). The data analysis consisted of the open coding method, which is an analytic process by which concepts are attached to the observed data during the analysis (Banister 1994; Willig 2008; Denzin and Lincoln 2011). To assure the validity of the data a co-reviewer (MB) also performed the open coding for half of the interviews and then we compared our nodes if we disagreed on the coding we reviewed that part in interview and discussed until the agreement was achieved.

After open coding, elements of the parental stress were classified using axial coding. Axial coding is the breaking down of core themes found in the data (Banister 1994; Willig 2008; Denzin and Lincoln 2011). After axial coding, important categories and their interrelationships were identified. The codes derived from the synthesis a total of 17 categories. It emerged from initial codes with examples of direct quotes from the participants that supported the intent of the code (*Appendix C*). “Units of meaning” in the table represent times when initial codes were transferred to specifically focused code was found (*Appendix C)*. After that I re-read, compared, and revisited these words from parents. In the end, a total of 4 focused codes merged into the three axial codes *(Table 14).* The major categories and concepts that emerged from the interviews and the pathways were connected and explored in the result section.

Table 14. The focused codes that emerged out of the categories of the nodes.

Focused codes	Categories
Before ASD/Before diagnosis	"It was so sudden" Partner's denial of the diagnosis Discovering about ASD before official diagnosis Lack of professional knowledge
First year with ASD	Disability label Adaptation in life Lack of support Emotional roller-coaster
Present life with ASD	Child characteristics Reconciliation/Denial Stigma and rejection Spouse Relationship Support from the surroundings Parenting ASD child Relationship challenges Siblings of ASD
Future of ASD	Education Child's future

5.2.4 Ethical approval

The study was reviewed and approved by the Central University Research Ethics Committee Medical Sciences division at the University of Oxford (Nr. R45389 – RE001) and the Lithuanian Bioethics Committee (Nr. Dok24674). Permission was given for 6 months to collect the data and perform any follow up interviewing if data saturation was not reached. Due to ethics regulations participants were not reimbursed for their participation as it is perceived influencing their decision to voluntarily participate in research if monetary reimbursement is used.

5.3 Results

A total of 56 participants were invited to the interview out of which 17 agreed to participate (30%). The high parental stress group consisted of 9 participants (mothers *N*=5, fathers *N*=4) while the low parental stress group had 8 participants (mothers *N*=3 and fathers *N*=5) *(Table 15).* The main reasons for not participating in the follow-up study were as follows: too sensitive (*N*=10); financial and logistical issues (e.g. to hire a nanny) (*N*=12); lack of time (*N*=12); lack of interest (*N*=5).

Table 15. Demographic information about the ASD child

Child ID	Child's age	Severity of ASD based on clinical diagnosis	Parent (grouped by level of stress)
C1	7 years	Mild	Mother (low stress) * Father (low stress)
C2	12 years	Severe	Mother (high stress)* Father (low stress)
C3	6 years	Severe	Mother (high stress) Father (high stress)
C4	12 years	Severe	Mother (high stress) Father (high stress)
C5	8 years	Moderate	Mother (low stress) Father (low stress)
C6	7 years	Mild	Mother (low stress) Father (high stress)*
C7	13 years	Moderate	Mother (high stress) Father (low stress)
C8	4 years	Severe	Mother (low stress), Father (low stress)
C9	8 years	Moderate	Mother (high stress), Father (high stress)
C10	7 years	Moderate	Mother (high stress) Father (high stress)

*Refused to participate

I used well-established open and axial coding methods; themes emerged on parental stress in parents of children with ASD. *Figure 17-20* (p. 162–172) showed the influences of time (past, present and future), the gender

of the parent, the child's characteristics, the parenting style, society's view of - and attitudes towards - ASD, support, and family dynamics on the parental stress construct among the parents.

5.3.1 Parental stress across time

Time and gender emerged as overarching categories that mediated the participants' experiences of parental stress. Time theory highlighted that parental stress was dependent on time and its trajectories, such as "Before ASD/Before diagnosis", "First Year with ASD diagnosis", "Present Life with ASD", and "The Future with ASD". The interviews helped identify unique parental stressors at different time periods that parents encounter while raising a child with ASD. The "Before Diagnosis" key stressors were a sudden regression in the child's abilities, a lack of professional knowledge, the partner's denial of the child's diagnosis, and discovering ASD before the official diagnosis. The "First Year with ASD" key stressors were the disability label, adaptation in life, the lack of support, the emotional roller-coaster, and relationship challenges. "Present Life with ASD" involved stressors such as child characteristics, reconciliation-denial, stigma and rejection, and parenting differences. The "Future with ASD" key stressors concerned the child's future and education.

The second part of the theory was gender; mothers and fathers defined their attitudes and experiences of stress differently. There were key factors: family roles, parental methods, perception of ASD, sensitivity to stigma, and the child's future that mediated the levels of experienced parental stress based on parental gender.

In the following sections, I have explored further time trajectory and its interaction with parental stress.

5.3.2 Before Diagnosis

Axial code 1 – “Before Diagnosis”. Every parent begins their personal journey into parenting with the hope of raising a healthy, successful human who will contribute to society in a meaningful way. For parents in this study, this was also true. They defined the pre-diagnostic stage based on expectations of everything being normal. While clinging onto the idea of a ‘normal child’, parents described the instinct of something being wrong and seeking further information on the internet:

"*It was just, so to say, when I suspected this, I immediately started looking for something on the internet, everywhere, but we did not know the answers yet, and we got them only later from the specialists but before that I have never heard about this and nobody told us it could be this...autism” (FC8*).

The regression in the child’s skills confirmed the worries that parents faced even before they received diagnosis. Most parents stated that they felt lost and stressed because their child stopped developing and started losing their abilities:

“…and later he somehow, when he was almost two years old. He then even stopped saying those words which he knew” (FC10).

This strengthened the existing fears. The denial from the partner or internal denial had complicated the process of seeking diagnosis:

"…*so, maybe it was more with my husband with his denial. He was also trying to persuade me, but it was already very hard for me to tell myself, that no, everything is okay, there is no problem…when I can see the problem staring at me…" (MC6).*

Eventually all of the parents sought an explanation about their child’s behaviour, however, most of the parents encountered difficulty from medical professionals. There was a challenge in acquiring a referral for assessment.

Parents claimed that medical professionals (GPs) were not equipped in diagnosing and had stereotypical explanations for ASD symptomatology, e.g. boys start speaking later:

"…so, this was the probably the biggest problem, that our family doctor said that he will start, will start, everything is fine here. Even though he was hard to control and was walking, I mean, from corner to corner, all being restless, this was "problem" only to my wife and me, apparently…" (FC3).

Altogether this code of "Before Diagnosis" was developed to express the initial stage in the process of parental stress. It encapsulated the experiences of moving from a parent to a healthy child to a parent of child with ASD. Within this stage, parents experienced doubts and denial from their partners or themselves. They found that medical professionals lacked knowledge about ASD and interfered with access of early diagnosis *(Figure 17).* All these experiences raised concerns, worries and stress about the child.

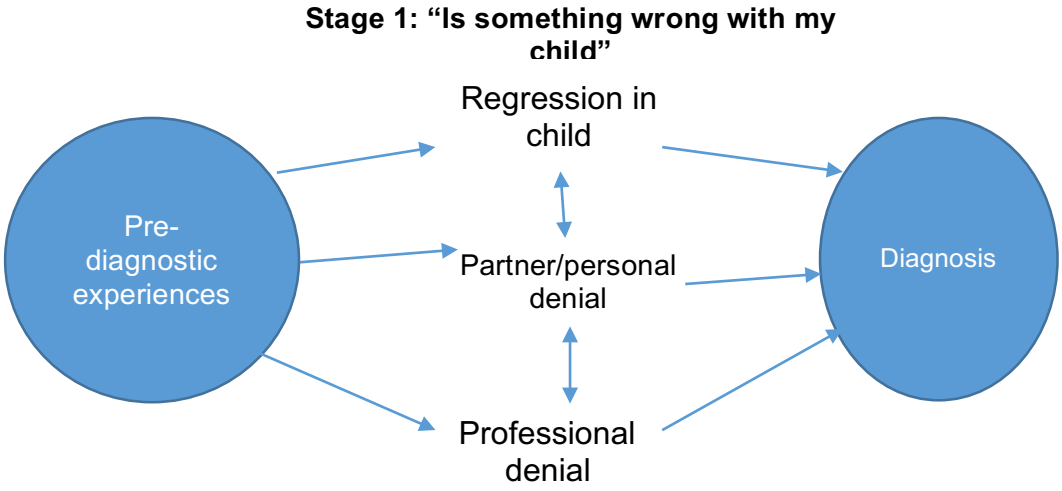


Figure 17. Axial Code 1 – Before Diagnosis

5.3.3 Diagnosis and Life After

Axial code 2 – Diagnosis and Life Post-diagnosis. Once the parents moved from the pre-diagnostic stage to actually receiving the diagnosis, the experiences of stress increased. Some parents described the diagnosis as

absolute fear that made them spiral into an “emotional rollercoaster” of despair and anger. This was explained by lack of structure and future steps after diagnosis:

“Obviously, it was that worry that when you hear the news you have natural reaction, it was, again depending from the age, education and etc., even more normal reaction but of course those 10 years ago autism was not even on the radar at all only now the education is getting more normal, but then it was like receiving the news of death sentence...it was just emotionally draining- you just get sucked into it” (FC7).

Other parents realised that their lives changed and they were losing the healthy child. However, they quickly moved from diagnosis into addressing the problem. Parents did not allow time to embrace diagnosis and restricted themselves from dwelling on emotions. They aimed in diminishing ASD symptoms:

"Your child is like every other child, he was growing healthy, there were no changes in life, everything was normal, but something was happening inside him. And I struggled to accept that he will not be like everyone else…him being not normal” (MC5).

Contrary to the above mentioned reactions, some parents experienced relief. Parents felt that diagnosis helped them to understand their child better and they could move forward:

“…not knowing what was going on probably bugged me the most, and it was bad for our relationship I think, yes. But when we found out it was a relief...a burden came off my shoulders...we made peace with it, and then we tried to know as much as we can about this disorder...” (FC8)

After parents came to terms with ASD diagnosis, most of them struggled with the disability label. In order to arrange financial support from the government, parents had to accept the term *disability*. This was more challenging than a diagnosis itself, because disability caries negative implications in Lithuanian society:

“There was not much information there about the disability. And we didn’t need to. I did not want to…Considering them as disabled is too harsh, they really

are able. We...uhm… this disability, they make it like… you know...incapable…especially in Lithuania…" (FC3).

After the diagnosis, parents started a transitioning period, wherein they had to come to terms with the diagnosis and move towards two pathways. Firstly, the family as a whole had to adapt their lives according to the needs of the child with ASD. The life aspects such as shopping, travelling, and visiting friends were changed in order to support the child. Due to a lack of post-diagnostic steps or advice, parents struggled in this process. Only through trial and error they learnt ways to live with ASD. For some parents, these adaptations made life easier but at the cost of being less sociable:

“Let’s say, shopping or going somewhere, is totally different, than it is with regular children. It is because, you cannot go to the concert with this kind of child, for example. Or at the shop. Now we can say that it is within the, normal limits, because you are able to control the situation at the shop and you adapt to the situations, but it takes time, nobody tells you how to do it…" (FC10).

“Until he was six he used to run away all the time, you had to hold him by hand. And it happened that our habits got smaller. We don’t go anywhere, we don’t do anything, and if we do it close to our home. Guests are very rare. So that was the change. Before that we loved to go on trips, travel, do something. So now with him is just… you don’t want him to be upset. Less stress, less tensions, less psychosis and so there is barely anything left" (FC1).

This code of “Diagnosis and Life Post Diagnosis” highlighted parental stress experienced after the diagnosis. It informed of the behavioural and emotional patterns that parents experience when they have to come to terms with an ASD diagnosis. Some parents experienced distinct fear and stress about their child, others experienced the loss of a healthy child, while others experienced relief. These experiences were not mutually exclusive and some parents went through all of them. These experiences were mediated by lack of post diagnostic support and recommendations for the next steps. In addition, the disability label and change in lifestyle instigated social exclusion that

heighten the experiences of stress. Parents also reported that they had to transition and accept the disability label and changes in life *(Figure 18).*

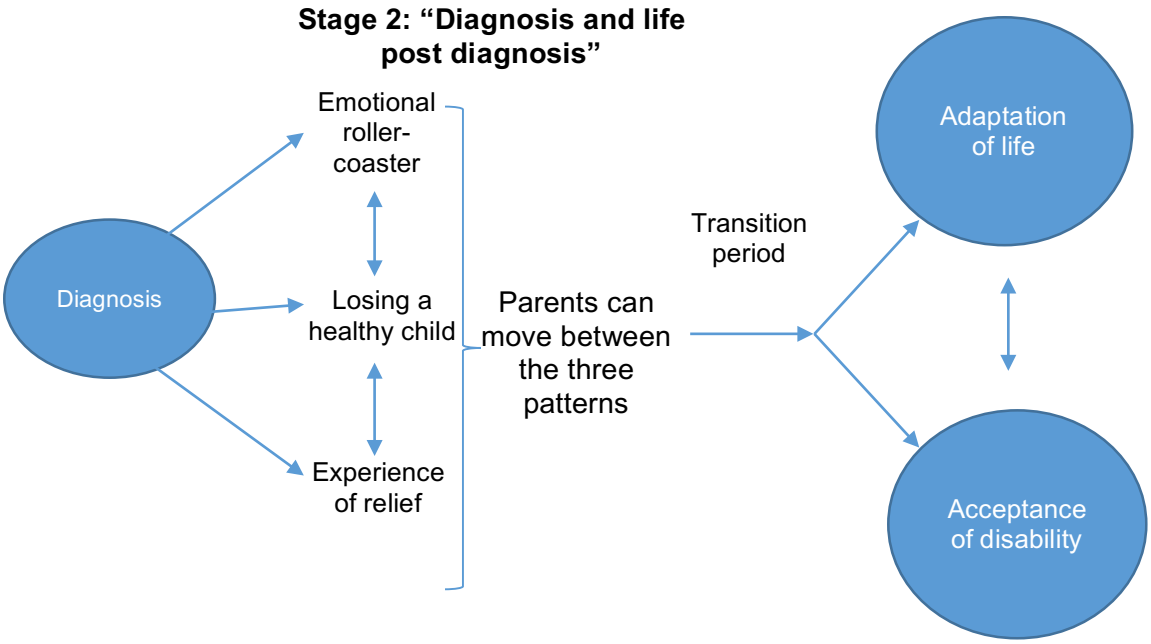


Figure 18. Axial coding 2 - Diagnosis and life post diagnosis

5.3.4 Present – Parent's Life with ASD

Axial code 3 – Present Life with ASD. The next major grouping of data clustered around present life with ASD. Firstly, parents had to re-learn how to parent a child with ASD because, up to this point, what they had learned or experienced about parenting was centred around a TD child. Parenting continued to develop together with the child. Participants claimed that they had to learn to manage specific ASD characteristics such as a lack of perception of danger, communication, and behavioural issues. Parents experienced agitation and stress because the child's perception of danger was non-existent. This was observed across the board, regardless of age and ASD severity. For example, parents had to be on guard constantly when they were outside:

"Yes, sometimes you have to be strict. But there are limits to that, in order for him not get out on the street or to start cuddling an angry dog. Yes, other children who are not autistic may also run to the street, but he is more likely to do so. Or to stop in the middle of the street" (MC3).

Another challenge parents experienced was a lack of communication, they stated that it was stressful when the child was sick and could not express if they were in pain. This was observed by parents of severe ASD children, who named a lack of communication as one of their worries:

"The major disadvantage is that child does not speak and we need to guess what she wants. That is a difficult. Language. Cognition that she does not comprehend and speak. Weakest spot. Yeah, yeah, yeah, that minus is the biggest, and is our problem. Because sometimes, I tell you, you cannot even know how to help her, because when the child doesn't speak and if it hurts and you don't even know…"(MC8).

Parents also stressed about behavioural issues (tantrums). This usually stemmed from the child's inability to express themselves:

"Angry with me, but clearly releases his anger at everyone. He becomes restless, then things start to fly around the house. As he does not know how to express himself, thus he simply to draw attention or else, but he has this very strong way of protest, this stresses me" (MC9).

Another aspect of daily life that parents named as stressors was the relationship with their 'healthy' children. All of the participants had typically developing children in their families. Parents stated that their personal relationship with the TD child was affected because of having a child with ASD. Participants relied on their TD children to assist them in various daily tasks. They found that their relationship with the TD child has changed and they worried that sometimes they rely on them too much:

"They have a good relationship, they normally fight, irritate each other, just like regular kids, at least I think like that…My wife and I have given her these feelings and responsibilities, so that she could look after him, help us. We imposed this on her, and we are trying to remove this. She started reproaching us, she sometimes says she needs something of her own, she is becoming a teenager. It is not easy for her… You buy her with attention or other things, try to compensate" (FC5).

Parents claimed that the TD child had to accept ASD and went through the transition phase while other children were still in the denial phase. Partially the denial from TD children comes from being ashamed of their ASD siblings. Thus, those parents whose TD children were in denial and ashamed of ASD sibling reported being stressed compared to those whose child accepted their ASD sibling:

"She really asks for attention from the birth. And now even more. She keeps asking why we let him everything, why he isn't speaking. I am trying to explain her he is different. She says how he is different if he is walking. She is usually upset…their relationship is quite problematic because of her being jealous" (MC4).

Parents also reflected that experiences of stigma were influential to significant levels of stress, knowing that their child with ASD will be rejected and mistreated caused grief for parents:

"You would see people and there was people, who had heard about it or seen it, or lived somewhere. The child is simply like... Person grows up, who doesn't speak, or is not capable of something - then people call him retarded. Like this popular expression, in older generation, like this idiot that everyone can mock" (MC7).

For some parents, this stigmatisation did not have a negative effect because it was balanced with the support from their friends and relatives. The support from the close family assisted parents in reconciliation with their child's disorder. In addition, this motivated the participant to move forward:

"So, because of that I really… If I didn't have it, maybe it would be harder for myself to survive all of this, but when you have these friends, who supports us…everything else seem less difficult" (MC8).

For other parents it was problematic because their relatives and friends added to the experience of stigmatisation. For example, parents claimed that visiting grandparents who did not accept the diagnosis - or friends who commented negatively about their child - increased levels of stress.

Stigmatisation from society and a lack of support from close circles influenced their experience of stress and strengthened the isolation:

"Again, this emotional intelligence, maybe it's a thing of generations, or else. It is not as developed as you would want. But they helped as they could, and all the time politely. To physically be with him they didn't want, didn't show any interest, and didn't wish to. Especially when he is bigger now, they say: 'We don't know how, we don't know', and that's it" (MC7).

Those experiences either led the parent to an experience of reconciliation or rejection. For some parents having to learn coping strategies with ASD characteristics, receiving support from their typically developing children and close environment directed them towards the path of reconciliation:

"How to say this, already eight years... more than eight years… we live like that. How to put this... we are trying... get out of the clutches of autism...So already eight years. It is not going easy, but it's going on. We accept what it is" (FC2).

While for others unable to manage their child with ASD's behaviour and experiences of stigma would stress the parent and cause them to slip even further into isolation:

"Most likely I did not accept that as I say I did. But maybe I am trying to close that page and open a new, white piece of paper so that I would get used to it, that nothing is wrong with my child. And we are trying to make it for her, so that her life would be easier...Probably no mother will accept this diagnosis as it is. That this child came to the world being special. Not like that. And, as they say, only strong people are given this challenge" (MC8).

The final stressor that parents named was conflicts with their partner. Participants identified 3 distinct causes of conflict: i) disagreement on parenting, ii) exhaustion, iii) lack of personal time. Thus, for most of parents, disagreements occurred because of the different perceptions of parenting. Fathers reported that they were stricter while mothers claimed to be more patient with their ASD child:

"It is not like we always agree, wife is more submissive and I am stricter...And if something doesn't work out, you try it one way or another...And we would get into arguments, but we still support each other and move forward" (FC1).

In addition, parents reflected that conflicts would start if they were tired. They reported that taking care of an ASD child is a 24/7 job and sometimes it became an overpowering task. Parents would lack respite and they would often feel exhausted, lashing out at their partner. This would cause conflicts and agitate the whole family:

"If I get tired I go to meet my friends alone, my husband or my son lets me out, or sometimes…because I just sometimes need the break, need to escape…caring for my child is a 24/7 job and I am not a robot" (MC4).

Finally, participants reported the importance of spending time together and balancing their lives. They claimed that a lack of personal time with their partner instigated frequent disagreements:

"One on one with my wife is a must...And that is all (laughs). You have to spend some time without children. Sometimes we take the kids to our parents for the weekend, we spend some time in the same city, relax somewhere without the kids…this helped as a lot to not get crazy and just live life for our kids." (FC8).

This code of "Present Life with ASD" highlighted the parental stressors that parents raising an ASD child face daily in Lithuania. It highlighted that parents are led towards two paths; acceptance or rejection. These experiences were not mutually exclusive and some parents went through both (one after the other). Parental stress was mediated by the effectiveness of coping strategies, the relationship with their TD children and their partner, and support received from the close family. Thus, these were the daily stressors that families of children with ASD faced. Some parents managed them well and moved towards reconciliation. For others, the inability to manage daily challenges led to chronic stress and isolation. Those participants isolated themselves and suffered silently (*Figure19).*

5.3.5 The Future Worries

Axial Code 4 – The future of ASD in Lithuania. This cluster of codes explained what particular stressors parents faced when thinking about their child's future, namely the uncertainty and societal attitudes. Stigmatisation from society influenced the parents' perception of the future:

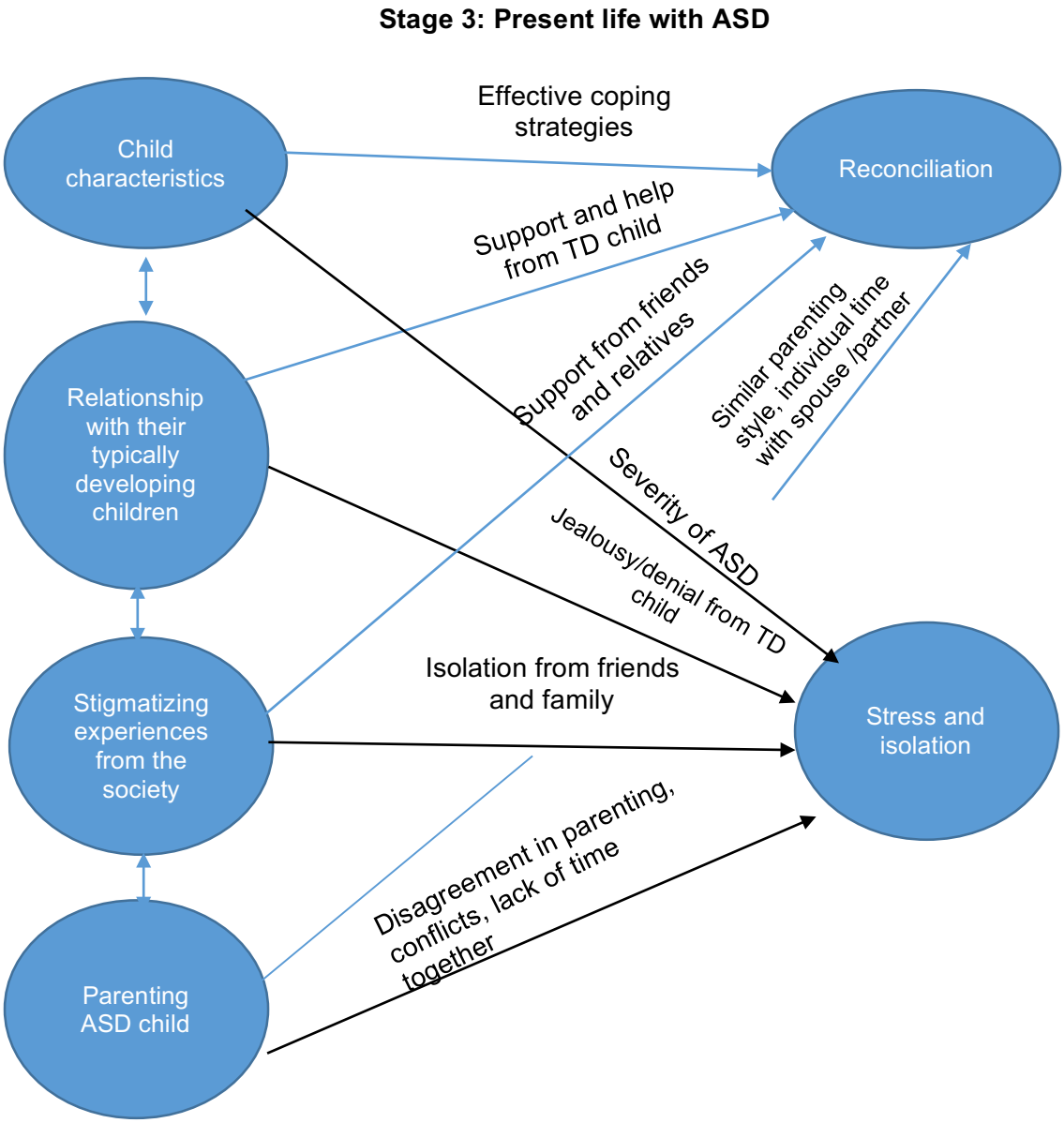


Figure 19. This summarizes the daily life experiences and potential stressors of parents with ASD child

"Yes, we do have a problem with him. Problems not only within him, but also with his social inclusion. Yes, here in Lithuania. I think that strengthened it. Because of course us... Well, it is difficult to talk about it, but we talk. Lithuanian society does not understand what it is. They think that autistic children are uncontrollable and unsound. The Lithuanian society does not have understanding what autism is and what kind of spectrum it is...that makes me worried…" (MC5).

For most of the parents' thinking about the future was stressful and emotionally challenging because it was tentative:

"Well yes. Everything stands in its place, worrying about the future, because the future as I think is foggy. Anyways this diagnosis will not go anywhere. This, it is not the illness, first of all. As many confuse them. Well simply, this all independence, future...Internal. This internal fight between yourself... If it is now that I am always worried about what the future will be like... during that time these worries were even bigger" (FC3).

Even after accepting their diagnosis and reconciling themselves daily with the situation, parents could not envision their child's future positively. All participants revealed their underlying fears and anxieties concerning the current situation on mental health in Lithuania, as they have heard stories about the lives of adults with ASD shared by other parents:

"We understand that one day we will be gone, and people with this syndrome live a long life, and what will happen next. It is not like everything is clear like it would be with a normal child, and this is not a usual situation, all of this is different. Sometimes you cannot even see what changes you need to make or what to do it make it better or more comfortable...Well the unknown… Who will look after her, where she will live? Maybe our children will not want to look after her and have this burden, maybe we will have to put her in a home, and this is the most difficult thing. While we are alive you can take care of her, but later… [Gets emotional, starts crying]. Maybe somehow it will get solved" (MC8).

Another aspect that worried parents in the present but also in the future was their child's education. Parents reported the struggle between public and special schools, they explained that their child could not thrive in public school, however if they put kid in special school it hindered the development of their social skills:

"Before we had this aspiration, so that he would go to school with all the kids, so that he would learn by the special program, with assistant. As it happens, it is also happening in Lithuania. But we realised that this won't work now, because he is unable to speak. If he would speak just a little, maybe it would work...Because in regular school, teacher might not understand, easily dismiss this child. It is twenty of them sitting in the class, thus I have to keep on going with them, I have this problem, and I need to move on. This topic is for discussion, but at the moment it is as it is. We are letting him to this school and we see, that there are things which I would like to change myself. But in general, it is not bad. And we see that little by little, there is something, there is progress. <...> Maybe, maybe someday it will happen" (FC10).

Thus, when talking about the future, parents underlined their worries that were driven by societal attitudes towards ASD. They also struggled to envision the positive future of their child in Lithuania. Furthermore, parents found education to be challenging and choosing school for their child psychologically tiring *(Figure 20).*

Stage 4: Child's future or "what will happen if I die"

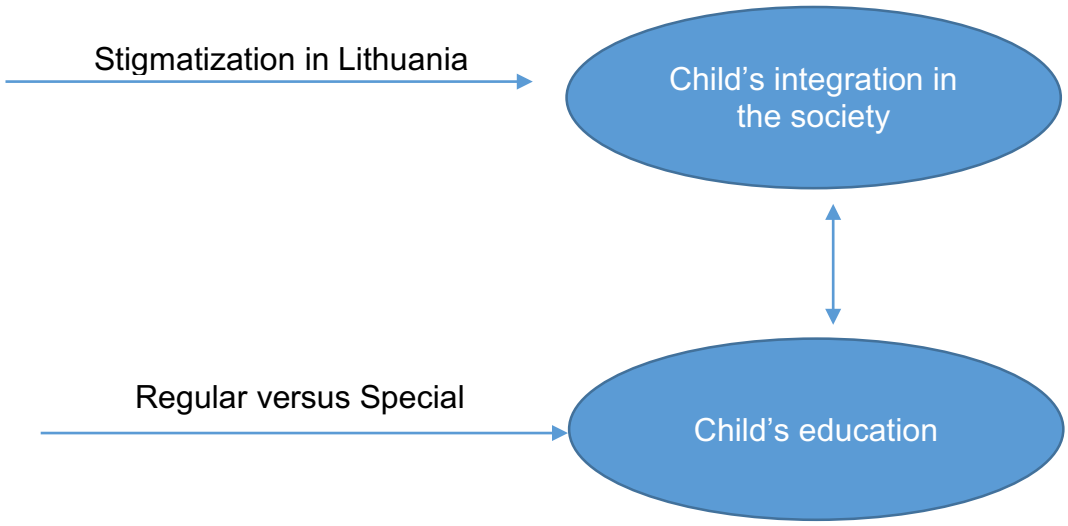


Figure 20. Shows potential stressors when parents think about the future

5.4 Discussion

While parental stress has been well studied in the literature, as previously noted, the specific aspects of parental stress in the ASD cohort is far less recorded. Furthermore, the question of how parental stress evolves in

general and specifically in the Lithuanian population remained unanswered. The focus of this chapter was to address the existing gap in literature by identifying an emergent theory that might explain how parents of ASD children experience parental stress in a Lithuanian culture. It was noted that this literature gap is a concern because there is an absence of knowledge and places limitations on developing effective intervention options for parents raising ASD children.

To address this question, grounded theory was selected. It was found that “Time” was a crucial aspect of parental stress experience in Lithuania. The intensity of experiences in each stage varied across each parent. Previous studies have demonstrated that individual differences in stress and coping strategies are moderately stable over time (Hartley, Papp, and Bolt 2016; Loepp 2015; Lyons et al. 2010; Thomas 2017). Parents of children with developmental disabilities who have effective coping strategies are less distressed when the child demonstrates the improvement in different stages in life (Shepherd et al. 2018a). However, in this study I showed the exception to this general conclusion. Although this may be true on average, some parents experience a remarkable decrease in parental stress over time as they adapt to life and accept the diagnosis of ASD. In contrast, the parents who developed coping strategies can still find themselves highly distressed and isolated even later in life. The results indicated that stress evolved and it was not linear but ever-changing and developing.

In the beginning, parents realised that their child was different and sought help. However, they faced denial from either the partner, family, or medical professionals. This seemed to be a primary stage of parental stress,

experienced by all the participants as they transition from denial to seeking answers. The latter brought parents to the second stage of parental stress (and ultimately the diagnosis). The deliverance of the diagnosis increased stress. Participants experienced parental stress that fit into one of the three categories: i) emotional roller-coaster, ii) losing a healthy child, and iii) experience of relief. However, results demonstrated that these categories are not mutually exclusive of each other. The review by (Bonis 2016) showed that parental stress was acute at the time of assessment and diagnosis, with parental adjustment improving over time for most. The parents had major concerns of the following steps after accepting the given diagnosis. The study by (Broberg 2011) has shown that early diagnosis contributed to parental stress in its own way. A large factor of this could be attributed to the parents' worries concerning their children becoming "labelled", thus not rushing to accept the diagnosis. Also, there were different levels of ASD severity and impairment across the families. It was observed that parents of children with severe ASD found diagnosis as an explanation of what is wrong with their child. They viewed it as a better parental adjustment, whereas resistance or denial was more observed among parents of children with moderate to mild severity of ASD. Nevertheless, parents of children with severe ASD (especially with severe behavioural challenges) had higher levels of chronic parenting stress in prolonged periods. Multiple studies have suggested that changes in the behavioural problems accounted for the highest decrease in parental stress across time (Firth and Dryer 2013; Hastings 2003a; Schieve et al. 2011; Zablotsky, Anderson, and Law 2013). It might have been a statistical artefact due to high correlations between time and behavioural problems. This can be

explained that parents of children with ASD have more re-occurring stressors that maintain or increase the parental stress in different periods of time (Benson 2014; Pozo and Sarria 2014). For example, in this study the education and uncertainty of the future were the new stressors for families whose children were due to be starting school soon. Parents realised the lack of systemic support in mainstream schools and worried for their children never being able to be independent. Thus, parents had to learn to deal with challenges across their child's lifespan. These included: navigating health systems, then receiving diagnosis, and then adapting to daily hassles and relationship challenges with their ASD child, spouse, and TD children. Arguably one of the largest challenges was to secure the future for their ASD child while battle the educational system. The results showed that sources of stress occur beyond the child with ASD and the family and included the lack of support, services, and the high level of stigmatisation in the society (socio-cultural aspect).

When the timeline shifted to the present, parents reported 4 different stressors: i) ASD characteristics in their child, ii) relationship with their typical children, iii) societal experiences iv) parenting together. This stage demonstrated that experiences of these stressors led parents onto two distinct paths: reconciliation or isolation. This stage was about learning and gaining the tools necessary for daily life with an ASD child. The access of the tools determined how these stressors were experienced by both groups. Those the path of reconciliation had to learn coping strategies, build a relationship with TD child and spouse, and receive support from the close environment.

The transition from stressors in the beginning involved gathering and accumulating resources, such as information about treatment and potential interventions. Parents found it extremely stressful after the diagnosis leaving the hospital as they got either too much or too little information. Parents reported being overwhelmed because of the amount of information and found it difficult to find the next steps, while others reported feeling lost because they lacked information about the potential help available (if any). This supports the conservation of resources theory by (Hobfoll, Schwarzer, and Chon 1998). It demonstrates that parents inherently are motivated to gather and keep resources. There are 4 categories of resources: objects (material goods), conditions (status), personal attributes (personality), and assets (knowledge and money). When there is psychological distress (in this case parental distress), these valued resources are placed in jeopardy or even lost. Thus, parents try to counteract this loss by utilising what resources they have left in order to maximise the recuperation of what was lost, and hopefully increase the amount of resources available to them (Hobfoll, Schwarzer, and Chon 1998). Therefore, stress rose when resources were threatened. The findings have shown that perception of demands, parental role and access to resources for meeting the demands of raising a child with ASD played a significant role in coping success. Mostly, stress occurred when demands exceeded the expectations and actual resources allowing parents to manage their parental role. The accessibility of resources and coping strategies are the core explanation of most theoretical framework of stress (Abidin 1992; Beck, Steer, and Garbin 1988; Deater-Deckard 2004; Lazarus and Folkman 2015; Schieve et al. 2007b).

Parents also demonstrated different patterns of adaptation to distress. Results showed that one parent was more in denial and coped less effectively than the other. This challenges previous findings by Doss et al. (2009) who showed that partners have similar patterns of adaptation in stress. On average, if the mother experienced high levels of stress then so did the father. They also found that both parents increased in parental stress over time. However, distress tended to occur more rapidly in fathers when their children were young, whereas for mothers the increase of distress was gradual over a 10-year period (Doss et al. 2009). In addition, social support was most useful for coping among mothers, whereas problem-focused coping appeared to be most useful for fathers (Doss et al. 2009). These findings were supported in this study.

The results also informed about the two existing frameworks: Parent-Child relationship (P–CRT) and Daily Hassles (DS). P–CRT is based on the resources available and maintenance of P–CRT. This theory is more inner focused, explaining the relationship development with a child with ASD (Abidin 1992; Beck, Steer, and Garbin 1988). According to this theory, the stress is located in different domains: child, parent, and child – parent. This theory explains the parent's own functioning (psychological wellbeing), while child domain stress is mostly linked with child attributes. The parent – child relationship is explained primarily by the conflicts attributed to the parent and child. This theory claims that the effect is bilateral, meaning that the child influenced the parents and the parents influenced the child. Although results showed that the parental stress mechanism unfolded over time and involved both parents and children, the adult's stress reaction to the demands of

parenting was a key factor that propelled the process forward. The findings also have shown that parenting stress deteriorated the quality of parenting and increased the child's emotional and behavioural problems. When parental stress decreased, the parenting and the relationship with the children improved.

Another theory explaining parental stress is Daily Hassles, which emphasises external stressors in the daily life of the parent that arise from taking care of the problematic child (Webster-Stratton 1990). Parenting stress occurs nearly every day. For parents of typically developing children, daily doses of stress are usually small and not manageable. Webster-Stratton (1990) stated that daily hassles are part of the parenting stress process. Its effects have to be serious and in an extreme form to create a potential threat to the parent's identity or role. Understanding the daily stressors of parents of a child with ASD underline how those daily hassles become unmanageable. The results have shown that effective coping strategies became crucial aspects in dealing with daily hassles. When parents learnt to cope with the changes in daily life after the diagnosis, the stress decreased. Thus, adaptation to daily stressors was part of the job and of high importance to family functionality that was arguably tantamount to the very definition of success in parenting. The findings complimented both theories but also extended the explanation of parental stress in ASD parents.

5.4.1 Partner Support and Parental Stress

The quality of the parent's relationship with their spouse or partner was also noted in experiences of parental stress. For most parents, this relationship served as a primary source of comfort and support in facing the daily

challenges of child-rearing. The study by Bluth et al. (2013b) demonstrated that lower levels of distress were found among parents who reported greater satisfaction in their relationship. On the other hand, a marital relationship serves as a major source of distress if there is disagreement, conflict, and disengagement. For example, children with behavioural disorders tend to have parents with more distressed marriages (Johnson et al. 2011). In this study I have found that, for most families, the relationship stayed stable or even became stronger. Parents stated that helping their child provided a common goal. Also, spouses identified that similar parenting reduced the stress on their marriage. Evidence from intervention studies suggested that when children's behaviour improved, family relationships advanced (Kazdin and Wassell 2000). The study by Hartley et al. (2010) has shown that marital difficulties were greatest in those pairs who demonstrated the largest differences in their reactions to their children's illnesses. Results have supported these findings showing that partner denial was one of contributing factors of distress when acquiring diagnosis. In addition, parents reported that there are differences in parenting styles. Mothers claimed to be more patient towards their children while fathers were more impulsive when dealing with challenging behaviour of the child. Also, analysis has demonstrated that in Lithuanian families the parenting dynamics were traditional; the mother was expected to take care of the child-rearing and the husband was there to provide financially, as found in previous studies (Melnikienė 2005; Simanavičienė 2011). Similar results were found in a Polish sample where parental roles were traditional among parents of children with Asperger's (Pisula and Porębowicz-Dörsmann 2017).

5.4.2 Lack of Support from the Society

The results have explained that the parents' view of disability was driven from overall societal attitudes towards disabled people. They claimed that disability is a verdict for their child and reduced the prospects of inclusion. Parents resisted the process of acquiring disability status for their child. Similar findings are reported by Russell et al. (2012) who showed that parents - after hearing about the child's diagnosis from professionals - went on to resist what they termed "the labelling" or "verdict". These were the parents who chose to "act to retain the 'normal' status of the child and avoided the diagnosis". Correspondingly in this study, parents resisted getting disability status for their child and receiving governmental support because of societal exclusions attributed to the label 'disability'.

When talking about the future, parents expressed different types of challenges that increased stress. This was mainly driven by the aspect of stigmatisation. Parents worried for their child's future and integration. They reported that experiencing stigma from the public made them realise that their child will not be accepted by Lithuanian society. One of the stressors was about their child's life when they would not able to take care of them. This stressor was reported from the beginning of the diagnosis; most of the parents said that receiving a diagnosis was associated with an uncertain future for their child. They were stressed not only about ASD-related problems but also about the challenges (imposed by society) of raising such a child. The second stressor was the child's education, as most of the parents had young children they experienced the stress of acquiring education for their child and the stress of facing the schooling system in Lithuania.

These findings show that parenting does not exist in isolation but works within the community and cultural context, which influences parenting stress. Parenthood constituted a social role that is highly valued in Lithuanian society. Parents must meet their own needs and those of their child, while also managing the demands placed on them by the community (friends, relatives) and the broader society. Thus, parenting stress occurred from feeling pressured by society to raise a child according to the norms. The socioecological framework by Bronfenbrenner (1996) placed the individual child at the centre of an extended series of concentric spheres of influence *(Figure 21).* Thus, the findings demonstrated that the *exosystem* has a direct link to parental stress in Lithuania, with stigma and lack of support from the society (*macrosystem)*.

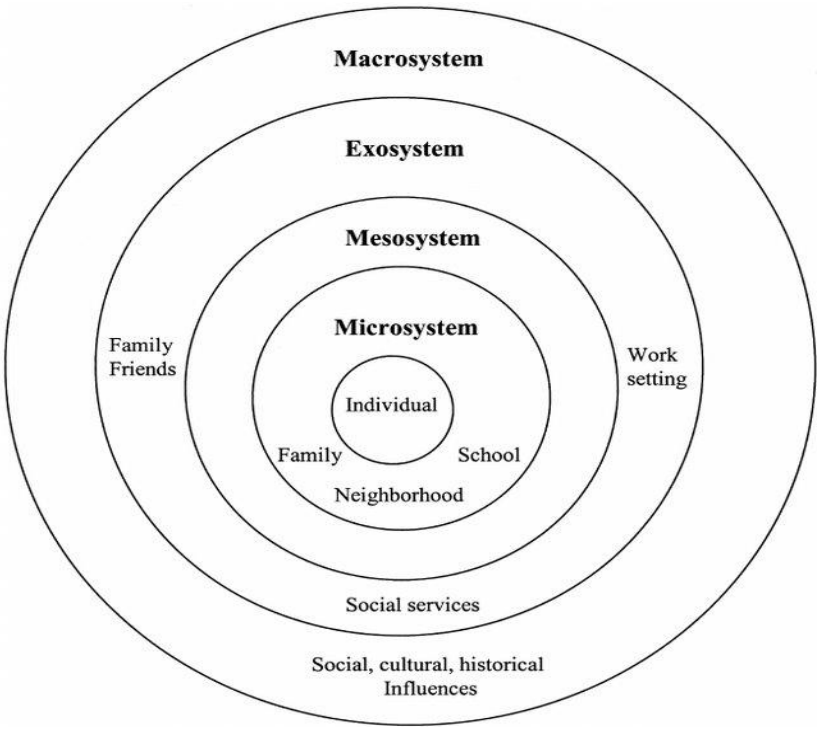


Figure 21. Bronfenbrenner's ecological systems theory (Bronfenbrenner (1996)

The results identified two types of coping with experienced stigma: i) significant isolation in order to avoid the stigmatising behaviours or ii) adjusting their lives and ignoring public comments. Although national and community social policies powerfully impact the lives of parents, the informal community support and interaction were most important in determining how parents coped and adjusted to parenting a child with ASD. Parents with lower levels of support and high stigmatisation were more isolated. Teti et al. (2017) demonstrated that parental distress and harsh parenting was more common in a household where parents were isolated. This indicates that providing community contact and support to parents in need (e.g. respite care) can reduce parental stress and benefit not only a parent but family as a whole (Cowen and Reed 2002; Floyd and Gallagher 1997; McLennan et al. 2012). In short, the links between parenting stress and society are complex. Parents reported that negative societal attitudes and stigmatising behaviour contribute to their experiences of stress. This chapter underlined the issue of stigma which is less explored in Western societies, and usually concentrated on the clinical model of ASD (Eremin 2011; Bernier, Mao, and Yen 2010; Canino and Alegría 2008).

The findings lead to understanding the complex system of the outcomes of parenting stress. A broader framework is needed to address additional factors such as parent perception and attitudes. These components are interconnected and operate in transactions that include bi-directional influences between the individual and society, between the person and adaptation, and between the person and coping strategies. Thus, more

research is required to examine cultural influences on parental stress in Lithuania and constitutes the topics of the next chapters.

5.4.3 Parental stress in Other Countries

The findings on parental stress experiences were similar parents in United Kingdom and United States 20-30 years ago, when there was little help and information about ASD. The stigmatisation and isolation were common factors that parents in USA and UK experienced (Kinnear et al. 2016; Papadopoulos, Lodder, and Randhawa 2017). In addition, previous research also showed that negative messages and difficulty in accessing services were common challenges that USA and UK faced (Parkin 2016; Montes, Halterman, and Magyar 2009). The changes in NICE (UK) and A.L.A.R.M (USA) guidelines has shown how the challenges mentioned above were addressed. The toolkits created for parents to help their children and access of information after diagnosis played significant roles in changes in the parent's reports and their psychological well-being. These similarities to the USA and the UK have helped to outline what the potential trajectories are for the upcoming 20 years in a Lithuanian context. It is already visible that parent organisations which are providing support to other parents are the main advocates for ASD in Lithuania. Therefore, the help and strategies used in the UK might be transferred to a Lithuanian context. This could save time and resources when searching for the best outcome for the issues named above.

5.5 Implications

This study has begun to answer the question of how parents raising children with ASD experience and cope with parental stress. This chapter suggests an emerging theory, regarding the process of stress and showed the

influence of time and provided the initial framework. Thus, every parent is at a different stage within different levels of parental stress. There is heterogeneity of experiences. The data identifies different aspects of stress depending on the trajectory and location of the parent at that specific moment in time (i.e. before or after diagnosis). As with all grounded theory, it is important to replicate these findings several times, and to shift the theory, if merited, from emerging towards established. Thus, for the future, it is important to replicate the findings with diverse groups. Also, within the proposed emerging theory, this study identified an overall process that offered discussion regarding two subgroups within this population taking different paths (acceptance or rejection) along the process of parental stress. This definitely requires further investigation as it has been facilitated that these subgroups differentiated in parenting behaviours, coping skills, and parenting methods.

5.6 Strengths of this study

This is study has described parental stress phenomena in a Lithuanian context, which provided specific information of potential factors that contribute to this experience. It also elaborated on the model built in Chapter 4 and helped explaining more in–depth which aspects of ASD, partner's relationships and stigmatisation are the most stressful for Lithuanian parents. In addition, this study allows to understand the conditions and needs of stakeholders, which can be used further to build upon intervention and support programmes for parent's raising children with ASD in Lithuania.

5.7 Researcher's Role and Limitations

I faced several challenges during this study. The first one common for all grounded theory research is being objective and putting aside personal

ideas about the nature of the process (Creswell and Poth 2018). I had read much on the topic of parental stress and was very interested in the effects of stigma and coping strategies. As a result, my interpretation might have tempered the objectivity and influenced the formation of the model by overemphasising some areas and underemphasising others. Therefore, constant awareness of one's own notion is required. To overcome the challenges and ensure trustworthiness, I used a co-reviewer that analysed half of the interviews, the agreement on the categories and their relationships was produced. This method is recommended by Hays and Singh (2012) to assure trustworthiness, the guidelines were taken from their paper. Finally, I documented the process of data collection and analysis carefully, to ensure that the results were justified by the experiences of the participants.

A general limitation for this study and any other qualitative study is the sample size as it is too small to generalise any conclusions. This study included the experiences of 17 parents selected from the previous sample in Lithuania. Caution should be taken with generalisations to the overall population of parents of children with ASD in Lithuania as the restricted sample allowed for only the experiences of these few participants to act as the voice of many.

Additionally, an inherent difficulty in studies about parenting stress is that it is a subjective construct, leading investigators to use self-report assessments that are subject to response bias such as defensive responses. In contrast, many child behavioural problems can be determined using observational measures, which may be more objective than parent reports. Given that parenting stress and child behaviour problems both were assessed

with parent-report questionnaires in the present study, shared method variance is a concern.

5.8 Conclusion

The primary purpose of this study was to explore parental stress among Lithuanian parents and enrich the findings from the previous chapter. As the number of children diagnosed with ASD increases exponentially each year, it becomes more pressing that clinicians working with this population have tools and information that support and motivate parents. Recognising that there are few studies that have investigated parental stress while raising an ASD child in Lithuania, the results of this study take on a greater importance. It is imperative that what is devised must take into consideration the perspectives those who need help, and be grounded in theories that are applicable to the population of interest.

Chapter 6. Focus Group Discussion - Experiences of Professionals and Parents of Child with ASD

6. Background

The previous chapter has demonstrated that a lack of support from professionals (education and medical) was an important factor for parental stress that was not significant in the model but were reported throughout interviews. Parents have told that lack of professional support significantly contributes to their stress experiences. Therefore, it was important to understand the interactions between parents and professionals. In order to caption the causes for lack of support for parents. I aimed to understand both sides because it would provide a broader picture and different perspectives about the same topic – parental stress and parenting a child with ASD.

The present research was conducted to further explore the experiences of professionals and their perceptions, knowledge, and attitudes about ASD and parental stressors while raising a child with ASD. The previous studies have shown that professional support is a mediating factor of parental stress (Dardas and Ahmad 2014; Elder and Alessandro 2009; Moh and Magiati 2012). Logic dictates, and the record shows, that professionals who are more knowledgeable in ASD help to reduce parental stress more effectively when delivering diagnosis. In previous chapters, Lithuanian parents reported that they encountered difficulties from medical professionals when acquiring the diagnosis. Also they shared their worries about the child's education and the challenges they face to assure their child receives adequate education.

6.1 Aims of Research

The following aims were derived in advance from the results of Chapter 5 and the research was carried out in Lithuania to:

- investigate the knowledge about ASD among various professional groups;
- examine the diversity of experiences and assess the challenges that different groups encounter;
- analyse the access of different resources and support systems available to professionals and parents;
- compare and contrast professional and parental perceptions of ASD;
- evaluate the reasons of conflict between parents and professionals.

6.2 Materials and Methods

This study investigated professionals' experiences and views on ASD in comparison with parental views. Professionals' attitudes and perceptions were explored via focus group discussions (FGD), which are a social method of obtaining research data through informal group discussions on a specific topic (Nili, Tate, and Johnstone 2017; O'HEocha, Wang, and Conboy 2011). This methodology was chosen to provide an opportunity for participants to compare experiences, develop ideas, and explore issues of importance (Denzin and Lincoln 2011; Krueger and Casey 2014). Ethical approval was obtained by Oxford University Medical Science Division Ethical board, Ref: R45354/RE001.

6.2.1 Participants

In order to maximise the diversity of experiences in Lithuania informing the investigation, a range of professionals' subpopulations were identified: general practitioner vs specialised; mainstream school teachers vs specialised school teachers; experienced vs less experienced; highly exposed to ASD vs less exposed to ASD; knowledgeable about ASD vs novice; rural vs urban. *Table 16* provides details of the focus groups.

Professionals were grouped as *experienced with ASD* if they answered positively to all questions below, otherwise they were grouped *less-experienced.*

> *Q1. I have been working with children with ASD more than 5 years. Yes/No*
> *Q2. I feel confident in providing my services to families with children with ASD? Yes/No*

Professionals were considered *highly exposed to ASD* if they answered positively to a question below, otherwise they were considered *less exposed to ASD.*

> *Q1. I am exposed to children with ASD regularly (once or twice a week) in my work setting? Yes/No*

Professionals were grouped as *knowledgeable about ASD* if they answered positively to all questions below, otherwise, they were grouped as *less knowledgeable*.

> *Q1. I can provide the definition of ASD and its characteristics?*
> *Q2. I think I am knowledgeable about treatments/ therapies for children with ASD available in my field?*

In terms of how the parents were grouped and categorised, mothers were coded with capital M and the letter of the pseudo-name, while fathers

were coded with capital F and a participant number. The parents were coded differently to make it easier for researcher to identify when comparing the data.

Table 16. Focus group composition

Group abbreviation	Group composition
GP	General practitioners, urban, less experienced, less knowledgeable, less exposed to ASD
SP	Specialised doctors, urban, experienced, knowledgeable, highly exposed to ASD
BM	General teachers, urban, less experienced, less knowledgeable, less exposed to ASD
BM	General teachers, rural, less experienced, less knowledgeable less exposed to ASD
SM	Specialised teachers, urban, experienced, knowledgeable, exposed
M(letter)	Mothers of child with ASD (child's age ranged from 3 to 14 years)
F(number	Fathers of child with ASD (child's age ranged from 3 to 14 years)

6.2.2 Procedure

The selection of professionals for the focus groups was purposeful: participants voluntarily responded to advertisements placed around their workplace or replied to the email provided in the newsletters of their organisations. Parents and professionals were interviewed separately. A total of 7 FGD lasting approximately 60-75 minutes each were audio recorded, with 6-8 professionals and parents. The discussions were conducted in the participants' workplaces, before or after their work or in the library (for the parents' discussion). All the participants received an information sheet and consent form prior the discussions to familiarise themselves with the study and prepare any questions before the start of the discussions. I introduced and explained the study the partakers. Their attitudes towards working with the

children's parents, as well as their thoughts on the ASD situation in Lithuania and the difficulties professionals in their field faced were discussed in these FGD. Participants signed the consent form. Afterwards, I introduced a colleague who took field notes and recorded significant body language or facial expressions after the FGD started.

All FGD were transcribed electronically. I read the transcriptions while listening to the original audio to double check the reliability of transcriptions. This was the first stage of familiarisation with the data. After the transcription, a professional interpreter translated the interviews from Lithuanian into English, trying to respect the original verbal expressions related to the discursive context from which they were elicited. Certain phrases don't have literal, direct translations, however, the closes meaning to English language was chosen. The translation was performed next to the original text. Non-verbal utterances, hesitations and pauses are omitted in a dry transcription. After this, I read all the translated transcripts, this was the second stage of familiarisation. After that, interviews were uploaded to the NVIVO 10 program and analysed.

6.2.3 Data Analysis

The data was coded using the Thematic Analysis method. Krippendorff (2004) defined thematic analysis as "a research technique for making replicable and valid inferences from texts (or other meaningful matter) that are later combined into subthemes and themes and analysed considering the context of their use" (p. 18-19). I familiarised myself with the data and produced the initial codes (Flick 2009). The codes were classified into relevant categories based on repeating themes that emerged throughout the data, and

were then divided into sub-themes. This method is favoured by Braun and Clarke (2006) as it is a well-known method to approach thematic analysis. The key aspect was to examine and detect the themes in each FGD that was transcribed and then look across all the data to find the topics that were repeated across different groups (Braun and Clarke 2006). Howitt (2013) stated that this type of analysis allows the themes to emerge instead of being speculated or chosen randomly by the researcher. This ensures that the participant's experiences are generalisable and not specific just to one individual, which is important for a scientific study. In addition, FGD is more appropriate for the generation of new ideas formed within a social context while one-to-one interviews probe individual experiences and encourage self-reflection on issues that could be distorted if social pressures were not placed on the individual.

To ensure objectivity, a reliability check was employed before making any claims about the prevalence of certain attitudes. An independent researcher, M. Bernote, who has extensive experience with qualitative data analysis and is trained as a clinical psychologist, was given the list of codes and asked to identify sentences/groups of sentences and match them with the code. According to Breen (2006) and Lindsay, Breen, and Jenkins (2002), code–to–sentence must match 80 per cent of cases to claim high reliability. In this study, excerpts from each FGD (consisting of approximately 200 sentences) were given to the independent researcher to code. The reviewer was provided with excerpts that I had performed and assured that those excerpts were appropriate, then she match them with the nodes that I have provided. The code–to–sentence analysis matched 83 per cent of cases

between the independent researcher and myself, the needed revisions for the codes were made and a consensus was reached. This ensured the objectivity of the analysis. In addition, I paid close attention at the level of agreement of statements and treated issues on which there was disagreement with caution. Then I have grouped the nodes into sub-themes and after that into subthemes.

The next stage was to group the emerging themes and to remove the themes that had limited data and were weaker in generalisation (*Appendix D*). The Thematic Analysis step-by-step guide by Braun and Clarke (2006) was used for this study and the following steps were applied (*Figure 23*). An accurate description of each theme and subtheme was provided by using direct quotations from the FGD to better explain professional and parental perceptions.

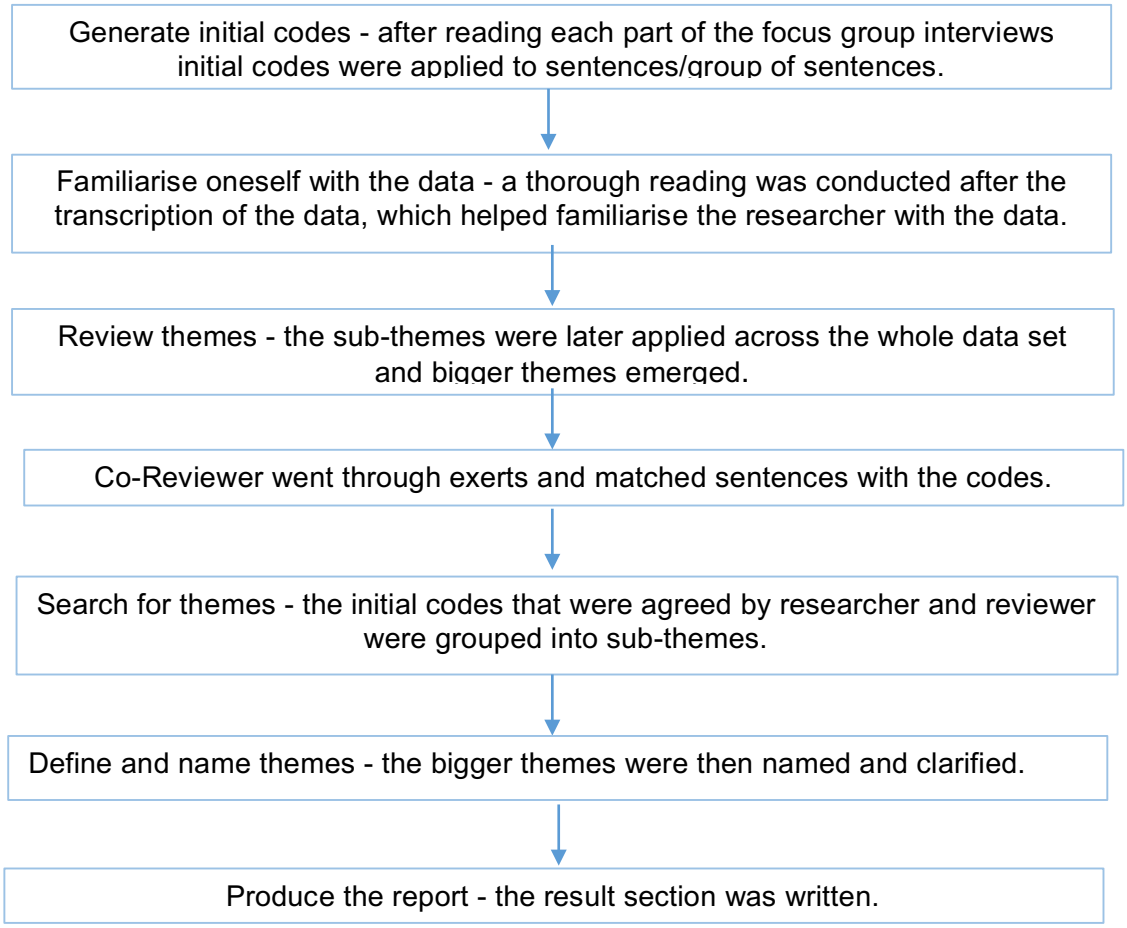


Figure 23.The steps used to analyse FGD data

6.2.3 Ethical approval

The study was reviewed and approved by the Central University Research Ethics Committee Medical Sciences division at the University of Oxford (Nr. R45354 – RE001) and the Lithuanian Bioethics Committee (Nr. Dok25621). Permission was given for 6 months to collect the data and perform any follow up interviewing if data saturation was not reached. Due to ethics regulations participants were not reimbursed for their participation as it is perceived influencing their decision to voluntarily participate in research if monetary reimbursement is used.

6.3 Results

The key themes mentioned across groups were: i) knowledge about ASD ii) receiving diagnosis, iii) resources and support iv) education and integration v) stigma in the society. The findings have shown that there is agreement among all the FGD participants on stigmatisation that people raising a child with ASD experienced in Lithuania. They talked about the detrimental effects it had on parents individually and the family as a whole. They also agree on a lack of resources and support for these parents, which in the participants' opinion added an additional burden to an already negative situation. All groups mentioned the absence of a systematic approach towards treating ASD and the deficiency of governmental responsibility in creating methodological steps to assist parents in raising a child with ASD *(Figures 24–31, p.197–214).*

6.3.1 ASD Definition and Perception

In the beginning, parents were able to provide clinical definitions of the disorder, but later in the discussion they reflected more on their personal views of ASD. They claimed that their view of ASD changed over time, and experienced different stages of grief. Also, ASD became part of their identity and lifestyle. In addition, fathers claimed that ASD altered their dreams and future:

MK: so, it happens that autism allows us to become better moms… ML: yes, yes
MF: yes, these children are our biggest teachers in the family, they teach us what we lack and we really are grateful for that [smiles]. So, this is good.

F4: When we heard the diagnosis, anyways, the child is born, you plan, the ideas of school, graduation, grandchildren… When you raise the child, you have these ideas, and when you learn the diagnosis everything stops, at least for me. Then I had thoughts what to do next in this whole thing, how to help [smiles]. So, the expectations are more like dreams, you hope and you know, that everything will be okay and then you try to live on…

6.3.2 Long Road to Diagnosis

Retrospectively, parents reported the unwillingness of GPs to refer for diagnosis. Their initial concerns were deflected by doctors and attributed to global developmental issues. They were assured that children would "grow out of it" or that "boys speak later" and the parents should not compare. As a result, this resistance may have caused delayed diagnosis and delayed access to treatment. They all wished to have received the diagnosis earlier than they did:

ML: I had the suspicion that something was wrong and my husband used to tell that I shouldn't look for something that wasn't there, and at first the doctor used to say the same but I felt that something was wrong, the result was not right, and what I noticed is that there is not enough information and even at medical practices there was always a lack of information [moms nodding - agreeing]. The rooted opinion that don't expect anything and don't raise your children by the ruler, this child is different and no one said where to look for help, and what other ways are there to help this child and so on, and when finally, at three and a half years old, we demanded to be hospitalised and be sent to the child development centre....we got diagnosis.

F1: We were worried from when he was three, but then they said boys…boys, and we didn't look on the internet what autism was but rather about development in general....and discovered it there so GP was clueless…

At the time of diagnosis parent's experiences were mixed. Some parents stated that they received support and tools to work with the child, while others described the experience as dreadful and extremely stressful. The importance of support, sensitivity and putting parents at ease were the qualities appreciated by parents. As a result, this empowered them to work with their child. Other parents experience hostility in the deliverance of diagnosis and highlighted a lack of optimism in prognosis. Therefore, they reported that hope for the future was diminished. Some parents were even discouraged:

MV: When I was told at the child development centre: "Accept that she is different, she will never be like majority." I was sitting there and thinking: "I want to choke you with same words that you are telling me." [Angry] I am sorry for my words, but I always wanted to shut up the doctor [from CDC] and said to myself that my daughter would have her life, she would graduate from school, she would have her family, children, I will devote myself whole but she would have all the best. And that belief pushes me forward. The CDC takes hope away from the mothers… [The mothers agree and nod].

The majority of parents felt that there was a lack of direction when leaving (CDC), particularly the future steps to take and access to benefits available. The lack of information forced parents to source everything themselves, from treatment, to welfare funds, to support groups:

F5: I lived through all of it in myself, after CDC as there was no information for what is next but then we took some instruments and move forward. Nothing will get better if you sit and do nothing, you have to think, and you have to move forward.

MV: When we were two we were in the CDC and we were given a pile of printed information and we were told 'go read and work.'
-'Jesus, yay, thank you very much' Yyy... What could I say...? I was in shock.

Summarising their experiences, parents wished for a more efficient

process of receiving the diagnosis. Time was named as crucial resource for children with ASD and early intervention would have provided the best outcome *(Figure 24).*

MD: - So, around two years old, but before we could get to the specialists and get documents it took a year for us. And it came to that point when I requested the doctor to issue me the document to see the specialist... and then...we got the diagnosis…but we lost precious time due to waiting.

F2:- Even when we realised that something was wrong, it was not a quick process in receiving diagnosis and being told what is happening to your child. We had to battle with our GP to give use the referral, than we stood in the queue to CDC and that was 6 months, precious 6 months. So in total we wasted 8 months approximately, which could been used for his therapy and support. This is soo upsetting! This is one thing that should be improved. We have just couple of places where you can get your child diagnosed for the whole country…

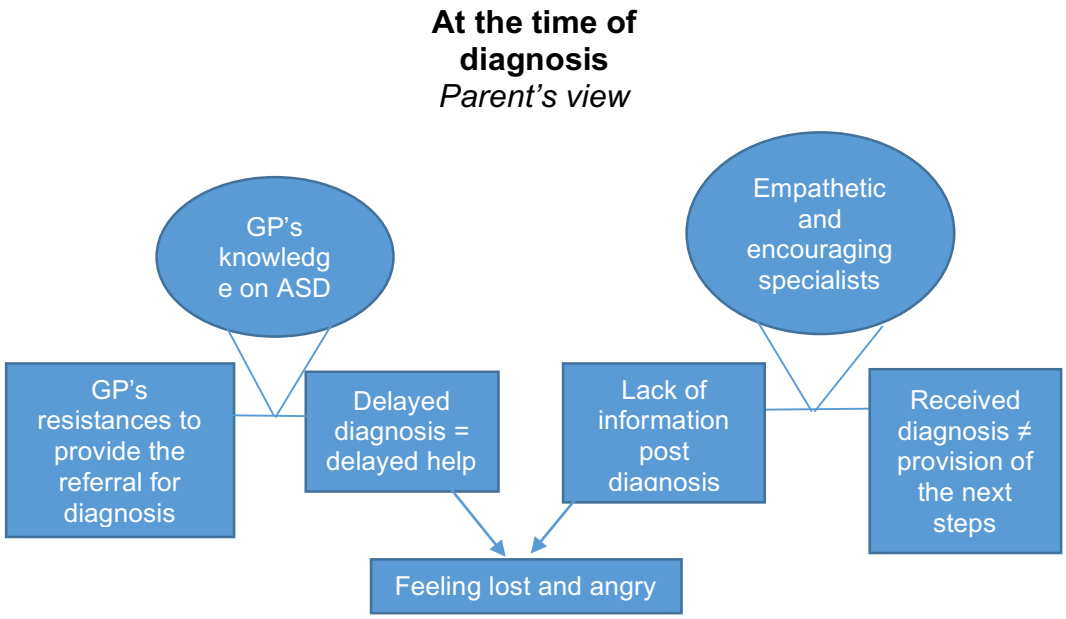


Figure 24. Parent's experiences with professionals at the time of diagnosis

6.3.3 Resources and Support

Parents underlined that their key support system was close family members (spouses and/or children), other parents of children with ASD, and various therapists. The family members acted as immediate support during

difficult times. The first support source for the parents were their spouses. Both mothers and fathers reported that their relationship as a couple became stronger due to the common goal of helping their child. When asked about divorces, parents (divorced ones) stated that they occur not because of having disabled child but because of differences in personality. Also they claimed that relationship discord happened even before the child was born:

F1: You cannot say that the disability breaks the family. This depends on the personality of the adult. If there is a big dose of egoism or some gaps in the family, then such child can just end everything, if the process started before, or if the person is not very good… But if you were raised right, you love your wife, you become even stronger I think [other fathers agree].

MJ: We split right before we learnt the diagnosis and he learnt about child's disorder via Skype, because he was working in Denmark at that time, after that he had depression, he really felt worried and came back to Lithuania…I think it was more difficult for him to accept than for me.

Parents stated that approachable and knowledgeable specialists can be part of a support network and provide encouragement. They reflected that (after diagnosis) to find specialists in their close environment was challenging. They wished to receive information about the links or suggestions where to look for specialists:

F5: And later on, the autism didn't look as scary. It didn't scare us so much, maybe then we knew the treatment, rehabilitation, help us all through this process...yeah the importance of therapist early in the process...

Also, throughout the group interviews, both mothers and fathers kept stating that their inner strength and motivation was the foundation they relied upon. Parents claimed that in an environment that is hostile and not supportive (i.e. 'constantly on your own') it all depended on their inner strength and their personal choices *(Figure 24):*

F1: you must understand very clearly that while you have an autistic child in Lithuania, especially if you live in the countryside, you are alone. And not because the relatives leave you, but because you are the only one who solves these problems. Nobody else does, right now, you are the only one who makes

the decisions, nobody cares, you can do whatever, and you can even choose to do anything with the child…

MJ: I quit my job, got another one, got a salary raise, I can do anything, who if not me? Why should I trust the government, so I thought if there is no suitable school, then I will fund one…And when you believe yourself, then everything works and even family helps.

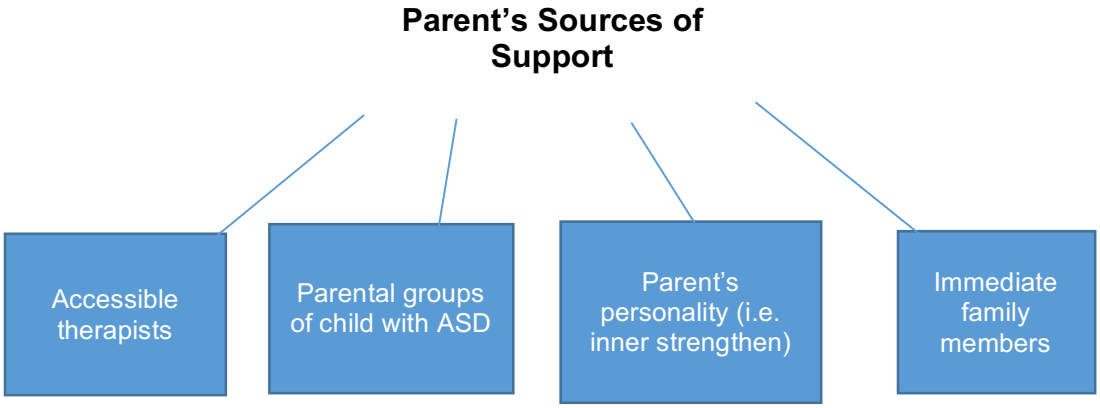


Figure 254. Parental resources when raising a child with ASD

Parents highlighted the financial burden of accessing the therapies and guilt of not being able to afford the best for their child. They highlighted that behavioural therapies produce the most effective results but they are also the most expensive:

MA: we do everything ourselves, there aren't much finances... it is very difficult, and nobody helps us…all we can afford is walking and being outside with the child if he is not in school…after school activities are too expensive…

F4: Sometimes no matter how much you want it, you don't have financial resources... it becomes really hard not to provide the best for your child…

When asked about financial support from the government, parents became bitter and angry, the discussions started to be sarcastic, highlighting the disappointment. Parents joked about their unfortunate situation. Several perspectives were identified, namely that the welfare money is not enough and governmental structures are not built to support children with ASD:

F1: There is nothing in Lithuania, just some angry isolated institutions that send you "under the bridge", you know. So, we looked for the legal ways to protect our rights, and Lithuania has ratified the disabled and children right convention

seventeen years ago. That means there is no law. Our children are not protected by a law, only by the constitution, which says that the treatment for the children is free. And that you must get an education. But the government's understanding that you must take the child at seven to school, even if he better went when he is eight. This is the government's position. There is nothing else. We can't even go to the court, because there are not specific things in the laws, it is ratified… What it means? It is the government's obligation to add these things to its laws during a certain period…

When asked what helped to move towards acceptance all parents claimed that seeing progress in the child provided necessary hope and allowed them to move forward:

F3: You fall to the abyss, then something suddenly happens, and of course expectations grow. The results are also positive, I won't lie. So, the expectations keep growing, they will never be the same as for the healthy child, but they are normal, they stabilised…

MF: So maybe at the beginning we were trying and nothing worked for a very long time, only then we went deeper to understand how to do everything correctly, and in the last year we can see how everything is working and there is a progress, and now my husband sees how everything improves and our relationship got better and he takes it and I can see many positive things, even our family got stronger…

6.3.4 School - Specialised or Mainstream?

Several points were identified with regard to specialised or mainstream school experiences. Parents wished to be informed of therapies and treatments. They wanted to be informed about educational sources for their child as it provided parents with sense of control and assurance for their child's future.

6.3.4a Integration Issue

Parents experienced resistance from the school administration and other parents in general schools. They argued that specialised schools can provide resources and were more knowledgeable about ASD. Parents claimed that they want their children to be exposed to neurotypical children, while in specialised schools their children do not progress well, because they are

exposed to children with developmental delays. Other parents argued that specialised schools are good because of the experienced teachers and the argument that their child would not be abandoned or ignored. Teachers would be able to work and the classmates would not bully their child. There was dissatisfaction and complaints surrounding mainstream schools for not trying to accommodate their child's needs and providing inefficient education. Parents claimed that a lack of knowledge and understanding of ASD were perceived to be the reasons for the school's lack of effort. It also reduced trust in teachers as they perceived them untrained and uninformed about ASD:

Interviewer: - Bullying by the kids..?
MI: - Yes...MD: - Yes, by children, by peers... Particularly by the peers. They can spot the weakness. They will use it that this child does not understand things. They will blame that kid for everything, it is easy to provoke that child.

F3: When it comes to general education… We evaluated the situation with the wife<…> that we won't be able to go to a general school. There is no need to go above our abilities, as we see it now. Maybe later we can change this.

6.3.5 Stigma in the Society

Parents reported that they received judgemental comments and stares from the public. There was direct criticism such as being a bad parent and not being able to control one's child. The comments occurred when the child had a tantrum. It was misinterpreted by people as an "ill-mannered" child. Parents attributed these comments to a lack of awareness and tolerance towards people who have different looks or display unique behaviours in Lithuania. They also mentioned that the normal appearance of the child creates even higher levels of stigmatisation, as the disorder was invisible to the eye *(Figure 26):*

MK: If before I had this difficult reaction, especially in the street when strangers would make remarks such as "oh, what a badly behaving child, this lady will take you", yes, I see how they look at my child, because he is smart and he

can speak, so very often they look at him like he is really bad.

F2: In Lithuania if someone sees a disabled person, at first they have a reaction of rejection, then the cold wall "I don't see anything", silence [everyone agrees]. If my son is not acting typical, speaks in his autistic language, and his tone, he makes it unnatural, you feel something is not right. Then you can hear "a fly in the air", it is silent. Nobody says anything, but you know…they understand…
F3: They listen…attentively and observe. Then typical reaction ignoring and isolating people.

Views on the stigma

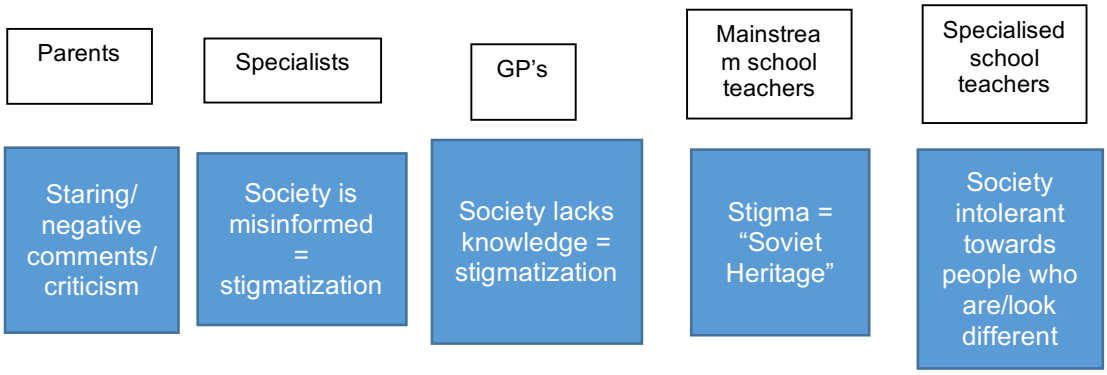


Figure 26. Views on the stigma and ASD across different FGD.

Most parents ignored comments or attributed that to "Soviet mentality"; only few of them acted defensively and confronted the negative comments:

MA: I said to him "wait, I told you, we have to pay for it first" and then he would have a tantrum and then these ladies would look and I would say "yeah, why are you looking, he has documents [refers to diagnosis papers], he is like that, why are you looking, is it like a circus to you?" They would reply "what kind of mother are you" and I would say "yes, this kind of mother, we have documents, mind your own business". And that is all.

Medical professionals (both family doctors and specialists) stated that they are aware about the stigmatisation parents experience because of their child with ASD. GPs stated that society is misinformed about ASD and is not interested to know more about it, unless they know someone affected. Specialists had even more examples about how strongly ASD and mental health in general are stigmatised in Lithuania:

GP6: My child cannot go to school, not because he is unable to learn, but

because other kids are disturbing him…bullying him…
GP1: But these things hurt, they read something somewhere, but I think that the majority of society does not…Is not even interested in autism unless they have a child with a problem… Then they start looking for information.
GP7: Or in the family. Otherwise, why should they be interested?

SP7: And I think that the reaction from the strangers not only in this institution, but in the streets, in stores as well as I see it from parents, is so negative. It is not motivating, but there are parents who stop trying, because what can you do, and this society's view has a really negative emotional impact.
SP2: Mostly people know the name. But they don't understand what they know is only a tiny part of what autism really is, mostly their understanding is wrong. For example, the kindergarten teacher informs that there will be an autistic child in the group. The first reaction is that the child will bite everyone, beat, without the teacher finishing the explanation. Maybe the child speaks, is behaving well. But the primary reaction is of "dark autism", "the ugly autism". A big part is because of the society or people who do not encounter autism.

Considering both special and general school teachers' opinions on negative and society's views of ASD, they reported that the reasons for this were a lack of knowledge, 'Soviet heritage', and negativity towards people who are different *(Figure 27):*

SM5: Everything is really sensitive now. I talked two days before with a mom, her child has some features of autism, so they say...Her boy started wanting something in the store and became very loud and disruptive. So, there was an old woman who was walking and mumbling how bad of a mother she was, how she didn't know how to raise her child, how she needed to hug him, help him and etc.
SM2: A mom of one of students said, I had them for a short time: "When we learnt the diagnosis, we lost almost all of our friends and part of the family, the grandparents turned away from us…"
SM4: Since my class is quite strong, physically able, I always try to take them somewhere with the public transport. The last we heard so many things in the trolleybus. We were being cursed from the time we got into until our last stop, because Y [Pupils name] got tired and lied on the ground. So, if you had to hear how everyone talked about us "as if it was your fault" – repeats SM6…
SM3: Unpredictably. The initial reaction. In addition, it is the same with the parents, when they say, why are you not disciplining? Why are you not doing this or that? The parents are constantly consoling to us. You go to a supermarket or a park…
SM2: Parents say that whenever they go, they cry.
SM5: The society doesn't know that this child is behaving like that because of the disability…

BM1: Disabled people were a taboo in the Soviet Lithuania, the biggest taboo.

Look at the Soviet Lithuania, the soviet building, was there even one made suitable for disabled person? Of course not, we were brought thinking, different people (disabled, homosexuals and etc.) are dangerous and unstable, hence should be institutionalised…
BM4: In general, the Lithuanian society, Lithuanians are terrible, intolerant for different people. PERIOD. Yes, just a little different person and straight away. He is like that or like that. We label. Disabled people are considered in a lower than we, and our people are very… critical, so critical, old-fashioned...
BM2: Lithuanians are intolerant to everything and everyone, not only to disabled people, also to sexual minorities...I would say things are changing younger generation are different but things are slow, very slow in this matter...I remember, God forbade, you were different in Soviet times, you are bullied by everyone, pupils, teachers, school by people in the street...those were the times, this is the heritage from Soviet times still alive and well today.

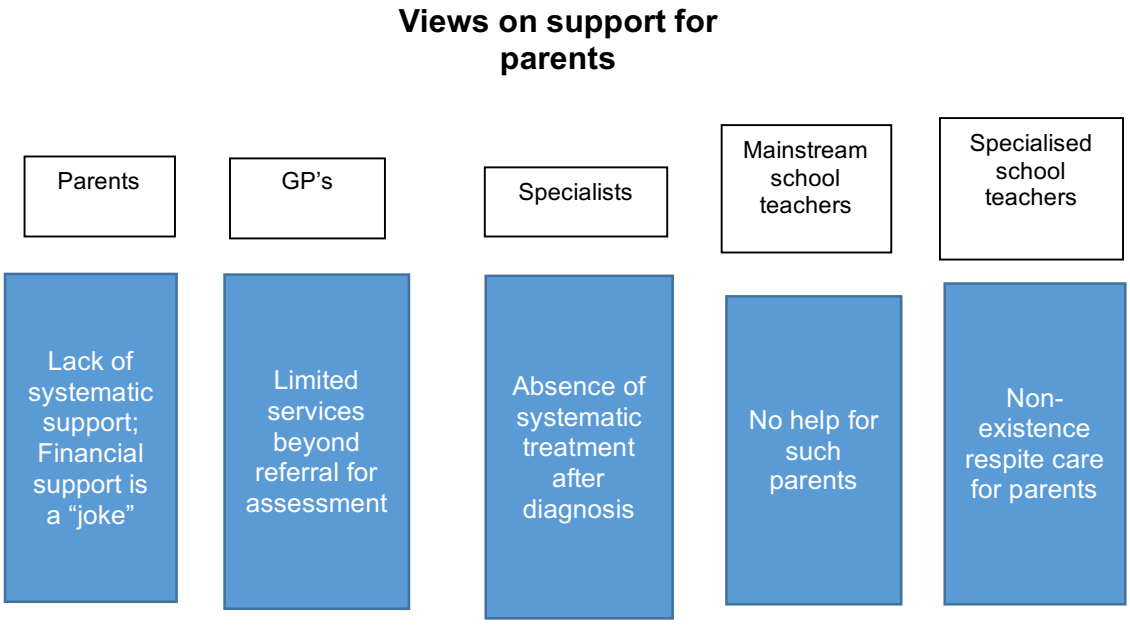


Figure 27. Absence of systematic support for parents with ASD child

6.3.6 General Practitioners and Specialist

6.3.6a Knowledge about ASD

When asked to describe ASD, both GPs and specialists stated the key aspects of the disorder: they claimed that it is a spectrum, characterised with behavioural challenges and communication issues. This was contrary to the parent's statement that GPs lack knowledge about the disorder. This could be interpreted that GPs were knowledgeable because they had patients with ASD

(Figure 28):

GP1: Autism is a very broad concept, with many symptoms and I don't think I can clearly tell you, but they have problems in their everyday tasks, have slower development. These are the main things.

SP2: It has the main features that appear very individually, and this is a different way to view the world. These impairments can be somehow a little bit compensated when using certain strategies.

GPs stated that they still encounter parents who refuse to vaccinate their children because of the Measles Mumps Rubella (MMR) vaccine scandal. They stated that parents want to understand the cause of their child's disorder and for some parents vaccination becomes the legitimate explanation. They also claimed that it was hard to disprove this theory for the parents, despite their efforts in trying:

GP1: Some time ago it was told that the composition of MMR might have some mercury and that is how autism is caused, so who gets vaccinated, those get autism. Some still think about this because of the stupid article from twenty years ago…

GP3: yes, and parents who have children they look for a reason/cause and ask about vaccines, I can deny the information but they still do not accept.
GP2: Nobody believes it, if they [parents] have this idea in their heads, you cannot change it…

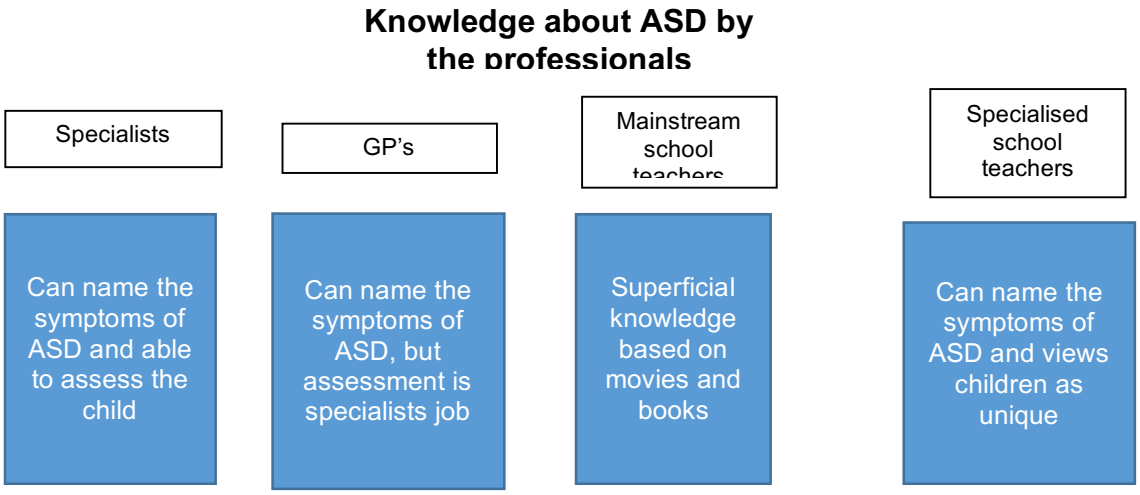


Figure 28. Professional's knowledge about ASD and its symptoms

6.3.6b Complexity of Diagnosis

When asked about the practicalities of diagnosis, GPs stated that parents have to wait in a queue before they receive diagnosis. This long process delayed treatment that could only be prescribed after the diagnosis. It confirmed previous statements made by the parents about long delays in receiving the diagnosis. When asked if there is a possibility that GPs do not know about ASD. They stated that the diagnosis was a specialist's job and not theirs, hence why they would not (and perhaps should not) know details about ASD. Also, they stated that ASD is a recent diagnosis and given rarely, most of the time specialists gave F83 (according to ICD-10), which is not ASD but an 'easier form of developmental delay'. This was also noticed by the parents who claimed this mix between F83 – F84 made them more confused than assured *(Figure 29):*

GP1: And working with speech therapists, waiting for a long time, they make an imbalance, and you get the answers, I look at the name and surname, and I see that the child was here a year before, in the child development centre, and I get the answer only now, and you do realise that I needed this a year before, not now… There are many problems in this area…
MV: And then there is a code after which one follows child autism, so.... when I asked at the CDC, they told me: "So, is diverse development disorder - autism?" They answered: "Yes, let's say so." MV: So, that's how it is... MD: The disorder codes differ...and are mixed…

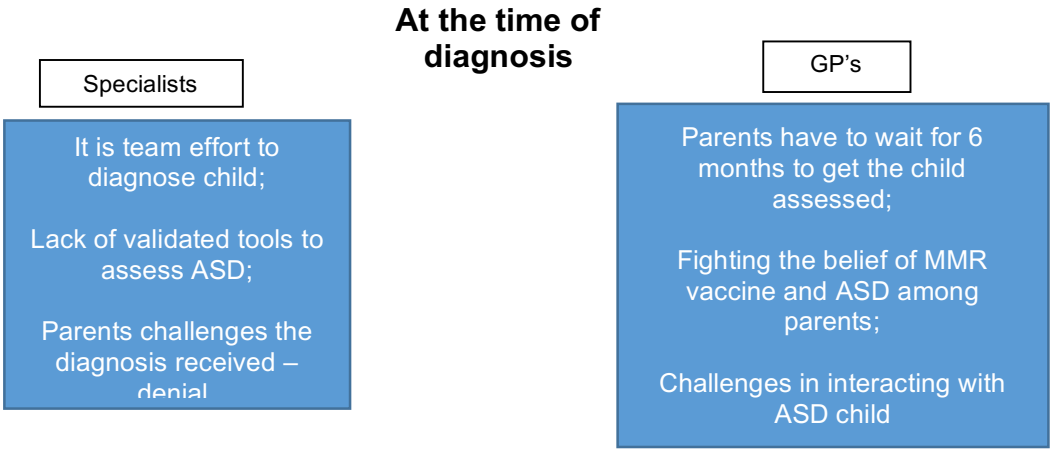


Figure 29. Medical professionals view on ASD and diagnosis

Specialists claimed that ASD is a complex diagnosis, requiring a team effort in order to have a broad picture of disorder, there is a lack of validated tools. Thus specialists diagnose children with ASD based on their experience. Having a team of specialists allows to diagnose a child with confidence:

SP2: Everything adds up from the tests that mostly psychologists use, we as speech therapists don't have specific instruments to evaluated autistic children. We rather use clinical observations, because in general we, speech therapists, don't have any adequate evaluation instruments in Lithuania. Everything goes to the everyday experience and the opportunities you get from the workplace.

6.3.6c Interactions with the Parents

Considering GPs' assertions that interacting with children with ASD was challenging due to child's behavioural characteristics: 'resisting', 'running around', 'talking'. Strategies used to address this issue were developed in collaboration with parents. Together they agreed to bring the child only if necessary and - when coming for the visit - parents prepared the child in advance. Another challenge was working with parents on the denial of diagnosis or resistance of disability. GPs stated that their services beyond referrals were limited. Also they claimed that treatment information should be provided by specialists:

GP6: Yes, the parents cooperate, they understand that this is their child…
GP4: They don't think that the medical specialist...will come and fix everything…
GP7: There is one that you talk with parents and their child is running around they just do nothing while others come and you can see they are prepared and everything is explained, how the appointment will go, and you talk very specific things and child understand all this…

GP4: Of course, the first step is that they always deny, that no, this is not happening to their child…
GP6: I have a girl with Asperger's syndrome and the mother knows that, but she doesn't go to psychiatrists here, she only goes to private practices, she just needs helps because she doesn't want this diagnosis to be written down, she understands but doesn't want the disability.

The parent-specialist partnership was problematic: specialists experienced a variety of negative emotions from the parents. Specialists agreed that it was a natural reaction after diagnosis. However, specialists found it challenging to distance themselves from parents' negative comments. They also reported that parents were concerned with prognosis and the lack of interventions supported by the government. As a result, parents would challenge the diagnosis. The resistance came in the form of a passive observer. Parents would not get involved in activities related to child support. These findings were in line with parents' claims about resisting the diagnosis and seeking optimism in the prognosis from the specialists. In addition, specialists felt that there is little that they can offer after diagnosis as there is no systematic approach to treatment to direct parents to 'the next stage of help':

SP3: I worked for more than twenty years but it still is extremely difficult to be the one who tells the bad news, because all developmental disorders are like a curse in Lithuania. Either it is autism or cerebral palsy or any other condition, there is not organised help or support for the parents of children like that. And really telling the diagnosis is extremely difficult. The diagnosis itself is very difficult to take, and after that parents ask what they need to do. And there is nothing you can say or offer<…>. On the other note, the indifference of government to these children and their families makes the diagnosis a lot more difficult to the person who has to tell the bad news… [Specialists agree].

6.3.6d Training

Both GPs and specialists claimed that they received little information while in training. GPs stated that there was a lack of specialisation in psychiatric disorders, it was "lumped into one lecture". Specialists, on the other hand, claimed that they learn "shallow knowledge" about ASD like prevalence, cause, and symptomology. Information about treatment and tools were only learnt when working. When asked about current training, family doctors stated

that they do not have time to do training. ASD is not an exclusive disorder that "they would have luxury to learn more about it". Specialists highlighted that there was a lack of standardised instruments as they were not adapted to the Lithuanian population. The main sources of information and support for both specialists and GPs were their colleagues:

SP6: I probably graduated the first here, I have never heard anything about autism, we learnt a lot of adult psychiatry and there was not even one word about children. I encountered them here [CDC] for the first time, to learn about them, read how to help them, simply learnt everything myself while working here.

GP1: Yes, no maybe it is taught now, but 40 years ago it was not a case...
GP2: [the youngest GP] There was, but during the residency in the child psychiatric division there was nothing, but in the studies, maybe in the fourth year, there were really classes in the CDC. They didn't let us to the rooms, they didn't show us anything, and it was just theoretical. There was no observation of their behaviour, just theory…
GP6: There are no programs... Nobody cares...

6.3.7 Specialised and Mainstream School Teachers

6.3.7a Knowledge about ASD

The knowledge about ASD was vague among the general school teachers, they could name some of the symptoms; their knowledge and attitudes about ASD were highly influenced by movies and television. Only one teacher could describe the actual characteristics of ASD, due to her past experience. On the other hand, special school teachers could provide an accurate definition of ASD. They based their knowledge from their personal exposure to children with ASD at work. Teachers perceived each child as unique and they were educated about the individual needs of their pupils in the class *(Figure 30):*

BM6: What is autism? I'd say an autistic person is the one who doesn't have social abilities, but not because mother of father neglected him. I think this is a feature of a disorder…
BM2: He doesn't understand body language, facial mimics…autistic people

understand only direct information, short sentences…
BM3: lack of empathy – isolated…I have worked in an integrated school, and what I remember the most is that these children have no empathy, they cannot feel the emotions they are demonstrating, they are not verbal, they have no empathy and that is why there are conflicts with the environment, with other people, and they live in their own world. You can joke with others and use your body language, but these don't understand it…

SM2: Autism is a neurodevelopment disorder, the symptoms include lack eye contact, interaction with others, understanding social norms, difficulty in communicating. This bouquet of symptoms…usually the symptoms appear early in infancy and typically diagnosed at age 3. Is that sufficient??

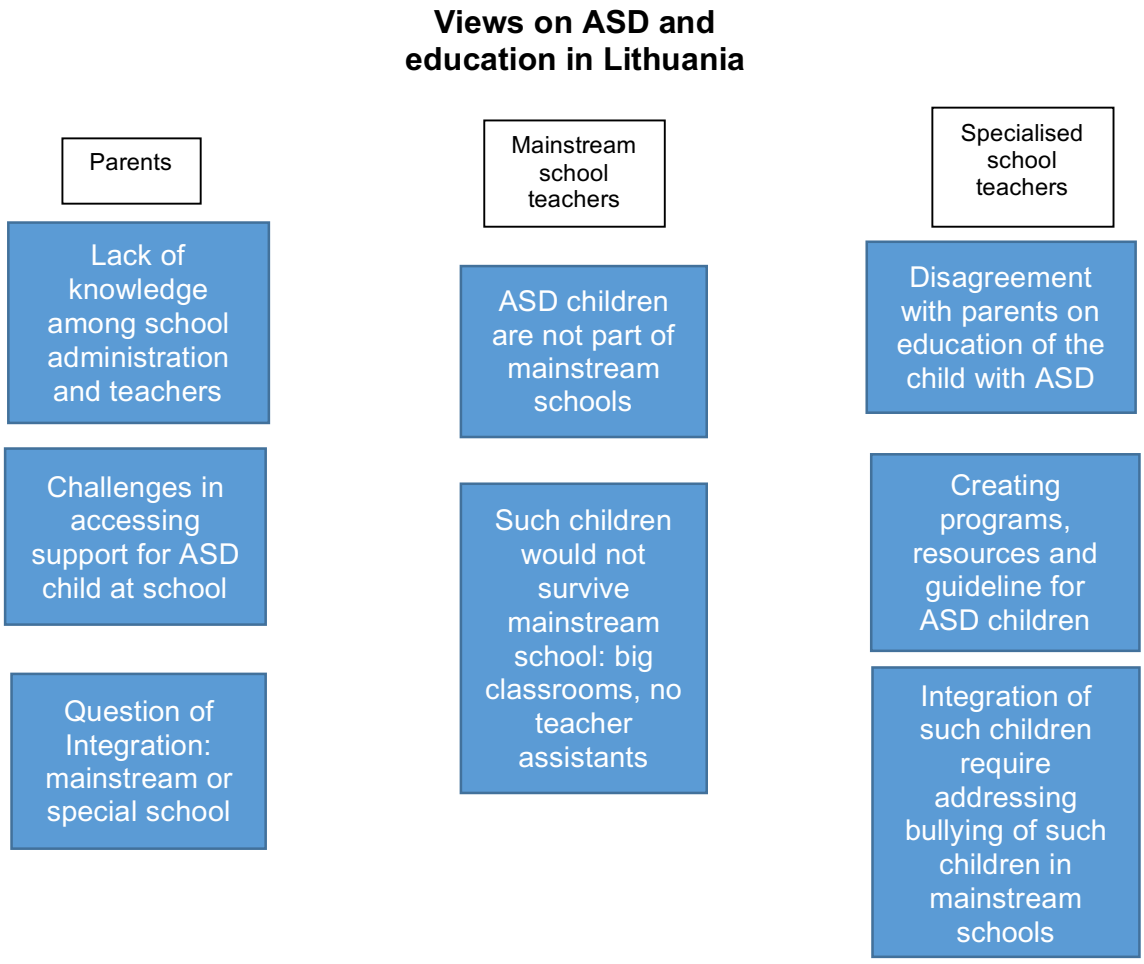


Figure 30. Views on schooling experiences for a child with ASD

6.3.7b Interactions with Parents

Teachers from general schools did not report their experience with parents of children with ASD; because they were subject teachers, their

interactions with parents in general were limited. In many cases, special school teacher-parent relationships were challenging Firstly, teachers found themselves correcting the behavioural problems which the children had learnt at home. Secondly, a lack of cooperation in educating the child at home - with parents perceiving education as only the teacher's responsibility – added to teacher's workload. Nevertheless, teachers tried to be sympathetic to the parents' situation and attributed behaviours to tiredness and a lack of respite care:

SM2: Of course, it is more difficult for the parents...
SM4: They just want to make it easier
SM2: It is more difficult, children spend more time in the family, then with us...
SM4: Yes, how, how other way...
SM3: It is not clear how would we be acting if we needed to spend the whole weekend with them... The whole two days, from the morning until evening, after work… of course these kids are usually better here [at school] than at home.
SM6 and SM4: Yes
SM3: So, you can understand the parents...
SM4: Yeah, because when you don't understand, it is extremely difficult… It is extremely hard for the parents to believe this and accept…their reality.

6.3.7c Training

Both general and specialised school teachers complained about the training they received about child developmental disorders. Teachers claimed that they had basic knowledge when studying ASD. They also stated that there was a lack of help from the Ministry of Education with resources or guidelines for classroom activities:

BM4: Something in the psychology, course, but very superficially, I doubt there really was anything...
BM6: Conversations on experience, but nobody really gave us the practical information...

General school teachers highlighted the division that in mainstream schools children with special needs were not accepted. There were no

guidelines on how to work with them and no support in adapting learning outcomes. Also, they reported that there was no time for training, because there was no demand; children with ASD did not go to general schools. They could not imagine having such a child in the classroom. Owing to the large size of classes, they asserted it would become an “either/or” situation - “either working with the 31 children in the class or working with 1 autistic child”:

BM2: Thirty - two kids in the class, what are we talking about nobody cares… [Agitated] The programs have to be adapted, students informed...too much work, for school and for governmental services…
BM3: There are all kinds of cooperation possibilities with schools and institutions, but when we have just single cases, the methods are not developed well...
BM6: But even this doesn’t work, and we still go forward in blindness… We do everything as we see it fit, very passively; we have no information, who has dyslexia you need to do this and this, with autism this and that… We have nothing…no guidance or support…

6.3.7d Classroom Dynamics

Specialised school teachers highlighted that having children with ASD in the classroom influenced the dynamics because of the challenging behaviour or moodiness of the child. The special education teachers were ‘more to model the behaviour of the child then to teach them’:

SM1: First of all, theoretical background, and as SM2 said theory is theory, but then you come to class and see how the theory works, how can you shift it? Using exactly those intellectual capacities or incapacities, from the other side, manifesting through behaviour and emotions, you have two different kids with different behaviours, and you are in different situations, so there are different ways how to deal with them. There are things that come with time and practice, through trial and error; I guess you could say so. No one can give you a recipe that would work all the time and you could use in all cases. It will be different every day with different results.
SM2: That is why we are here. I am sorry… To model the bad behaviour <…>We must model and we have to sometimes; you just cannot expect them to act like that, or you think they will act in that way, but you don’t know… they can start screaming inhumanly loud or something. The colleagues hear this and I have to modify the situation, take the child out of the class.

6.3.7e Integration

Teachers claimed that children with ASD rarely attended mainstream schools because staff are not prepared physically, professionally, or psychologically. Classes were too big in general schools and there was insufficient space to have smaller classes, not least because of such a high demand of pupils especially in the city. Professionally, there is a lack of methodology to work with mixed classrooms and psychologically the need to address the question of bullying and stigmatisation *(Figure 31):*

BM2: Yes, and in special schools there is a teacher assistant or a special pedagogue, or a speech therapist, they cooperate and work together in different directions. If it is a school like that, but this is a big school, when we have only single cases, and we don't have such opportunities.

The specialised education teachers reported that they are trying to expose children from general school to children with various disabilities in their school. They work towards integration and information, but face difficulties from children, and more specifically from the parents of TD children:

SM2: We had a project with the XYU (place name) gymnasium, I don't know what exactly that was, but my son started to internship there so I have heard that half of the parents didn't let their kids come here [to our school] because they thought it was not safe. There is simply a lack of information among the parents…

SM4: They don't understand. I had a physical education class and I organised it so that healthy children could play with one of ours. So, the healthy ones were afraid to take our children's hand. You tell them there is no need to be scared, you can say this and that, you explain them, only later they really see that these kids don't bite or kick, but at first, they really were really scared and touched kids very carefully, some were even disgusted…

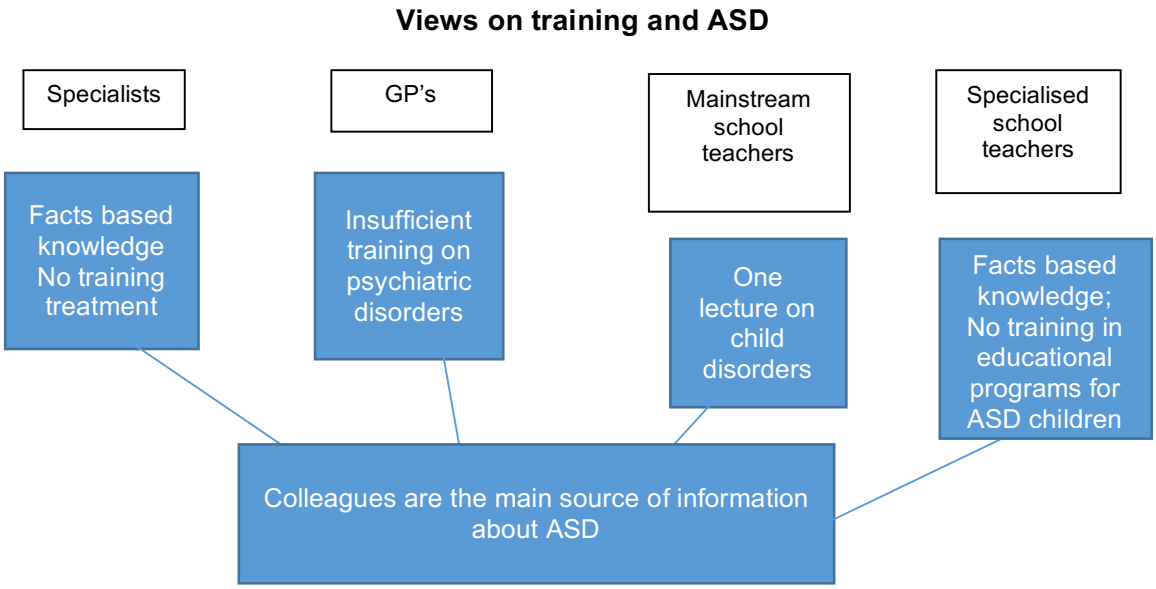


Figure 31. Views on training and ASD

6.4 Discussion

This study explored the attitudes and opinions of professionals and parents of children with ASD. FGD with parents, medical professionals and teachers raised six key themes: knowledge and perception of ASD; the process of diagnosis; the complexity of the relationship between parents and professionals; integration; training and resources; stigma and society. There were multiple discrepancies found in aspects of care, diagnosis, education and resources, thus divided into different themes or domains concurrently. The comments reported represent the lives of parents and portrayed their experiences of raising a child with ASD in Lithuania.

6.4.1 ASD Knowledge

The first theme described was knowledge about ASD. Across the different focus groups, the knowledge varied depending on the amount of interaction professionals had with such a child. The most knowledgeable were medical specialists and specialised school teachers as they were exposed to such children daily. Mainstream school teachers based their definition on

movies and stories, because they have not worked with children with ASD. Therefore, their views were stereotypical and inadequate. GPs were able to define and give examples of ASD and its characteristics, based on their experience with such patients. However, in this study and in previous chapters, parents claimed that there was a lack of knowledge about ASD among GPs. This indicates that knowledge has not been adequately transferred to the care of children with ASD. This discrepancy could be explained in the lack of information received by GPs at the time of training. Also, parents stated that their children were first cases in their GPs practices, while GPs in this study had children with ASD in their practice. Thus there were inconsistencies between parental and GP FGD. Similarly in the UK the primary care provider's knowledge on ASD varied significantly (Parkin 2016). They have shown that GP's lacked practical understanding on how to approach a child with ASD or the signs that should be considered in early development that are characteristic of ASD. As a result, NICE guidelines in the UK and A.L.A.R.M in the USA were developed to support medical professionals in working with ASD. The findings in Lithuania require similar development for the benefit of all the stakeholders involved (child with ASD, parents, medical professionals).

Both medical and educational professionals claimed that they received "superficial" training. Most of them stated that the knowledge about ASD was theoretical and may lack practical information about diagnosis management. Similar results were also found in previous studies which claimed that the training about ASD varied across the specialists groups and was insufficient to support professionals in their work with ASD (Daley and Sigman 2002; Eseigbe et al. 2015; McConkey and Samadi 2013). There were no differences

between older and younger teachers on the quality of training received. The results challenged findings in the study by Heidgerken et al. (2005) conducted in USA, which showed that there was such a difference. In this chapter, professionals learnt about ASD only when they started working with such children. This supports previous studies that claimed exposure was the most effective way to learn about the disorder (Alnemary 2017; Carrington et al. 2016; Rahbar, Ibrahim, and Assassi 2011). In addition, professionals reported that there was a lack of practical training on instruments and shortage of time to do additional training when working with such children (Alma et al. 2017). This calls for a revision of the study programs for professionals in Lithuania. The study by Eseigbe et al. (2015) showed that knowledgeable specialists are optimal service providers and supporters of families. As a result, this reduced the burden associated with ASD for parents and society.

6.4.2 Receiving the Diagnosis

Results confirmed previous studies that the diagnosis of ASD is a complicated process taking an extensive amount of time (Alma et al. 2017; Bölte et al. 2016). Parents reflected that the diagnosis process was overwhelming, ambiguous, and uneasy to follow. Also, there were no clear guidelines on how to proceed after diagnosis. Parents highlighted the importance of balanced messages about the child's capabilities and disabilities when delivering diagnosis. Similar reports from parents in UK has showed that it is important how the diagnosis is delivered – the importance of balance between the positive and negative aspects of ASD. As result, the Royal College of Psychiatrists and NICE guidelines provide information and guidance for professionals in delivering a balanced message when informing

parents about diagnosis (https://www.nice.org.uk/guidance/cg128/resources & https://www.rcgp.org.uk/ASD).

The study by Dillenburger et al. (2010) found the importance of the tone, body language, and the content of information delivered. It was identified that unbalanced messages had negative consequences in terms of treatment and long-term prognosis. Parents suggested follow-up sessions that would provide crucial information about the treatment, financial benefits, and support networks by health care professionals. A study has shown that parents who did not receive such support felt lost and prone to maladaptive behaviours (e.g. refusing to accept the diagnosis, avoiding interventions) (Dillenburger et al. 2010). This could be prevented if health care services provided the required information. As a result, it would lead parents in the right direction by enabling them to advocate for their child and adjust their lives after receiving diagnosis. Timely and effective services would provide early diagnosis and treatment, and that would enable greater outcomes for the child and the family in Lithuania (Feinberg, Augustyn, Fitzgerald, Sandler, et al. 2014; Gulsrud et al. 2014; Mitchell and Holdt 2014).

Medical professionals (both specialists and GPs) stated that they experienced high levels of distress and resistance from the parents at the time of diagnosis. GPs and parents talked about the vague and confusing coding system used by the specialists. The study by Parsons et al. (2011) has shown that a lack of standardised tests aggravated parents' attitudes and raised doubt about the specialists' competence. In addition, GPs claimed that, despite their efforts to inform, parents believed that the MMR vaccine caused ASD. It is a common misconception across different societies (Oldstone 2004). This

phenomenon was explained by Gross (2009), who proposed post-diagnosis stages of grief. She claimed, that parents shifted the blame from themselves towards the external factors. MMR vaccine was one of the convenient explanations, as children receive the vaccine at around the time that their ASD symptomology becomes noticeable.

After the diagnosis, medical professionals claimed that there is limited help that they can offer, because of a lack of structural information available in Lithuania. Moreover, they stated that they didn't have time to add extra tasks to their existing workload, and if they did, it would prolong access to patient services. Therefore, they proposed additional specialised services that would work closely with the family through the process and would provide the required guidance. These practices are found to be effective in other European countries like UK, Germany, Norway and etc. (Alma et al. 2017).

6.4.3 Resources and Support

Results demonstrated that most parents rely on their own inner strength in stressful situations. For parents, ASD was closely linked to their identity and lifestyle. In their qualitative study, Woodgate, Ateah, and Secco (2008) found that parents took ASD as a part of their identity because they wanted to be understood. Also, they used it to explain difficulties in their lives. Another source of support was the parent's immediate family; their spouse and TD children. These sources of support are highlighted in existing research (Benson 2014; Sim et al. 2015; Keenan et al. 2010; Broady, Stoyles, and Morse 2017; Cappe et al. 2011; Ekas, Lickenbrock, and Whitman 2010b).

The progress in the child's development motivated parents to persevere in difficult times and provided hope. It was achieved through therapy and hard

work. Parents valued the support received from specialists. However, some parents named therapies that were difficult to access and financially demanding. Others claimed that therapists provided information which was relevant to their case, and supported them through major life changes. This inconsistency may be explained by the absence of a systematic approach to post-diagnosis interventions and a lack of money for these services in Lithuania. All of the parents commented on the poor funding schemes provided by the government. While in UK, Norway, Germany or France were structured post-diagnosis system has been developed, children with ASD were able to benefit more from structured therapies (Alma et al 2017). The research performed by Stahmer et al. (2011) found that structured therapies improve outcomes for children with ASD. They also recommended personalised therapies, where the needs of each child and family are considered and met. This would require a collaboration between the therapist and parents, allowing informed decisions. Also, it would increase the sense of control in parents when raising the child with ASD. These changes (if implemented) could be beneficial for Lithuanian parents.

Another important point is the accessibility of the therapies, parents stated that therapies are mostly available solely through the private sector. Therefore, some parents felt guilty for not being able to afford the most effective treatment available. Research has shown that creating a public, structured therapy with concrete guidelines could increase accessibility and reduce guilt (Stahmer et al. 2011).

Several parents also mentioned the importance of support groups, however, the information about such groups was not provided at the time of

diagnosis. This may be due to the professionals' lack of knowledge about such groups or failure to communicate. Nevertheless, this required further investigation. Parents, who accessed support groups cited benefits such as encouragement, relevant information, and a sense of hope for the future. It also increased their social circle in the midst of isolation from other groups of people. The studies found that parents benefit significantly from such groups in terms of reduced stress levels and an increased quality of life (Ekas, Lickenbrock, and Whitman 2010b; Lu et al. 2018; Siman-Tov and Kaniel 2011), and without social support Eastern European parents tend to perceive ASD negatively (Serapinaitė 2014; Pisula and Porębowicz-Dörsmann 2017).

6.4.4 School Experience

Parents encountered high levels of resistance from public schools. They claimed that a child with an ASD 'label' would be refused from mainstream schools and strongly encouraged to go to specialised schools. Some parents attributed it to the severity of ASD and its symptomatology. They claimed that mainstream schools are understaffed and not ready to educate children with severe ASD, thus the parents would prefer their children went to specialised schools. Although parents of children with mild ASD aimed to be in mainstream school. This supports findings by multiple studies showing how parents perceive mainstream schools as a gate of integration into society (Fabri et al. 2016; Parsons et al. 2011; Simpson et al. 2005). Despite their efforts, parents faced stigmatisation in mainstream schools, and were requested to go to specialised schools, adding to the existing challenges of isolation. Firstly, teachers lacked training and support (e.g. teaching assistants) to work with such a child. The lack of support instigated the hostility between parents of

children with ASD and teachers. These findings were supported by Stone and Rosenbaum (2005), who showed that disagreement between teachers and parents had reduced collaborative working and added further stress to parents in USA. This was also highlighted by mainstream school teachers who claimed that having such a child would require them to concentrate on the ASD child and abandon the others. This demonstrated how mainstream teachers concentrated on the deficits and found it difficult to have a balanced view. Research by Ališauskas (2006) highlighted that educational services concentrate on the clinical-deficit model when assessing children with special needs in Lithuania. Similar findings were made in the USA and Saudi Arabia where parents aimed to have their children with ASD in mainstream schools and encountered resistance from school staff. The resistance usually occurred in schools that did not have resources to support such children and where there was a lack of governmental funding to provide teaching assistants (Alnemary 2017; Angell, Meadan, and Stoner 2012). This demonstrates the importance of increase in governmental funding for such children that teaching assistants could be used as resource for mainstream schools.

Another challenge parents faced was that parents of TD children resisted having a child with ASD in the classroom. This was confirmed by specialised school teachers, who shared their experience about parents of TD children not allowing their child to come to events organised between mainstream and specialised schools. According to Vignes et al. (2009) the implementation of inclusive education is influenced by many factors, but the key factors are the attitudes of the TD children and their parents towards children with ASD who are pupils in mainstream schools. Also, stigmatisation

occurs due to a lack of positive information and the negativity that is associated with ASD (i.e. behavioural issues) (Broady, Stoyles, and Morse 2017).

Results highlighted the knowledge gap between mainstream teachers and specialised school teachers. General school teachers claimed that they do not see the need to educate themselves as they don't see how children with ASD could be included in a mainstream school. Therefore, a lack of perspective provided a narrow view by the teachers and fed to the circle of exclusion; teachers do not get trained to work with such children and as a result they are excluded. The study by Alnemary (2017) explained that special school teachers are more knowledgeable about ASD than mainstream school teachers, due to the training and exposure they receive. The study also highlighted a lack of interest in getting training from mainstream school teachers.

Special school teachers claimed that their relationship with parents can be strained because of a lack of involvement with homework and involvement in the child's educational path. Similar assertions were found previously, confirming that the Lithuanian teacher-parent relationship is still hierarchical (Kišonienė and Dudzinskienė 2007; Šukys, Dumčienė, and Lapėnienė 2015). Park and Holloway (2017) observed that parents are more likely to be involved in their children's education when parents and teachers view their relationship in a similar, positive light. Results confirmed the view expressed by Oostdam and Hooge (2013) that, sometimes, instead of creating a dialogue with parents, teachers tend to tell parents what they should do or to keep them at a distance. Another potential factor could be the parent's level of education. In their study, Šukys, Dumčienė, and Lapėnienė (2015) found that parents in the group with

a higher level of education became involved in their children's education more often than did those with lower levels of education.

6.4.5 Integration

The problem of integration was address by all of the groups (parents, special and mainstream teachers). Most of them wished for integration, but they were sceptical of having such a model successfully implemented in Lithuania. As stated by Boer, Pijl, and Minnaert (2011) there are many obstacles limiting the collaboration between parents and teachers. First, teachers hold negative or neutral intentions towards students with special needs (ASD included). They also claimed that intentions of teachers with less teaching experience are more positive than those of teachers with more experience. This notion was challenged in the focus groups, because experienced teachers had a more positive perspective towards ASD than inexperienced teachers. Experienced teachers hold pragmatic attitudes towards inclusive education than teachers with little experience (Čekanavičiūtė 2011). Boer, Pijl, and Minnaert (2011) also claimed that success for integration is dependent on the socio-cultural factors, such as the adapted environment, an informed school community, and the willingness to support. In this study, professionals claimed that these factors were missing in the mainstream schools, thus challenging the inclusion model (Galkienė 2006; Ruskus 2003; Čekanavičiūtė 2011).

Another explanation for the unsuccessful integration of children with ASD into schools was given by Vignes et al. (2009). They pointed out that teachers expressed doubts about the desirability and success of the inclusive education of children, both in the teaching community and among the parents

of children with ASD. This scepticism was observed by parents in this study, who claimed that integration might be more damaging to the child than beneficial. Therefore, it requires more in-depth study about integration problems and potential methods to address this issue.

6.4.6 Stigma and Society

The experience of stigma was one of the main findings in Chapters 4 and 5. In this study, the themes of stigma and society were mentioned among groups. Participants agreed that stigma had negative outcomes towards families raising children with ASD. From the perspectives of the parents, their sense of isolation was based on external sources (e.g., society's lack of understanding), rather than personal ones (depression or emotional problems). These findings confirmed a global trend that parents raising a child with ASD experience high levels of external stigma (Broady, Stoyles, and Morse 2017; Gill and Liamputtong 2011; John, Knott, and Harvey 2017; Stewart et al. 2017; Bernier, Mao, and Yen 2010; Canino and Alegría 2008). The issue of stigma from the public, which was strongly perceived to be due to the normal appearance of the child, confirmed the existing findings in research. This resulted in the public's misinterpretation of the child's behaviour, as 'mischief' or 'being naughty' (Gill and Liamputtong 2011; John, Knott, and Harvey 2017; Bernier, Mao, and Yen 2010).

Study by Papadopoulos, Lodder, and Randhawa (2017) has created a short intervention to empower parents when facing stigma. They argued that to inform the whole society is unrealistic but to teach coping strategies when facing stigma is achievable. However, a knowledgeable public contributes to lower levels of stigma. A study by the National Autistic Society (2017) in the

United Kingdom has demonstrated that even though 97% of the population were aware of ASD, they lacked knowledge of how to interact with such people and that is where the challenge lies. This requires the government to consider programmes in Lithuania that informs not only about what ASD is, but also empowers the general public with knowledge of how to react and behave when encountering people with ASD.

6.5 Limitations and Implications

Due to the lack of research in this area in Lithuania, the qualitative methodology was used to explore the existing issues in-depth. Even though the sample size was small, efforts were made to ensure that themes found from analysis could be transferable to other contexts. Reoccurring common themes indicated that difficulties and problems were experienced by all participants. However, the recruitment of the sample was purposeful, this implies that the experiences reported might be unique to this sample (those who are willing to share their experiences). Parents and professionals in other contexts may share different experiences.

The sample of research participants may not be representative and further research is required to gain insight into more diverse experiences. Parents were from the major cities, had a high level of education and the children were aged up to 14 years. This study excluded parents from rural areas and financially disadvantaged parents, as it was difficult for them to arrange transportation and time to participate in focus groups. Also, families that had not received official diagnosis (or did not accept it) were excluded.

Although the sample used in this study had limitations in terms of its small size and homogeneity, FGD allowed for a great depth and insight into

the experiences of parents and professionals. The nature of design allowed close interaction and awareness in the lives of parents and professionals.

Many quantitative studies, taking the form of questionnaires and experiments, have been conducted in the field of ASD, yet the number of qualitative studies remains small (Mansell and Morris 2004; Mitchell and Holdt 2014). This study provided a Lithuanian perspective to the current knowledge base which is biased by Western perspectives.

In the future, research should focus on the training programmes of professionals and validation of the instruments used by the professionals to diagnose ASD in children and adults in Lithuania. It is important to explore potential interventions to allow parents to cope with experienced levels of stigma. Finally, improving the transfer of information for parents and professionals working with ASD at the time of diagnosis is necessary. This will highlight the extent of interventions required and prioritise the needs of families with children with ASD.

6.6 Researcher's Reflexivity

I faced several challenges during this study. The first one (common for all focus group discussions) is how my own viewpoint might have influenced the way I have moderated discussion and allowed the participants to be truthful in their discussion (Hays and Singh, 2012). I am a psychologist by training and I was aware of the potential causes for lack of support from my personal experiences. As a result, it might have tempered the objectivity and influenced reporting of the results, overemphasising some areas and underemphasising others. Therefore, constant awareness of one's own notions was required. To overcome the challenge and ensure trustworthiness, I used a co-moderator

who was present during FGD and took notes of the participants and supported me in asking questions that I might have missed. In addition, I used a co-reviewer that analysed half of the interviews, the agreement on the categories and their relationships was produced. This method is recommended by Hays and Singh (2012) and the guidelines to assure trustworthiness were taken from their paper. Finally, I documented the process of data collection and analysis carefully, to ensure that the results were justified by the experiences of the participants.

6.7 Conclusion

In summary, there was agreement between medical professionals and parents on many issues, such as the need for future improvements with regard to help after diagnosis. Also, participants agreed on the levels of stigma in Lithuanian society and how destructive it is to the families. However, there was some discrepancy in the transfer of information between medical professionals and parents for next steps after diagnosis. Knowledge of ASD symptomatology in young children should be the focus of GPs to help refer children early.

Also, experiences of parents indicated the need to equip mainstream school teachers in methods of working with children with ASD. It also highlighted the pressing issue of integration and the preparation that needs to take place for such people to be part of a mainstream school. It was reported that parents worried and struggled when dealing with school administration and teachers. The government should aim at an increased awareness of ASD in the general public to reduce stigma. Advertising mental health in a positive light, promoting importance of seeking help and discussion around inclusion, may be first steps-towards awareness.

Chapter 7. Sibling Experiences of Having an ASD Child in the Family

7. Background

The incongruence of the findings surrounding the resilience and risk among siblings who are growing up with ASD children raises difficulty in the development of support programs for children, parents, and families. In some studies, siblings experience rivalry and isolation, while other sibling pairs experienced warmth and supportive relationships. The research has suggested that different research methods and comparison groups as well the severity of ASD could explain the mixed results related to the sibling's relationships (Meadan et al 2010).

In Chapters 4 and 5 we discovered that parents experienced the guilt of not providing balanced attention, while simultaneously relying on their healthy children's help and support. These aspects cause distress for parents and required further exploration. In this chapter I considered the siblings' experiences. This helped to draw a more conclusive picture of the current family dynamics and experiences with ASD in Lithuania. As a result, I decided to use a qualitative method to explore the siblings' experiences in the Lithuanian sample.

7.1 Aims of the Chapter

In this chapter I aimed to:

1) explore the potential risk and resilience factors in siblings of children with ASD;
2) understand the relationships and the dynamics between the siblings;

3) identify if there are any differences in the siblings' experiences based on the influencing factors of age, gender, and ASD severity;
4) understand how parents can support their TD children.

7.2 Methods

In order to explore sibling dynamics and their subjective experiences I used thematic analysis. Even though there are studies on sibling dynamics, the existing ones are incomplete or provide contradicting conclusions. Furthermore, there are no studies specifically identifying sibling experiences of growing up with ASD children in Lithuania (post-Soviet context).

For the above reasons, I decided to use qualitative methodology (semi-structured interviews), because it maps the experiences and provides deeper knowledge when there is insufficient information in the research area. Semi-structured interviews were chosen because children, in general, open up more and feel less pressured in one-on-one interviews than in FGD (Denzin and Lincoln 2011). The data was studied using thematic analysis, because it explains personal experiences (Braun and Clarke 2006; Creswell and Poth 2018). A full description of thematic analysis can be found in *Chapter 6 p.191-192.*

7.2.1 Participants

For the purposes of this chapter, I referred to the TD siblings as "participant siblings" and to the siblings with ASD as "ASD siblings". The participants were included in the study if they had ASD siblings and were between 11–25 years old. The sibling participants were excluded from the study if they did not live with the ASD sibling (i.e. left to university/home when the ASD child was born) or were not Lithuanians. A total of 15 siblings

expressed interest in participating. The participant siblings varied in gender, age, living place, and the severity of their sibling's ASD *(Table 17)*. Some participant siblings came from the same family and were both included. A total of 8 brothers and 7 sisters of 13 families were interviewed. The siblings' age had a median average of 15 years (*IQR*=7) and on average there were 5 members in the family including parents.

Table 17. Demographic information of the sibling's data

Participant sibling code	Participant sibling sex	Participant sibling age	Place of living	Sibling with ASD gender	Sibling with ASD age	ASD severity
S1	Boy	11	Urban	Boy	8	Mild
S2	Boy	24	Urban	Boy	20	Severe
S3*[A]	Girl	11	Urban	Boy	12	Severe
S4*[A]	Boy	25	Urban	Boy	12	Severe
S5	Girl	12	Urban	Boy	8	Mild
S6	Boy	17	Rural	Boy	7	Moderate
S7	Girl	18	Urban	Girl	12	Moderate
S8	Girl	12,5	Rural	Boy	9	Mild
S9	Boy	14	Rural	Boy	10	Moderate
S10*[B]	Boy	14	Urban	Boys	5	Mild
S11*[B]	Girl	19	Urban	Boys	5	Mild
S12	Girl	15	Rural	Boy	10	Severe
S13	Boy	22	Urban	Boy	22	Mild
S14	Girl	11	Urban	Boy	7	Moderate
S15	Boy	17	Urban	Girl	18	Moderate

** [letter] - Siblings from the same family*

7.2.2 Procedure

The semi-structured interview questions were developed by my supervisors (Prof. Charles Newton and Assoc. Prof Audrone Prasauskiene)

and I. It was piloted with 2 siblings (of different age groups; 11 and 17), whose interviews were not included in the current analysis. Minor changes in the language were made in order to make the questions broader and more understandable across different age groups. The data collection started in June 2017 and finished in September 2017.

I contacted a parent association, which emailed their contacts on my behalf and asked parents to get in touch via email/phone with me if their TD child expressed interest. When parents contacted to be part of the study, both parent and child were sent a Participant Information Sheet by email at least 24 hours before the interview. I followed the A25 protocol guidelines (from Oxford University Ethics committee Nr. R52782/RE001) and provided two types of information sheets (one for the parents and one for the child) with different levels of literacy. If both child and parent were eligible for the study and wanted to proceed further, the date and time was agreed for the interview.

The meetings occurred in a public place; a signed informed consent form was obtained and the study was explained to the sibling. The interview was audio recorded and took approximately 30 - 45 minutes. The interview questions were used to explore the elements of the sibling experiences (Howitt 2013). Participant siblings were asked to talk about 5 different domains: i) family dynamics; ii) ASD; iii) the relationship with their ASD sibling; iv) life with an ASD sibling; v) stigma. Neither the parents nor the child were paid for their participation in the research and travel costs were not reimbursed either. The motivation of the participation was solely based on the wish to enhance the knowledge of sibling experience with ASD siblings in Lithuania. Each participant was given a code and the data was anonymised. The data was

stored according to University guidelines. I reviewed the data multiple times (using field notes and listening to the interviews) until data saturation was reached and data collection stopped. Data saturation occurs when data collection reached the point where sampling more will not lead to additional information related to research aims (Glaser and Strauss 2006). In other words, enough data has been gathered to answer research questions. The interviews were transcribed and professionally translated within three months (October – December, 2017). The transcripts were thematically analysed in April 2018, using NVIVO 12. The major themes and sub-themes that emerged from the interviews were further analysed *(Figure 31)*.

7.2.3 Ethical approval

The study was reviewed and approved by the Central University Research Ethics Committee Medical Sciences division at the University of Oxford (Nr. R52782/RE001). Permission was given for 6 months to collect the data and perform any follow up interviewing if data saturation was not reached. Due to ethics regulations participants were not reimbursed for their participation as it is perceived influencing their decision to voluntarily participate in research if monetary reimbursement is used in Lithuania.

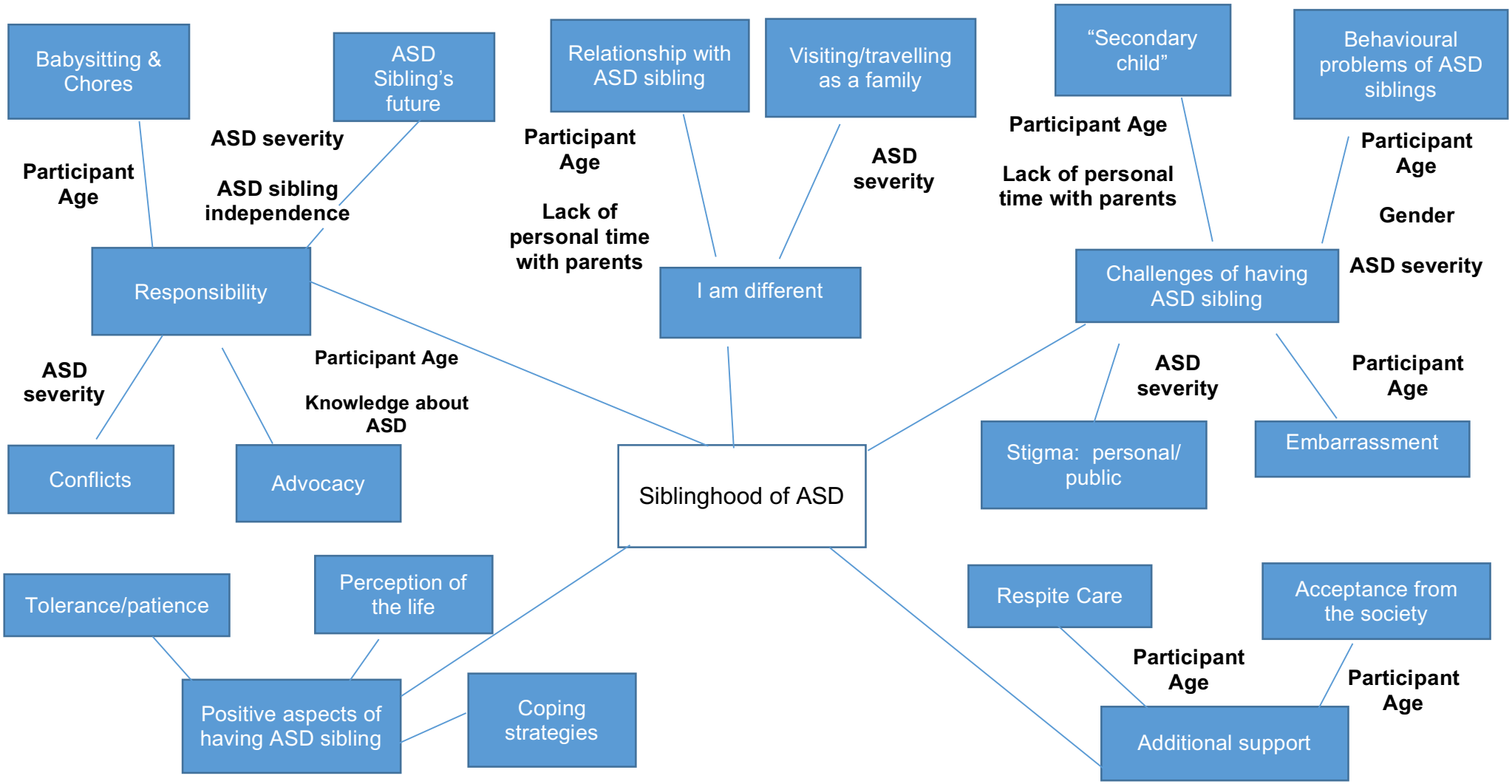


Figure 32. The axial coding of the sibling data

7.3 Results

During the analysis and axial coding, 5 categories emerged which defined the experiences of participant siblings: i) ASD is “my” responsibility; ii) I am different because I have sibling with ASD; iii) the challenges of having sibling with ASD; iv) the positive aspects of having an ASD sibling; v) additional support *(Appendix E)*. Within these main categories, sub-categories were identified and explored further in this section.

7.3.1 ASD is “My” Responsibility

This first category was one that was highlighted across the interviews and mentioned by all participants despite their age, gender, place of living, ASD severity of their sibling, or birth order. There were no explicit questions about responsibility and this category emerged when discussing topics such as daily life and family dynamics. Siblings defined responsibility as a duty to help and take care of their ASD sibling. However, the perception of that word was interpreted differently depending on the child’s age. For the older children (>16 years) responsibility became part of them and they referred to it as “my” responsibility, while younger children (<16 years) describe it as parent-imposed, and they “must take care” or “have to help”. Naturally it is expected that responsibility will be felt by the older sibling based on family roles. However, siblings with older ASD siblings reported that they behaved as the responsible ones and took over the elder sibling role. Within this domain, several sub-categories emerged: babysitting and house chores, handling conflicts, the future, and advocacy.

In light of the ‘babysitting and house chores’ sub-theme, age mediated the attitudes towards taking care of the ASD sibling. Younger children reported

babysitting as mandatory – “if parents ask, I obey” - while older children perceived it as “supporting their parents”. Also, the participant’s perception of babysitting varied. Some said that babysitting was part of the sibling’s role in the family ”this [babysitting] would be the same with any younger child, as I am older brother”; while another said “babysitting is part of to do list”. In this study, babysitting was defined as taking care of their sibling when parents are not around, chores were viewed as doing household tasks. It was defined by family roles and the distribution of responsibility among family members. This was noticed in the families of moderate to severely ASD siblings. If their ASD sibling played and left toys or spilled things, siblings were asked to help the parent clean or manage the situation. Participant siblings claimed that the ASD sibling’s inability to understand social norms required them to take responsibility for their sibling’s “daily messes”. They defined it as “mandatory”:

S12: “He does not understand, thus there is no point in thinking he will be blamed, parents ask me to help instead.”

Participant siblings reported that cleaning after the siblings raised frustration and feelings of injustice. However, they dealt with those feelings by trying to actively attribute this to ASD severity. Handling conflicts was another sub-category defined as part of sibling responsibility. Some siblings reported that they fight with their ASD sibling. Participants reflected on conflicts ending in their defeat as parents took the “ASD sibling’s side”. They reported feeling guilty afterwards as they knew their “sibling does not understand” and they “should have handled conflicts with their sibling better”. Thus, participants internalised the outcomes of the conflict as part of their responsibility:

S10: “I get mad, begin to shout at them. If I lose it completely. But I handle myself. My mom says I cannot do this, and I stop. Sometimes she punishes me. I get mad at her and tell her this isn’t fair. But that’s what it is…”

Children also reported anger due to the ASD sibling's teasing behaviour and provoking conflicts. They claimed that parents did not believe them as "ASD siblings cannot manipulate people". This was reported by the participant siblings whose ASD sibling had mild to moderate ASD. Participants also observed that increased challenging behaviour had a negative influence on the person's patience. Patience was identified as a crucial part of the relationship with their ASD sibling. They defined the ability to control one's emotions, even at the highest peak of emotional overload, such as when experiencing anger or frustration. They reported that developing patience was a mandatory coping strategy:

S8: "You have to be patience otherwise your reaction will make you guilty. As parents will not believe me anyways,
Interviewer: what do you mean they won't believe you?
S8: They will not believe that X can provoke me but only I provoke him."

Participants talked about their sibling's future when they were reflecting on the ASD and differences in lifestyle questions. The future of the ASD sibling was described as part of the participant sibling's responsibility. Older children reported that they have discussed this topic with their parents. For some participants, parents agreed to take this responsibility and plan their ASD sibling's future independently from them. Conversely, younger children reported that they have not talked about this with their parents. They all reported feeling anxious for their sibling's future. In order to cope with the anxiety, they aimed to teach their ASD sibling to be more independent e.g. how to do shopping, or how to tie shoelaces. Increased numbers of skills were perceived as promoting independence. The remaining sibling participants reported that even though they feel responsible for their sibling's future, they view it as positive and independent. These variations in attitudes towards

future were mediated by the severity of ASD symptomatology and the sibling participant's perception of independence in the ASD sibling. Sibling participants that had a severe-to-moderate ASD sibling expressed more worry than those with mild-to-moderate ASD.

Another subcategory of responsibility was advocacy, which was defined as educating their surroundings about ASD. Sibling participants viewed advocacy as part of their responsibility. Most of it occurred in close circles, such as among friends and relatives. However, in the beginning, talking about ASD was challenging as participants reported hiding their sibling's condition due to a feeling of embarrassment and/or shame. This was especially noticed in the younger children who were challenged by their friends to explain why their sibling "does not talk", "flap his hands", "scream" and so on. The struggle was attributed to a lack of understanding of ASD, especially when participant siblings were asked to define ASD in their own words. The other children reported advocacy as a process that allowed the acceptance of ASD siblings for themselves:

S6: "It was therapeutic - the more you talked the more you came to terms with it [ASD]".

In addition, it helped siblings to understand certain aspects of their sibling's condition as they sought information from their parents.

7.3.2 I am Different Because I Have ASD Sibling

Having an ASD sibling changed the lives of the families in different ways. Sibling participants reported that ASD distinguished them from other families. Several participants referred to changes in family activities and interactions with others. They also reflected that they experienced stigma (through negative comments and behaviours) because they have an ASD

sibling.

Less than half of the siblings reflected that their family activities had changed and/or evolved around the ASD sibling. These experiences were captured when siblings talked about their family's daily activities. Firstly, participant siblings claimed that activities adapted and depended on the ASD sibling's "mood of the day". The examples were visiting friends or travelling. Sibling participants reported that mutual family activities were rare. The ASD severity was also observed in restricting family daily life. Some of them attributed it to fear of the ASD sibling's reactions to novelty:

S2: "Our biggest problem was that my parents didn't try to do anything, like traveling. We thought about it but we were scared that it might be difficult for my brother or he might react to things somehow."

Other siblings reported that parents arranged visits with friends or allowed them to spent time together. In these cases, parents had established effective ways of coping. For example, before the start of activity family agreed on "a plan B" in case the ASD child became overwhelmed:

S13: "Yes, we did not change much as a family we still do all the things we want, because I don't know… we learnt to have Plan B and thus we never stopped doing things like we did before having X."

Effective coping strategies allowed families to enjoy the activities. Thus, parental decisions about various activities shaped participant sibling's experiences and their perceptions of themselves "we are different from other families [refers to TD families]".

Another area that made sibling participants different was relationship dynamics with the ASD sibling. They claimed that a lack of similar interests, playing time together, and increased levels of responsibility formed their atypical relationship. Siblings reported that they wished to experience a

"normal" sibling relationship, i.e. "playing together", "sharing struggles and joy", or "showing affection". It must be noted that participants were not asked about how their relationships differ from typical sibling relationships, instead they were asked to describe their relationship with the ASD sibling. This atypical relationship made them different because they never experienced 'true' sibling rivalry or support from their ASD sibling:

S3: "He will never react the way the typical siblings do like support each other, protect and be there for one another, so we are not normal siblings as I will always have to protect him."

Most siblings expressed sadness and the grief of losing a "normal sibling". This was observed in different answers throughout the interviews. Younger siblings (<16 years) struggled to accept ASD and some of them even wished that their sibling did not have ASD. The lack of parent's time with their TD child was observed as explanation from the participant sibling's point of view. On the other hand, older siblings *(N=7)* had adjusted to their family life because they were independent and did not need the parent's attention anymore.

7.3.3 Challenges of Having an ASD Sibling

Children reported that their relationships with the ASD sibling were multifaceted and varied across time. They claimed that challenging situations and experiences influenced them. It formed this category that consisted of subcategories such as "secondary child", ASD sibling's behavioural problems and aggression, the embarrassment, and the stigmatisation from the environment.

Several participant siblings reported feeling left behind or being treated as a secondary child. The "secondary child" definition was described as the

ASD sibling being a central figure in the family and life evolving around the sibling. Some siblings tried to talk with their parents and were assured that they are loved equally; however their feelings and experiences did not comfort them. Others understood that different parenting is inevitable because of ASD characteristics and used it to justify their parent's behaviour:

S15: "He gets more attention because he needs more, he has ASD".

In addition, they reported that a lack of spending one–on–one time with their parents fuelled that understanding of being a secondary child. Children who did not experience the secondary child scenario highlighted that parents arranged one–on–one time with them. They felt assured and confident in their relationship. Thus, quality time with parents reduced the feeling of inequality.

The issue reported by participant siblings was different parenting standards. Children reported higher expectations and lower thresholds for mistakes from parents. This increased pressure and raised stress for the participant siblings. This was noticed across different age groups and was independent of gender or severity of ASD. Also, some of them attributed it to the role of being the older sibling, thus different standards are inevitable due to birth order. They normalised and said that it is typical for Lithuanian families that oldest child has the most responsibilities.

Another challenge reported was behavioural problems. Behavioural problems were described as aggression (kicking, punching, pushing, etc.) or inappropriate behaviour (screaming, crying, falling on the ground, etc.). None of the interview questions directly asked about behavioural issues. The participants talked about it when discussing the difficulties of having an ASD sibling, and when referring to their personal relationship with their sibling.

Several participants reported experiencing aggressive behaviour from their ASD sibling. This usually happened when ASD siblings were not given what they wanted. In addition, some participants explained that the aggressive behaviour of the ASD sibling was observed in their school and often reported to the participants, who came to pick them up, or were in the same school. This occurred among mild to moderate ASD cases. Siblings claimed that predicting problematic behaviour was complicated:

S10: "I just get lost and unable to do anything… I feel hopeless every time they fall on the ground and start screaming".

Siblings argued that calming their sibling with ASD was challenging and overwhelming, hence they sometimes felt hopeless. The age of the participant mediated the experiences, because older siblings (>16 years) were more confident in addressing aggressive or challenging behaviour. In addition, female participants reported being more patient with their ASD siblings compared to male participants.

The siblings reported feeling embarrassed due to behavioural problems or inappropriate social activities exhibited by their ASD sibling. In all cases the embarrassment was felt when it appeared in a public place and the participant sibling would observe reactions of the public or hear the comments. When referring to embarrassment, siblings defined feelings of shame, frustration, and sadness. Embarrassment was reported mostly by the younger siblings or reflected retrospectively by older siblings on their past experience.

The embarrassment was closely related to the experience of stigma, which was observed across the interviews. There were different types of stigma; the personal and public. The personal stigma referred to experiences of negative comments and the reactions of friends and relatives:

S1: "When he starts talking about me to other kids…I don't… but I felt embarrassed many times because of him."

Personal stigma evoked shame among the participants. Public stigma was defined as receiving looks or comments when being in public with the ASD sibling. However, the reaction towards the public stigma was defensive; it evoked anger and frustration. Sibling participants were prepared to fight in order to defend their ASD sibling. In addition, siblings with more severe ASD siblings were observed to experience frequent stigmatisation compared to milder ASD cases.

7.3.4 Positive Aspects of Having an ASD Sibling

The participants told about the positive aspects of having ASD siblings. These were observed across different interview questions. When talking about stigma, sibling participants reported about being more tolerant towards others compared to the rest of society. In this case tolerance was defined as accepting others, being more patient towards others and not judging others. Older participants (>16 years) also added that they noticed people's emotions and "non-verbal cues" faster than their friends:

S12: "I notice people who hide their emotions better, I sometimes feel I can see through them, it is because my brother does not speak and thus we learnt to "read" him".

This was equally reported by female and male siblings. In addition, sibling participants claimed that having an ASD sibling provided a "different perspective towards the world". This referred to seeing people and the environment differently because of being exposed to a sibling with ASD. Participants described that this view of the world as "broader and more colourful". This was observed when participants reflected on the daily life with

ASD sibling. Participants reported being more patient compared to their friends:

S7: "I have learnt patience; I learn a lot about disorders. This is actually very interesting. Mostly it teaches me, and helps me to be patient and I know more about people who are different".

Another positive aspect was learning coping strategies that are effective when facing conflicts or difficult situations. Participants *(N=8)* reported using these coping strategies: calm explanation, distraction, or retraction. For the calm explanation, some sibling participants *(N=8)* reported that patience is key in achieving wanted results. For tantrums, they *(N=7)* used the distraction of the ASD sibling and when feeling overwhelmed they *(N=6)* retracted to their rooms. Siblings said that having a variety of strategies allowed them to think "on their feet" and be more confident when facing stressful situations. They claimed that knowing these coping strategies enriched their personal relationships with the ASD sibling as well. This was observed when they compared their reactions to their friends/classmates when exposed to stressful situations. These coping strategies were reported by older siblings (>16):

S15: "I think also being able to cope under stressful times, I have noticed that when it comes to exams I am able to be more 'cold headed' compared to my friends, and I think it is because I learnt to live with my unpredictable sibling".

7.3.5 Additional Support

Another category emerged when siblings talked about experienced exclusion. They also wished to be more accepting. Some participants highlighted the need for respite care. The experience of defeat and anger was observed in response to emotionally intense thoughts and events related to stigma and exclusion among children. These events were based on people mocking or commenting on their ASD sibling when in the public. Often siblings

felt constrained and in need of remaining patient towards other people regardless of their own feelings. Even though the negative feelings were brief towards people, thoughts lingered and formed attitudes towards their ASD sibling's future. All of the siblings wished that people would be more tolerant and supportive towards families with ASD children.

Sibling participants reflected on the current situation in Lithuania and wished that there was respite care for families with ASD children. For some participants, respite was described in the context of the relationship with their parents. They claimed that, because parents were constantly busy of taking care of their ASD sibling, they witnessed parents being stressed and tired without any support, thus they wished for services for the family. Some of them wished to have a possibility to leave their sibling in professional hands and spend quality time with their parents. Others claimed that observing their parents being tired made siblings worried. They wished for support, and were emotional when talking about it.

In addition, when talking about the future, participants feared for their ASD sibling. This was closely linked to experiences of stigma and rejection in the society. The lack of support from their surroundings was reported by older participants who claimed that their ASD sibling's future is highly depended on acceptance from the society and support from the government. They articulated the need to provide a lifelong support for families raising children with ASD in Lithuania.

7.4 Discussion

Research findings showed distinct dimensions of participant siblings' experiences. There was a variety in the perceptions and interpretations about

responsibility, identity formation, and importance of support. The same participants reflected on positive and negative experiences. This study showed mixed findings about participant siblings' experience. On one hand they found battling responsibility, embarrassment and fear for their sibling's future, but on the other side they could perceive the positive aspects, such as cultivating tolerance and patience towards others.The positive and negative experiences were not different ends of the spectrum showing that the sibling relationship can be both positive and negative. This supports findings of current research on TD siblings experiencing both positive and negative at different degrees not one or the other (Mandleco and Webb 2015).

7.4.1 Responsibility

The sense of responsibility was a dominant category observed across all interviews. In sub-categories, parental role and sibling demographics (age and ASD severity) were important mediating factors of responsibility. The existence of increased responsibilities of TD siblings of individuals with ASD has previously been documented in the literature (Angell, Meadan, and Stoner 2012; Mascha and Boucher 2006; Mehok 2017; Petalas et al. 2009; Ward et al. 2016). A recent review revealed that the perception of increased responsibility was not consistent and some siblings regarded it positively while others were frustrated with the added responsibility (Mandleco and Webb 2015).

The results showed that siblings viewed babysitting and chores as their responsibility. These findings were similar to the review by Smith and Elder (2010), who claimed that siblings internalise the responsibility and became 'second parents' to their siblings with developmental disorders. This second

parenting was observed when taking care of their sibling daily. They also found that parents relied on their TD children for support and this had negative effect on the siblings' perception of the ASD sibling. Chapter findings are in line with the current research stating that parents can influence the child's perception of responsibility (Angell, Meadan, and Stoner 2012; Hastings 2007; Petalas et al. 2009). Thus, parents should be conscious about the responsibilities of TD children in order to avoid putting extra stress on their child.

Secondly, siblings reported their experience of conflicts with ASD sibling. Participants internalised the blame and guilt. They claimed it was always their responsibility. When describing their relationship, sibling participants mentioned that they experience frequent conflicts, especially at a younger age. Orsmond and Seltzer (2007) reported that siblings of the child with ASD experienced less conflict because interactions among them were less frequent. While, Kaminsky and Dewey (2001) concluded in their study that siblings of children with ASD reported greater warmth in their sibling relationship than siblings of TD individuals. In this study, participants claimed that they experienced conflicts and a lack of communication from their ASD siblings. In addition, they reported being frustrated due to the parents' disbelief that the ASD sibling can initiate conflict. The study by Mascha and Boucher (2006) demonstrated that the ASD sibling's disruptive behaviours were common triggers of stress for participant siblings.

Current research demonstrated that each family member (and families as a whole) worry about the ASD child's future (Ferraioli and Harris 2009; Petalas et al. 2009). In this study, most of siblings were uncertain about their ASD sibling's future. The study by Beyer (2009) claimed that siblings worried

about the care of the ASD sibling in the future if their parents were no longer able help them. In this study participants viewed independence as an important factor to improve the ASD sibling's chances for a better future. As a result, participants had taught their siblings social skills. This was also found in the study by Shivers and Plavnick (2015), who said that a typical sibling aimed to be a model of socially appropriate behaviours in order to improve the ASD sibling's social outcomes. These findings support observational theory about siblings being the effective teachers and examples of positive development for their ASD siblings (Lam, Solmeyer, and McHale 2012). In addition, results had showed that when children were involved in planning and/or were talking with parents about the ASD sibling's future, they worried less. The dissertation by Smith et al. (2015) showed that parents talked with their children about ASD and shared their expectations of the future, as a result this helped their TD children understand ASD and be more confident about their sibling's future. Thus, parents should plan their ASD child's future and involve their TD children in the process in order to reduce uncertainty. In this study, siblings felt responsible in educating people about ASD in their close circles. They claimed being knowledgeable about ASD helped when they had to explain the ASD sibling's behaviour to friends. Research by Smith (2006) showed that parents who help their children to understand ASD increased their child's confidence in talking about ASD with others. Also, they highlighted the importance of information being age appropriate. Therefore, parents are encouraged to talk about ASD and assure TD children when they have concerns and/or share the responsibility of teaching about ASD in their immediate surroundings (relatives/friends).

7.4.2 I am Different

The second theme showed how siblings perceived themselves and how they compared family with others. Participants reflected on how having an ASD sibling differentiates them from others because of their relationship with the ASD sibling and the daily activities with their ASD sibling.

I found that their family had different daily activities than other families. In some cases, family lifestyle changed drastically when having an ASD child. Walton and Ingersoll (2015) showed that ASD families have little time to spend together and were more isolated compared to families of children with developmental disorders. Siblings attributed this to characteristics of the disorder, especially children who had a severe ASD sibling. The study by Howe and Recchia (2014) showed that mutual family activities are important developmental blocks that help in forming relationships, especially at the middle childhood stage. Similar findings were found by Angell et al. (2012) and Beyer (2009) demonstrated that spending time as a family helped form strong bonds among family members.

The siblings faced the difficult task of trying to form a bond with their sibling and have a “normal sibling relationship.” In addition, siblings struggled to have common interests or feel supported by their ASD sibling. These findings are in line with the existing literature that showed siblings of individuals with ASD have less mutual affection and lower levels of contact compared with individuals of TD siblings (Orsmond and Seltzer 2007). This is due to the majority of individuals with ASD having cognitive impairments and behavioural challenges that limited the sibling’s interaction (Orsmond and Seltzer 2007). In addition, a lack of common interest and play reduced time spent together

among the siblings. The study by Howe and Recchia (2014) showed that mutual and balanced interactions were important components of healthy sibling relationships. They also highlighted that a lack of it might lead to severe bonding problems and ultimately have a negative impact on the sibling's mental health. Thus, it is vital for TD children to form bonds with their sibling. The study by Beyer (2009) found that siblings who have only ASD siblings struggled more in forming relationships with other children compared to those who had more than just ASD siblings. Parents should encourage children to spend time with friends/same age relatives to assist children in developing mutual bonds that might be missed with ASD siblings. It is important that families with ASD children would not isolate themselves but strive to perform regular family activities.

7.4.3 Challenges of ASD

Participants talked about the difficult aspects of growing up with ASD siblings such "secondary child" aggression or behavioural challenges, embarrassment, and stigma. In this category, results supported literature and also added culturally relevant findings to the discussion of ASD siblinghood in Lithuania.

Firstly, siblings felt as a "secondary child" and had to fight for their parents' attention. Siblings also reported a lack of encouragement and personal time with parents. These tendencies were well-documented in the literature investigating TD siblings of individuals with ASD (Mandleco and Webb 2015; Orsmond and Seltzer 2009). Secondly, the study by Conway and Meyer (2008) showed that the parents of children with disability tend to overprotect, be over-attentive, and allow the child to engage in behaviours that were unacceptable

if done by another family member. In addition, the study also showed that a lack of personal time and intimacy between the TD child and parents increased the risks of depression, oversensitivity and resentment towards their sibling with disability. Thirdly, the study by Rivers and Stoneman (2003), showed that different treatment from parents correlated with poorer relationships among the siblings. However, they also found that talking about different treatment with their child reduces the risks of negative relationship development between family members. This is an important consideration given the fact that different parental interventions had a negative impact on sibling relationships (Coldwell, Pike, and Dunn 2008; Jensen et al. 2013; Mehok 2017). Fourthly, Feinberg et al. (2013) highlighted that parents must balance duties with compliments for TD children to avoid competition. Finally, studies by Petalas et al. (2009) and (Mascha and Boucher 2006) suggest having open conversations with their children about personal expectations. In this study participants reported that talking was not helpful if there was no concrete change from parents. Therefore, it is important that parents aim to have personal time with each child in the family and encourage support between siblings.

Another challenge expressed by the siblings was behavioural issues and aggression. These findings support the existing literature that demonstrates aggression and disruptive behaviours as common stressors for the siblings (Mascha and Boucher 2006; Ross and Cuskelly 2006). Behavioural problems may be explained by social learning theory, which states that specific behaviours reinforce actions, and these actions transfer to other settings (Patterson, Dishion, and Bank 1984). Thus, aggressive behaviour reinforces a reaction from the sibling and that is used in other settings. In this

study, we found that participant siblings internalised the sibling's behaviours and perceived it as their responsibility. For younger siblings this created maladaptive coping strategies or negative experience, while for older siblings it served as training place for reacting to problematic behaviour in their daily life.

In this study, I also found that ASD siblings' behaviour made siblings embarrassed when surrounded with friends/relative, while comments and stares from strangers made siblings angry. According to a recent literature review, embarrassment has been repeatedly documented by researchers as a common theme used to describe the experience of siblings of individuals with ASD (Angell, Meadan, and Stoner 2012; Beyer 2009; Mandleco and Webb 2015). Many TD siblings have reported feeling embarrassed of their sibling with ASD, especially in the context of challenging behaviours (Mandleco and Webb 2015). Siblings of children with ASD tend to be more embarrassed in the presence of other children and peers compared to other groups of siblings (Mehok 2017).

Stigmatisation played a vital role in participant perceptions of their ASD sibling's future in Lithuania. Society's response may have driven the sibling's attitudes of ASD. The study by Milačić-Vidojević, Gligorović, and Dragojević (2014) conceptualised stigma as internalising the blame for the ASD sibling's condition and fighting exclusion and negative comments. They also found that in the environments that have greater knowledge about ASD siblings experienced less stigma. Milačić-Vidojević et al. (2014) claimed that teaching siblings about ASD and appropriate coping strategies reduced the experienced levels of stress and embarrassment. In addition, Moyson and

Roeyers (2012) has documented the impact of ASD's 'invisibility' on TD siblings. More specifically, they found that siblings felt that the behavioural expectations for their sibling reflected their 'normal' appearance and not the reality of their diagnosis. As a result, participants worried that their sibling with ASD would be unfairly judged (Moyson and Roeyers 2012). TD siblings of individuals with ASD have shared these fears in other research studies (Angell et al., 2012). The existence of fear is often associated with increased levels of empathy and warmth towards the sibling with ASD (Lam et al., 2012; Pilowsky et al., 2004). Interestingly, for siblings in Lithuania, the experience of stigma and the perception of their sibling's future motivated some participants to work on their sibling's independence. The aim to support their ASD sibling is reported across literature (Mascha and Boucher 2006; Petalas et al. 2009).

7.4.4 Positive Aspects of ASD

In the fourth category siblings reflected on the positive aspects of having an ASD sibling and claimed that they are more tolerant, with a wider worldview and advanced emotional skills due to the ability to effectively cope with challenging situations.

They claimed that having an ASD sibling allowed them to socially adjust and observe things with greater detail. This finding is reported in many studies that showed how TD siblings had higher competencies socially and were adaptive in stressful situations (Macks & Reeve, 2007; Pilowsky et al., 2004). Macks and Reeve (2007) also demonstrated positive influences as research has indicated that siblings are more tolerant and have greater levels of control towards their behaviour and emotions than other TD children. Parents of children with disabilities have also recognised the positive impact on siblings

including learning about diversity (Hastings 2003b; Mehok 2017; Taunt and Hastings 2002). Findings from a longitudinal study investigating the effects of positive sibling relationships implied that affectionate relationships between siblings moderates the relationship between stressful life events and subsequent life adjustment in children (Gass, Jenkins, and Dunn 2007). This showed a balanced view of ASD experiences.

7.4.5 The Respite Care

In the final category siblings talked about the importance of respite care and acceptance from the society. They reflected on the need for programmes and structures to support families with ASD in Lithuania. The participants' age was a mediating factor, highlighting that younger children know less compared to older ones. It challenged the results by Kim et al. (2007), who claimed that older siblings concentrate less on provision of care and interest in ASD compared to the younger ones, and it declined severely in adolescents, which was not observed in this sample. The participants were actively involved and interested in ways to support their families despite their age.

Another aspect mentioned was the support in developing effective programs and informational resources about ASD. Participants also wanted to be taught effective coping strategies. They also sought social support which is one of the five coping strategies that McCubbin et al. (1993) identified in their theoretical framework on resilience. In their study, Conway and Meyer (2008) showed a positive correlation between the severity of ASD and siblings' adjustment problems. In this study, participants' descriptions of their adjustment and coping strategies also reflected this relation, especially in light of maladaptive behaviours. Some of interviewees said that they sought quiet

time and space when they needed respite from their siblings. Consideration of siblings' explanations on the coping strategies used may be helpful in planning support programmes for these children in Lithuania. Siblings said that there was no support available and they hoped for practices to emerge were they can openly communicate and share their experiences with others in similar circumstances.

7.4.6 Influencing Factors

Influencing factors played mediating roles in explaining the ASD siblinghood phenomena. In this study, we found that participants' age, gender, and ASD severity were important factors that had to be considered when reporting results.

Participants showed that - despite age difference - all TD siblings developed a sense of responsibility. The study by Petalas et al. (2009) suggested that the responsibilities discussed by the participants were moderated by ASD symptoms and not simply by age. In addition, findings had demonstrated that age contributed to perceptions of favouritism, the relationship with the ASD sibling, and acceptance of ASD. The older sibling's attitudes were less dependent on the parent-child relationship compared to the younger ones. This challenged the findings by Macks and Reeve (2007) who highlighted that older siblings struggled to adjust in psychosocial and emotional domains compared to younger ones. Hastings (2003b) claimed being younger than one's ASD sibling decreased emotional difficulty in TD siblings. However, I found that younger siblings struggled with the emotional and psychological aspects of the relationship with their ASD sibling. Age played a role when talking about embarrassment; the younger children

struggle to inform friends when not aware of ASD.

Gender also showed to have significant implications for siblings. Male participants reported a lack of patience when exposed to an ASD sibling's difficult behaviour. The current literature has shown that sisters of children with ASD had higher levels of competence than brothers of ASD siblings or TD sisters (Kaminsky and Dewey 2001; Verte, Roeyers, and Buysse 2003). According to the review by Halladay et al. (2015) there is a higher rate of males being diagnosed with ASD than females. Thus, siblings may be on the autism spectrum themselves, especially boys, which may explain the gender differences between the siblings.

The ASD severity mediates conflicts among siblings, the perception of the future, stigma, and family time. Pilowsky et al. (2004) demonstrated that the severity of ASD negatively affects the sibling's adjustment and it was most commonly identified as a key factor that challenged the sibling's relationship. In addition, siblings claimed that it was difficult to have public activities as a family because of sibling ASD severity. Study by Angell et al. (2012) demonstrated that ASD severity contributed to families' daily activities and were the mediating factor of family isolation.

7.5 Strengths

This study provided information about experiences of siblings living in an Eastern European context. The study by Hodapp and Urbano (2007) claimed that most of studies about siblings of ASD children are rooted in Western middle-class cultures, thus the experiences of other cultures tend to be neglected. They also highlighted that culture influences sibling roles and family dynamics therefore it should be considered. This study also reflected on

age, gender and ASD severity which are usually not reported or assessed when studying siblings of children with ASD (Angell et al., 2012).

7.6 Limitations

The first limitation of this study is that I did not establish extended relationships with the participants. I interviewed each sibling only once. Multiple interviews may have produced further data. However, I feel that interview data and analysis provided a strong foundation for examination of these participants' perspectives and their experiences as siblings of children with ASD. Secondly, I recognise that the generalisability of the findings may be limited by the nature of participants. Although these findings are based on the perspectives of only 15 siblings from a small geographic area within one country, these participants ranged in age from 11 to 25 years and reflected a variety of family lifestyles. Thirdly, ASD is a heterogeneous disorder in terms of severity of symptoms and the level of social and intellectual functioning. It is difficult to generalise the information from this study to all siblings of individuals with ASD. Finally, I have not considered the Broader Autism Phenotype. The genetics have shown that the chances of having ASD grows by 20% if you have an ASD sibling (Losh et al. 2008). In other words, the siblings themselves might have autistic characteristics and not be diagnosed with ASD. Therefore, the struggles they experienced could be attributed to themselves having autistic characteristics and not just having a sibling with ASD. A lack of data on siblings' health requires critical evaluation of the findings.

7.7 Researcher's Reflexivity

I faced several challenges during this study. The first one common for all qualitative studies is being objective and putting aside personal ideas about the nature of the process (Denzin and Lincoln 2011). I had read much on the topic of sibling experiences and was very interested in the effects of risks and resilience's factors. As a result, it might have tempered the objectivity and influenced reporting of the results overemphasising some areas and underemphasising others. Therefore, constant awareness of one's own notions was required. To overcome the challenge and ensure trustworthiness, I used a co-reviewer that analysed half of the interviews, the agreement on the categories and their relationships was produced. This method is recommended by Hays and Singh (2012) and the guidelines to assure trustworthiness were taken from their paper. Finally, I documented the process of data collection and analysis carefully, to ensure that the results were justified by the experiences of the participants.

7.8 Implications

I suggest for further research on the assessment of the functioning of all family subsystems when children with ASD are involved. My findings identified an abundance of information for practitioners and researchers when studying siblings of children with ASD in Lithuania. I suggest to apply these preliminary findings to large-scale studies in order to shed light on siblings' experiences that may inform schools and practitioners and create the support service for this youth. I also suggest considering the Broader Autism Phenotype, and in future studies collecting medical data or acquiring evaluation of possible autistic characteristics for the siblings to assure that the

findings are accurate. More longitudinal research on the effects of growing up with an ASD sibling is necessary. Such longitudinal research would extend knowledge on family members with experiences. There might be a specific age or transition period in life when more support is required. In order to develop an appropriate system of support, it is important to understand the unique support needs of siblings of children with ASD across their lifespan.

7.9 Conclusion

In conclusion, this study highlighted the impact of ASD on sibling relationships. It informed about existing family dynamics from the sibling's point of view. While it is not possible to mediate the sibling's age, gender, or severity of ASD, there are strategies that could be employed to facilitate more positive relationships between sibling participants, ASD siblings, and the family as a whole. Moreover, parent–TD child relationship dynamics played a significant role in mediating relationships among the siblings. Negative experiences in this study require further research on sibling experiences with ASD in Lithuania. At this point, there are more questions than definitive answers concerning the best way to support siblings of children with ASD.

Chapter 8. Lithuanian Population Study on Knowledge, Attitudes and Practices towards ASD

8. Background

In the previous chapters, stigma shown to have significant effects on parental stress and family experiences. All the participant groups – parents, professionals and siblings - shared about stigma and negativity experienced from the general public in Lithuania. Stigmatising behaviours and attitudes appeared to be based on generational differences; older generations (those that lived in the Soviet Union) are more stigmatising than the younger ones (those that live in Independent Lithuania). Thus, it is important to evaluate knowledge levels, varying attitudes and practices towards ASD and to investigate where the general public stands in terms of knowledge about ASD. The understanding gained from this study could help to design specific interventional strategies to address the issues of stigma towards the ASD community.

8.1 Aims of the Chapter

This chapter assesses:

- the knowledge of Lithuanians regarding people with ASD;
- if there are any particular demographic factors: gender, age, education, place of living that influence the understanding of the general public about ASD;
- the attitudes of the general public towards people with ASD and perceptions concerning their own potential role and ability in helping an ASD person;
- perceptions and practices of the general public in various daily life situations if exposed to ASD.

8.2 Methods

This novel study sought to understand the knowledge and practices towards ASD in Lithuania. Age was chosen as a defining factor because information acquired from the FGD on parents, medical professionals, and teachers in Lithuania revealed that the older generation of Lithuanians (the one which grew up in the Soviet Union) exhibited more stigmatising and intolerant behaviour towards people with ASD and their family members compared to the younger generation (that grew up in Independent Lithuania). In addition, the population study by Dobryninas and Gaidys (2003) highlighted these tendencies.

Inclusion criteria:

- people born after 1985 (the Independence cohort age 18 – 32 years) people born before 1985 after 1978 (Transitional cohort age 33 – 50 years) and people born before 1978 (the Soviet Union cohort age 51 – 80 years);
- people living in Lithuania (including urban and rural areas);
- all levels of education, social-economic status, places of living and financial background.

Exclusion criteria:

- refused to participate in the study;
- age does not correspond to the defined age group;
- people not living in Lithuania – Lithuanian expatriates.

8.2.1 Sample Size

Estimations of total number of participants were based on the statistical power calculations using a two–tail statistical power of 0.80 and alpha 0.95,

the number of participants for each age group was 521. I decided to collect 566 per group to accommodate those that refuse to participate, thus making a total of 1700 participants.

8.2.2 Participants

Participants were invited to take part in the study by filling in the survey. A total of 1651 of 1739 approached participants (95%). The participants were from various regions of the country. Total of 19 cities and 26 villages were covered and they were representative of the country as a whole. They were grouped into distinct categories to test the hypothesis. The age was divided into three distinct cohorts: Independence cohort, Transitional cohort, and Soviet Union cohort. The Education was classified as High School degrees and under (Primary, Secondary, High School), Professional (College and Professional Schools), and Higher degree (Bachelor, Masters, Doctorate).

8.2.3 Measurements

The survey was adapted to a Lithuanian context from questionnaires used in previous studies on knowledge, attitudes, and practices of ASD. The questionnaire consisted of four parts. The first part recorded demographic information. The knowledge scale consisted of 12 ‘Yes/No’ statements (with an option for ‘I don’t know) about an ASD child’s development, which were taken from the study by Liu et al. (2016) that analysed public knowledge on ASD in China. Survey items included: “Vaccination of MMR causes ASD” [correct response - no], “ASD is a spectrum that varies from severe to mild” [correct response - yes]. One point was awarded for each correct response, whereas incorrect responses got -1, and “I don’t know” received no credit. The study by Liu et al. (2016) claimed that to get a sufficient knowledge score, the

respondents had to provide correct responses to more than 50% of the items. However, a sufficient knowledge score in this study was calculated referring to the data and performing a median split (as data was not normally distributed). Total knowledge scores from -12 to 4 were named insufficient knowledge and from 5 to 12 sufficient knowledge on ASD.

The third part of the questionnaire asked about participants' attitudes towards ASD people, answered with multiple choices. People were asked about Lithuanian attitudes towards people with ASD as well as their personal attitudes towards people with ASD. I used individual items to assess attitudes.

The final part was the set of questions on people's practices towards ASD. It consisted of 6 questions designed by Dillenburger et al. (2013). Each question portrayed the situation that involved an ASD person. The participants had to choose one out of three answers: "comfortable/uncomfortable/I do not know". The answers were scored: 1 if they felt comfortable with the situation; -1 if not comfortable or 0 did not know. The positive scores on this scale showed tolerant practices towards people with ASD, the negative scores intolerant and 0 is neutral. I used the median as a reference point and split the data accordingly. The practice scores were split into: "intolerant practice" (total scores that varied from -6 to 1) and "tolerant practice" (total scores from 2 to 6).

The questionnaire was thoroughly reviewed by a panel comprising health care professionals (1 child psychiatrist, 1 child psychologist, and 1 general practitioner), parents (2 mothers and 2 fathers of ASD children) and 2 lecturers from Vilnius University. The purpose of this content validation was to ensure that questions were not ambiguous and content was appropriate. To

assess the legibility and ensure the clarity of translated version of questionnaire, I gathered data from 100 participants in one week's time (August, 2017), across three different locations (city, town and village) and different age groups. I also asked the participants if they found any questions difficult, and edited the questions accordingly. Feedback from the study concerning item wording was integrated into the final version of the survey.

8.2.4 Procedure

In order to access a wider representation of the general population in Lithuania based on age differences, I used a stratifying method by age to recruit the sample. I used a data collecting company "Vilmorus" that used the OmniBus method, which required traveling in a minibus across Lithuania and asking people face-to-face to fill in questionnaires. The survey was done by trained professionals in data collection, paid by the "Vilmorus". It was a multi-stage, probabilistic selection – every Lithuanian citizen had the same probability of being interviewed. Potential participants were approach in public places by the team member from "Vilmorus." Potential participants were asked if they were interested in participating in this study. If the potential participant agreed, s/he was presented with an information sheet and a consent form that s/he then signed. The information sheet stayed with the participant and the signed consent form stayed with the data collector. The person was given a demographic sheet and a questionnaire to fill in, which took 7-10 minutes to complete. Participants were then thanked for taking part and informed to contact me via email if they had any further questions or concerns. "Vilmorus" was paid for the data collection, but participants did not receive money for participating in the research. The data collection occurred over one month's

time, starting in September 2017. Then the company provided anonymous results in an Excel file and I analysed them. Ethical approval is not required for such surveys in Lithuania, as the data does not have any identifying features and the company is responsible for maintaining ethical regulations.

8.2.5 Statistical analysis

Data was analysed using SPSS 21.0 statistical software package. For ease of interpretation, all data was presented both as integers and as percentages unless stated otherwise. The knowledge and practices scores were summed and the median was used a reference point to split the data. Missing values were excluded from the analysis of that variable. Basic statistics, such as chi-squared and rank order, are used to explore specific differences regarding the levels of knowledge, attitudes, and practices towards ASD. If differences were found they were incorporated in final model. I also examined whether demographics (e.g. age, gender, education, and finances) had an effect on the results. The data was not normally distributed so I used the Kruskall-Wallis, and the Mann–Whitney U test to detect the differences between dependent variables (Knowledge and Practices total scores) and various independent variables (gender, age, education, nationality etc). I used a post-hoc test to detect, where the differences occurred. The non-respondents and missing data was not included in the analysis.

8.2.6 Ethical Approval

The study was reviewed and approved by the Central University Research Ethics Committee Medical Sciences division at the University of Oxford (R52768/RE001.Permission was given for 3 months to collect the data and perform any follow up data collection if needed. Due to ethics regulations

participants were not reimbursed for their participation as it is perceived influencing their decision to voluntarily participate in research if monetary reimbursement is used in Lithuania.

8.3 Results

8.3.1 Demographics

Sample demographics are provided in *Table 18*. According to the Lithuanian Statistics department, women make up of 54% of the total population. There were more women (62%) than men (38%) in this sample, but there were no significant differences between other variables. There was one third of data missing on occupation (33.6%), income (43.2%) and marital status (33.8%), this was due to participants treating it as a sensitive data and refusing to provide answers for those questions. This can be explained due to the nature of the study, as they were interviewed face-to-face by data collectors, therefore feeling uncomfortable in responding. There was no significant difference in knowledge and perception scores between those whose socio- demographic data was missing and the rest of the sample.

Table 18. Demographic data of the population sample

Demographics of the participants	Frequency (N)	Percentage (%)
Gender		
Male	619	37.5%
Female	1032	62.5%
Age		
18-20 years old	164	9.9%
23-27 years old	223	13.5%
28-32 years old	167	10.1%
33-40 years old	209	12.6%
41-50 years old	235	14.2%
51-60 years old	268	16.2%
61-70 years old	203	12.3%
71-80 years old	128	7.7%
< 81 years old	54	3.4%

Demographics of the participants	Frequency (N)	Percentage (%)
Education		
Elementary	30	1.8%
Secondary	102	6.2%
High School	403	24.4%
Professional	188	11.4%
College	280	16.9%
Bachelor	411	12.3%
Master	224	7.7%
Doctorate	13	3.4%
Place of living		
City (>10,000 people)	677	41.0%
Town (1000<x<10,000 people)	549	33.2%
Village (<1000)	424	25.7%
Other	1	<1%
Nationality		
Lithuanian	1525	92.3%
Russian	77	4.7%
Polish	28	1.7%
Other	21	1.3%
Occupation		
Unemployed	78	4.7%
Housewife	34	2.1%
Retired/Disabled	358	21.7%
Student/pupil	47	2.8%
Businessman/Owner	29	1.8%
Farmer	9	<1%
Manager	19	1.1%
Specialist	142	8.6%
Service worker	109	6.6%
Qualified	207	12.5%
Unqualified	60	3.6%
Other	4	<1%
Did not answer	555	33.6%
Marital Status		
Single	180	10.9%
Married	546	33.0%
Cohabiting	77	4.7%
Divorced	123	7.4%
Widow	167	10.1%
Did not answer	558	33.8%
Members in the family		
One	282	17.1%
Two	446	28.9%
Three	161	9.7%
Four and more	179	10.8%

Demographics of the participants	Frequency (N)	Percentage (%)
Did not answer	552	33.4%
Do you have children under 18		
Yes	209	12.6%
No	891	53.9%
Did not answer	551	33.3%
Financial earnings per family per month (EUR)		
400 or less	697	42.2%
401-550	140	8.5%
551-1000	95	5.7%
1001 or more	5	<1%
Did not answer	714	43.2%

In the sample 1220 (74%) reported that they have heard about ASD. Most people (82.5%) had heard about ASD through various media outlets (TV/Radio, Journals/Newspapers/Internet). When asked how often they meet people with ASD in their daily life most participants (*N=943,* 57%) said they do not meet people with ASD *(Table 19).*

Table 19. Lithuanian answers about ASD exposure

Questions	Frequencies (N)	Percentage (%)
Have people heard about ASD?		
Yes	1220	74.0%
No	431	26.0%
How people have heard about ASD?		
Newspapers/Journals	397	32.5%
TV/Radio	438	36.0%
Brochure	14	1.3%
Health care professionals	55	4.5%
Family members/friends	117	10.0%
Church	1	<1%
Internet	175	14.0%
Schools/Teachers	10	<1%
Other	2	<1%
Did not answer	11	<1%
Do you know anyone with ASD?		
Yes	265	16.0%
No	1234	75.0%
I do not know	152	9.0%

Questions	Frequencies (N)	Percentage (%)
The person you know with ASD is?		
My child	42	16.0%
My family member	30	11.0%
Relative	91	34.0%
Friend/their family member	13	5.0%
Acquaintances/their family member	33	13.0%
Colleague/their family member	5	2.0%
Neighbour	41	15.0%
Other	10	4.0%

8.3.2 Misconceptions about ASD

People had general misconceptions about ASD. Some thought it was caused by the MMR vaccination (*N*=148, 8%), or bad parenting (*N*=95, 6%), whilst others thought children with ASD develop schizophrenia in adulthood (*N*=151, 9%), or that children with ASD deliberately misbehave (*N*=221, 13%) *(Table 20).*

Table 20. Knowledge scale: answers of individual questions

Questions about Knowledge	Frequency (*N*)	Percentage (%)
13. Child with autism often presents with speech and language delay between 2-3 years old		
Yes	868	52.5%
No	80	4.8%
I do not know	703	42.5%
14. Autism is caused by vaccination (like MMR)		
Yes	148	9%
No	525	31.80%
I do not know	978	59.20%
15. Autism is a developmental disorder		
Yes	1035	62.6%
No	152	9.2%
I do not know	464	28.1%
16. All children with autism will be unable to pursue further education at the university level		
Yes	158	9.6%
No	879	53.2%
I do not know	614	37.1%

Questions about Knowledge	Frequency (*N*)	Percentage (%)
17. Changing the diet of a child with autism will make a difference to his/her disorder		
Yes	339	20.5%
No	580	35.1%
I do not know	732	44.3%
18. Autism is caused by poor parenting skills or poor home care		
Yes	95	5.7%
No	1074	65.0%
I do not know	482	29.2%
19. Autism occurs in less than 10% of the population		
Yes	481	29.1%
No	150	9.1%
I do not know	1020	61.7%
20. Autistic children do not show their affection, even to their parents		
Yes	334	20.2%
No	541	32.7%
I do not know	776	46.9%
21. Autistic children usually grow up to be schizophrenic adults		
Yes	151	9.1%
No	543	32.8%
I do not know	957	57.9%
22. Autistic children are deliberately misbehaving and noncompliant		
Yes	221	13.4%
No	827	50.0%
I do not know	603	36.5%
23. Autism is a spectrum (varies from severe to mild form)		
Yes	1048	63.4%
No	33	2.0%
I do not know	570	34.5%
24. Autism is heritable		
Yes	481	29.1%
No	361	21.8%
I do not know	809	48.9%

These misconceptions are more prevalent among people who knew someone with ASD compared to those who do not. The findings showed that 10% of the total sample who heard about ASD and 15% of people who personally knew someone with ASD believed that 'MMR vaccination caused ASD'. Similar tendencies were noticed with 'poor parenting skills causes ASD'; 'children with ASD usually grow up into schizophrenic adults' and 'children with ASD deliberately misbehave'. All these tendencies were statistically significant p <.001 *(Table 21).* It is important to underline that there was large amount of people who chose "I do not know" (IDK) option to these statements. Questions on vaccination (q14) and schizophrenia (q21) had the highest proportion of IDK answers, which were incorrect statements about ASD. Nevertheless, there were high proportions on the correct ASD statements like prevalence of ASD (q19) and heritability (q24) as well. No further information can be provided to explain what is behind the answer "I don't know".

Table 21. Misconceptions and exposure to ASD among participants

	Misconceptions											
	ASD is caused by vaccination			ASD is caused by poor parenting skills			Autistic children usually grow up into schizophrenic adults			Autistic children are deliberately misbehaving		
Have you heard about ASD	Yes	No	IDK*	Yes	No	IDK*	Yes	No	IDK*	Yes	No	IDK*
Yes	128 (10.5%)	462 (37.9%)	630 (51.6%)	70 (5.7%)	964 (79.0%)	186 (15.2%)	114 (9.3%)	503 (41.2%)	603 (49.4%)	170 (13.9%)	761 (62.4%)	289 (23.7%)
No	20 (13.5%)	63 (12.0%)	348 (80.7%)	25 (5.8%)	110 (10.2%)	296 (68.4%)	37 (8.6%)	40 (9.3%)	354 (82.1%)	51 (11.8%)	66 (15.3%)	314 (72.9%)
Do you know anyone with ASD personally	Yes	No	IDK*	Yes	No	IDK*	Yes	No	IDK*	Yes	No	IDK*
Yes	39 (15.9%)	97 (39.6%)	109 (44.5%)	15 (6.1%)	212 (86.5%)	18 (7.3%)	12 (4.9%)	137 (55.9%)	96 (39.2%)	29 (11.8%)	199 (81.2%)	17 (6.9%)
No	105 (7.9%)	413 (31%)	813 (61.1%)	77 (5.8%)	836 (62.8%)	418 (31.4%)	127 (9.5%)	395 (29.7%)	809 (60.8%)	178 (13.4%)	610 (45.8%)	543 (40.8%)

**IDK – I do not know*

The age was divided into three categories to test the hypothesis based on generational differences. The misconception on “MMR vaccination causes ASD” was significantly different across the three cohorts: Independence generation, Transition generation, Soviet-Union generation H (2)=18.25, p<.001. Post hoc test – a pairwise comparison with adjusted p-values showed that there was a significant difference between the Independence and Soviet Union Cohorts (p=.03), but not between Soviet Union (p=.13) and Transitional, or Independence and Transitional (p=.17)

There were significant differences between generations on the misconception that “autism is caused by poor parenting”. Independence generation, Transition generation, Soviet-Union generation H (2)=140.96, p<.001. Post hoc test – a pairwise comparison with adjusted p-values showed that there was a significant difference between the Independence and Soviet Union Cohorts (p<.001) and Transitional and Independence (p<.001), but not Transitional and Independence (p=.76).

The misconception that “autistic children usually grow up to be schizophrenic adults” was tested between the three generations. Independence generation, Transition generation, Soviet-Union generation H (2)=146.23, p<.001. Post hoc test – a pairwise comparison with adjusted p-values showed that there was a significant difference between the Independence and Soviet Union Cohorts (p<.001), Transitional and Independence (p<.001) and Transitional and Independence (p=.019).

Finally, the misconception that “autistic children deliberately misbehave” was tested across the groups: Independence generation Transition generation, Soviet-Union generation H (2)=171.43, p<.001. Post

hoc test – a pairwise comparison with adjusted p-values showed that there was a significant difference between the Independence and Soviet Union Cohorts (p<.001), Transitional and Independence (p<.001), and Transitional and Independence (p=.001).

8.3.3 Knowledge about ASD

When answering the knowledge questions, each participant's response was summed into the total score called the 'Knowledge of ASD' score; the higher the score the more knowledgeable person was about ASD. When calculating the knowledge points there were 867 participants (53%) who had insufficient knowledge on ASD based on median split calculations. The remaining 784 (47%) participants demonstrated sufficient knowledge on ASD, 374 (23%) people scored between 7 and 9 points on the knowledge scale and 138 (8%), 68 (4%) people scored 10 and above *(Figure 32).*

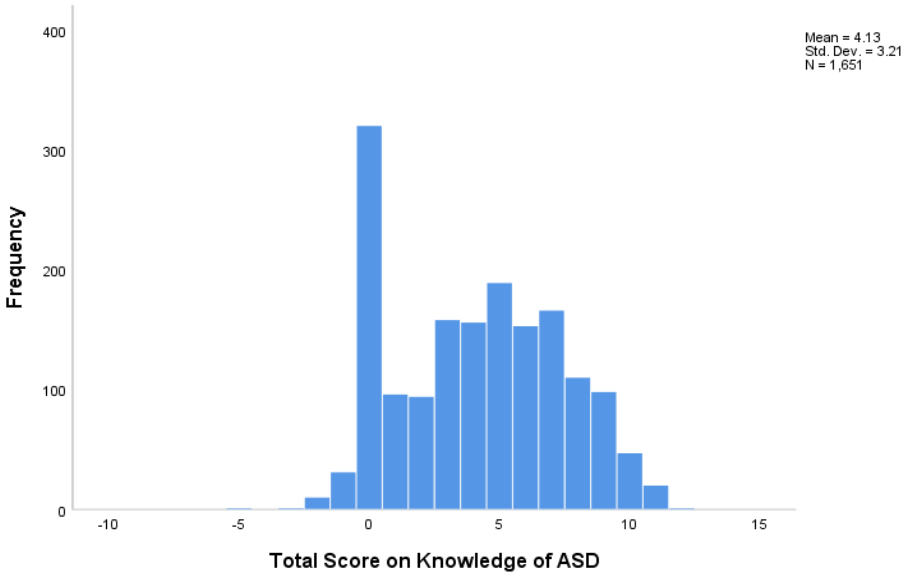


Figure 33. Participant's scores on their Knowledge of ASD

I investigated the difference between knowledge scores, based on being knowledgeable (scoring total ≤5 points) or not knowledgeable (scoring total ≥4) and exposure to ASD. The chi square test revealed significant differences between the groups *(Table 22).*

Table 22. Knowledge score and exposure of ASD among participants

	Total Knowledge Scores on ASD		
	Insufficient knowledge on ASD	Sufficient knowledge on ASD	Statistics
Have you heard about ASD? (*N*/%)			
Yes	368 (22.3%)	852 (51.6%)	$\chi 2$ (1)=317.22, p<.001
No	343 (20.8%)	88 (5.3%)	
Total	711 (43.1%)	693 (56.9%)	

Further analysis has shown that there were significant differences between the knowledge scores based on age, education, nationality and financial status *(Table 23).* In order to investigate the differences, I performed non-parametric tests.

Table 23. Total knowledge scores across sociodemographic data

Sociodemographic data	Insufficient knowledge	Sufficient knowledge	Statistics
Gender (*N/% - out of total N*)			
Female	359 (21.7%)	673 (40.8%)	$\chi 2$ (1)=76.93, p<.001
Male	352 (21.3%)	267 (16.2%)	
Age (*N/% - out of total N*)			
18-20 years old	48 (2.9%)	38 (5.5%)	$\chi 2$ (8)=171.43, p<.001
23 -27 years old	55 (3.3%)	73 (10.5%)	
28-32 years old	49 (3.0%)	46 (6.6%)	
33-40 years old	65 (3.9%)	52 (7.5%)	
41-50 years old	100 (6.1%)	72 (10.4%)	
51 -60 years old	135 (8.2%)	143 (20.6%)	
61-70 years old	126 (7.6%)	145 (20.9%)	
71-80 years old	92 (5.6%)	83 (12.0%)	
< 80 years old	41 (2.5%)	41 (5.9%)	

Sociodemographic data	Insufficient knowledge	Sufficient knowledge	Statistics
Education (*N/% - out of total N*)			
Elementary	28 (1.7%)	2 (0.1%)	
Secondary	59 (57.8%)	43 (2.6%)	
High School	206 (12.5%)	197 (11.9%)	
Professional	105 (6.4%)	83 (8.8%)	χ^2 (7)=170.86, p<.001
College	153 (9.3%)	127 (13.5%)	
Bachelor	112 (6.8%)	299 (31.8%)	
Masters	46 (2.8%)	178(18.9%)	
Doctorate	2 (0.1%)	11 (1.2%)	
Place of Living (*N* (*N/% - out of total N*)			
City	248 (15.0%)	677 (41.0%)	χ^2 (3)=41.92, p<.001
Town	225 (13.6%)	549 (33.3%)	
Village	238 (14.4%)	424 (25.7%)	
Nationality (*N/% - out of total N*)			
Lithuanian	644 (39%)	881 (53.4%)	
Russian	43 (2.6%)	34 (2.1%)	χ^2 (3)=5.69, p=.06
Polish	13 (0.8%)	15 (0.9%)	
Finances per (*N/% - out of total N*)			
EUR 400 or less	429 (45.8%)	268 (28.6%)	
EUR 401 -550	71 (7.6%)	69 (14.9%)	χ^2 (3)=28.94, p<.001
EUR 551-1000	36 (3.8%)	59 (6.3%)	
EUR 1001 or more	0 (0.0%)	5 (0.5%)	

The age was divided into three categories to test the hypothesis based on generational differences. The scores about the knowledge of ASD were significantly different across the three cohorts: Independence generation (Mdn=6, IQR=4), Transition generation (Mdn=5, IQR=16), Soviet-Union generation (Mdn=3, IQR=15), H (2)=180.41, p<.001. Post hoc test – a pairwise comparison with adjusted p-values showed that there was a significant difference between the Independence Cohort and Transition Cohort (p=.03, z=1.41, r=0.03), between the Independence Cohort and Soviet-Union Cohort

(p<.001, z=-14.43, r=-0.36.) as well, the Transitional Cohort and Soviet-Union Cohort (p<.001, z=-13.81, r=-0.34) *(Figure 33).*

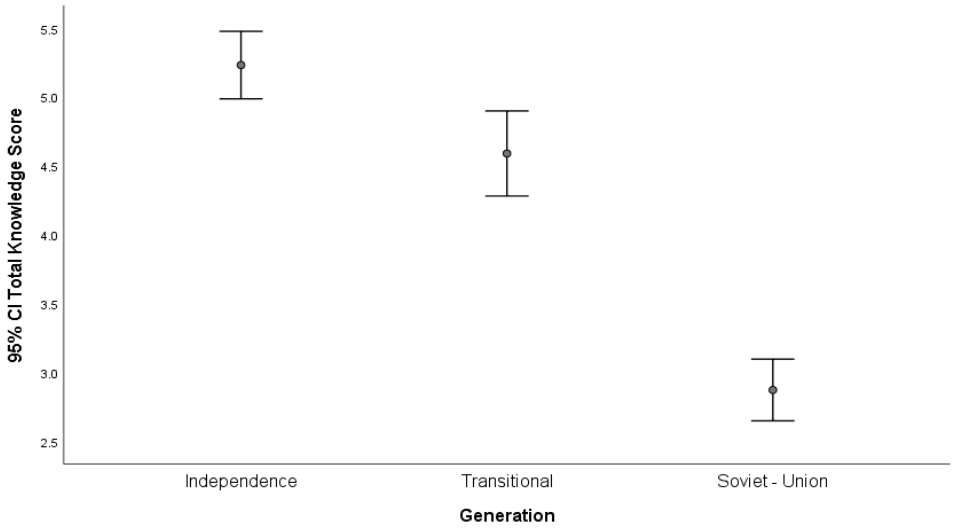


Figure 34. Error bars of total knowledge score on ASD between different generations, with 95% Confidence Intervals

When comparing knowledge scores on ASD based on participants' education, the Kruskall-Wallis test has revealed significant differences between the participants based on their education: High school degree (*Mdn*=3, *IQR*=6), College (Mdn=3, IQR=15) and University (Mdn=6, IQR=5), H (2)=9.68, p=0.008. Post hoc test – a pairwise comparison with adjusted p-values showed no significant difference between High School degree and College (p=1.0, z=-0.49, r=-0.01). While, there was significant difference between participants with High School and University degree (p<.001 0.014, z=2.82, r=0.07), as well between College and University (p<.001, z=2.47, r=0.06) and total knowledge on ASD scores *(Figure 34).*

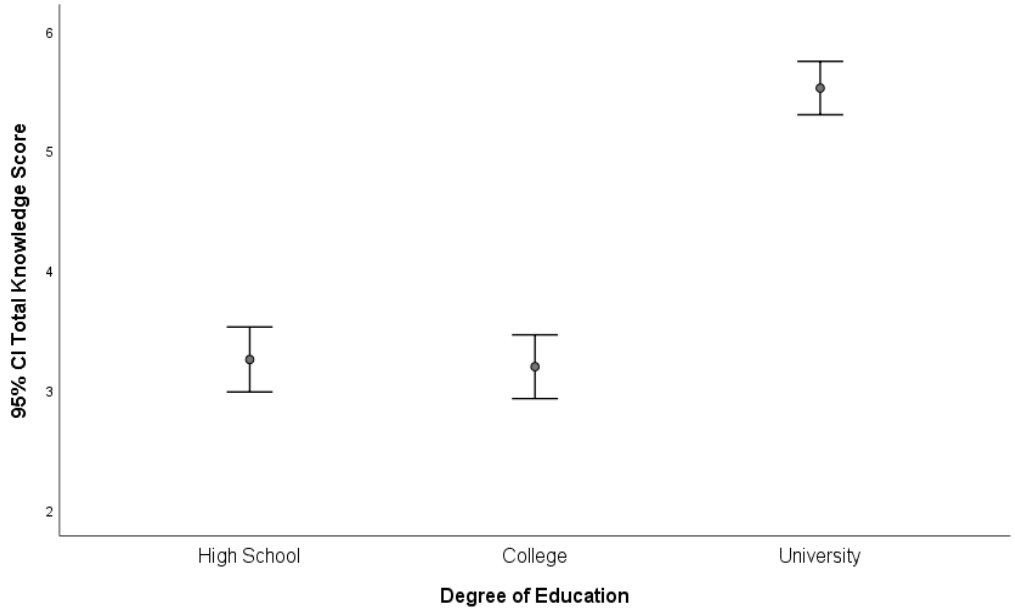


Figure 35. Error bars of total knowledge score on ASD between education groups, with 95% Confidence Intervals

A Kruskall–Wallis analysis based on ASD knowledge scores and financial earnings per month revealed that there was significant difference between the scores of participants earning EUR 400 or less per month (Mdn=2, IQR=5), between EUR 401 – 550 per month (Mdn=3, IQR=5) and EUR 551 and more per month (Mdn=5, IQR=4), H(2)=10.13, p=.006. Post hoc test – a pairwise comparison with adjusted p-values showed that there was significant difference between participants who are earning <400 Euro and 401 – 550 Euro (p=.005, z=1.16, r=0.03). Also between participants earning 401 – 550 Euro and 551 or more Euro (p=.013, z=1.71, r=0.04) and between <400 Euro <551 more Euro, based on their ASD Knowledge scores (p<.001, z=3.10, r=0.08) *(Figure 35).*

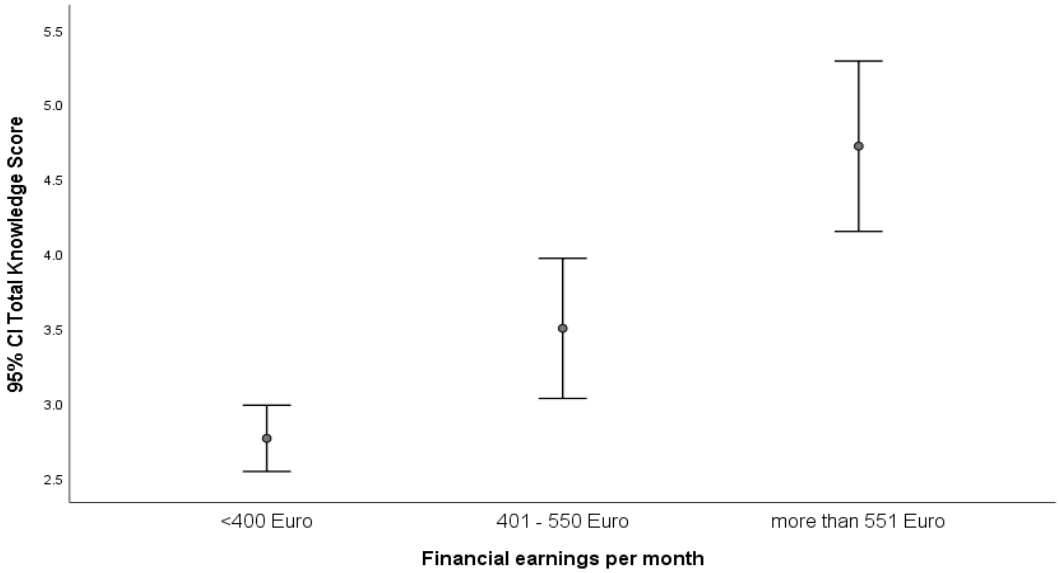


Figure 36. Error bars of total knowledge score on ASD between financial earnings, with 95% Confidence Intervals

8.3.4 Attitudes towards ASD

Participants also reported how a person with ASD is usually treated in Lithuania. Some claimed that Lithuanians would reject people with ASD (*N*=418, 25.3%), others stated that people were generally friendly, but would avoid people with ASD (*N*=669, 40.5%). Some claimed that Lithuanians are mostly supportive and helpful towards people with ASD (*N*=284, 17.2%) and the remainder reported 'Other' (*N*=280, 17%). Participants elaborated on their response, or highlighted their personal experiences, when choosing option "Other" (*Appendix F*).

When participants were asked about their personal attitudes towards ASD, they reported accordingly: 'I feel compassion and desire to help' *(N*=745, 45.1%); 'I feel compassion but I tend to stay away from people with ASD' (*N*=163, 9.9%); 'It is ASD people problem and I cannot get ASD (*N*=28, 1.7%); 'I fear them because people with ASD are unpredictable' (*N*=29, 1.8%); 'I have

no particular feeling' (*N*=619, 37,5%); 'Other' (*N*=52, 3.1%); 'did not respond' (*N*=15, 0.9%).

Participants were also invited to reflect on their feelings on how they would feel if they or someone they loved had been diagnosed with ASD: 'fear' (*N*=373, 22.6%); 'surprise' (*N*=288, 17.4%); 'shame' (*N*=20, 1.2%), 'hopelessness' (*N*=614, 37.2%); 'joy' (*N*=1, 0.1%); 'other' (*N*=197, 11.9%); 'did not respond' (*N*=158, 9.6%).

8.3.5 Practices Scores

Participants' perceptions were measured using the total sum on the practice scale. The frequency table showed that people were most comfortable if a child with ASD (60.6%) or adult with ASD (50.4%) moved next door, and if the child with ASD was in their family member's class (53.4%). People were least comfortable if an ASD person was their boss (39.0%), if an ASD person married their family member (26.7%) or was their colleague (23.4%) (*Figure 36-41).*

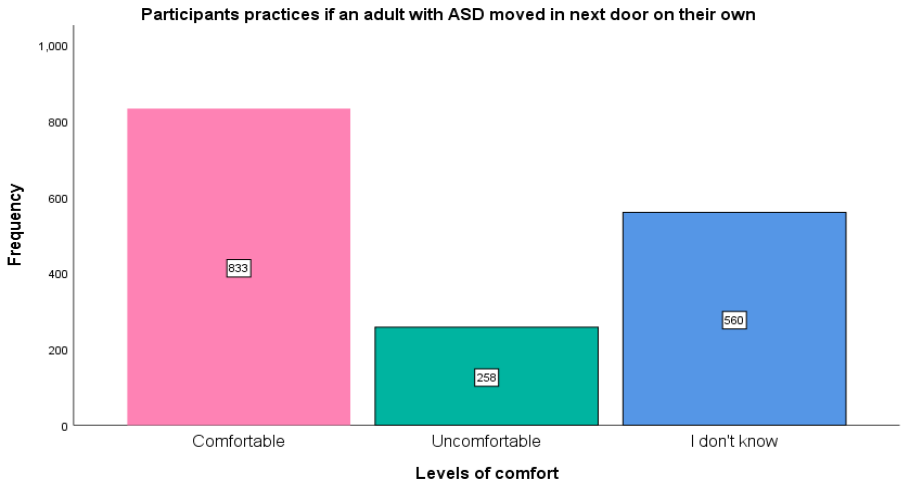


Figure 37. Participant practices if an adult with ASD moved next door

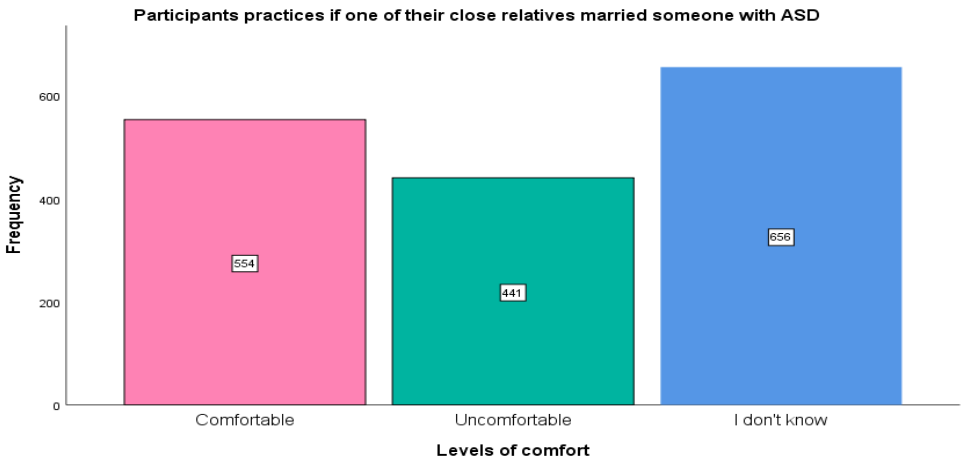


Figure 38. Participant practices if relative married a person with ASD

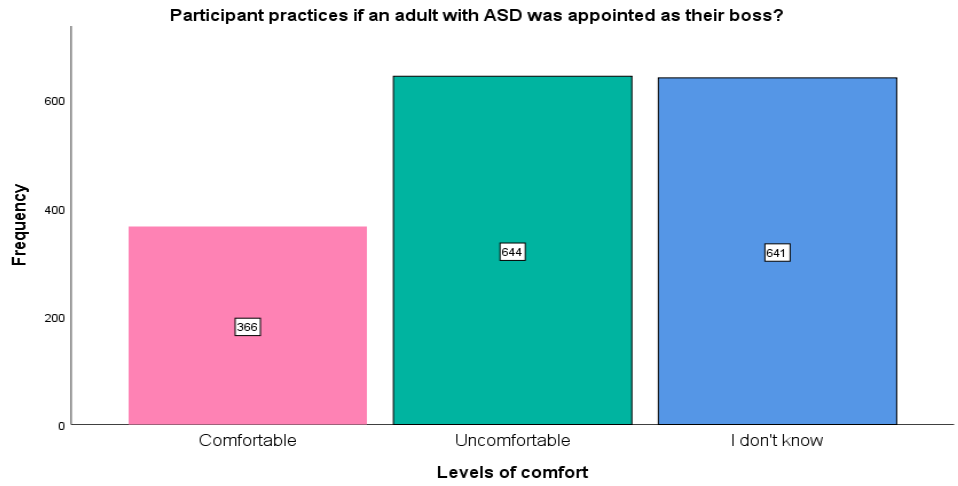


Figure 39. Participant practices if an adult with ASD was their boss

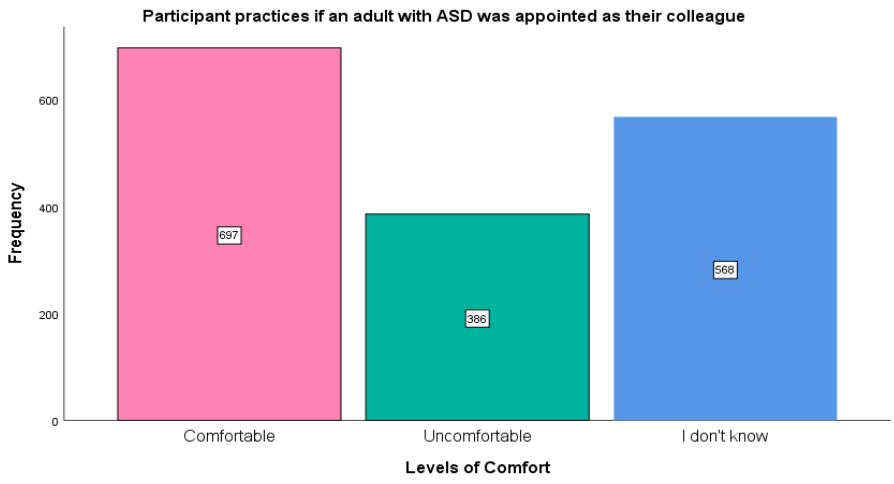


Figure 40. Participant practices if an adult with ASD was their colleague

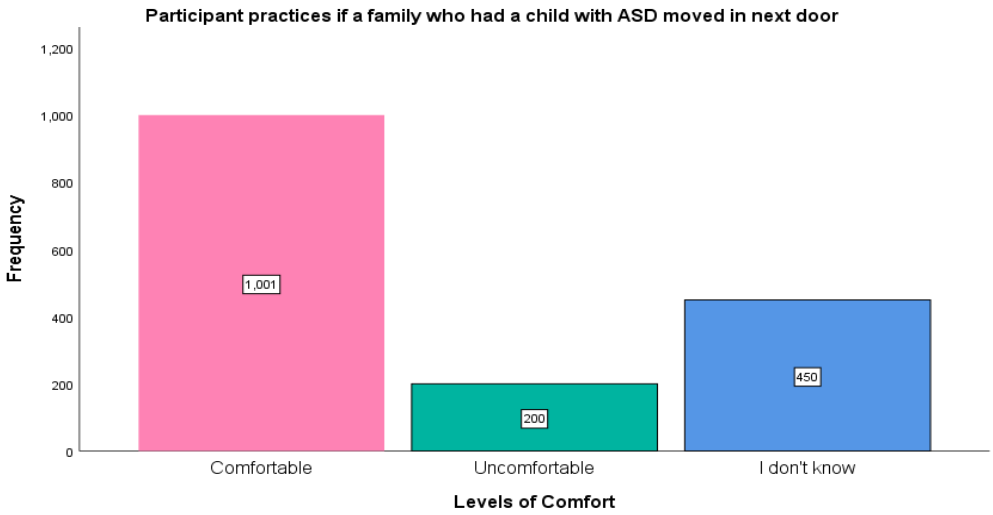


Figure 41. Participant practices if family with child with ASD moved in next door

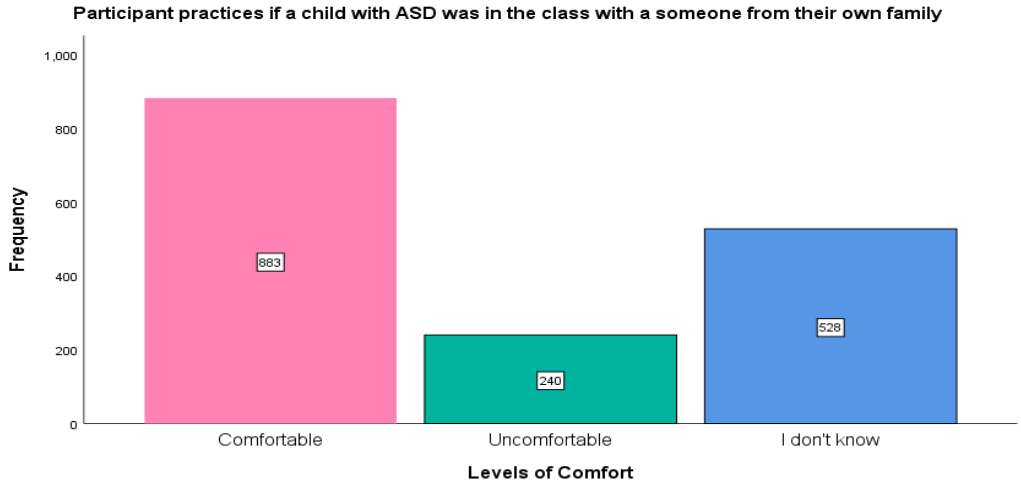


Figure 42. Participant practices if a child with ASD was in the class with someone from their close family

I was interested to understand if there were any differences between practice scores, based on being tolerant (scoring ≥ 2 points) or intolerant (scoring ≤1) and exposure to ASD. The chi square test revealed a significant difference between the groups. This demonstrates that being aware does not mean you will be more tolerant towards ASD *(Table 24).*

Table 24. Total practice scores and the exposure to ASD among participants

	Practices towards ASD		
	Intolerant practices	Tolerant practices	Statistics
Have you heard about ASD? (*N*/%)			
Yes	520 (31.5%)	700 (42.4%)	χ2 (1)=144.66
No	313 (19.0%)	118 (7.1%)	p<.001

Furthermore, the analysis of total knowledge scores and total practice scores towards ASD had revealed that people who scored above the PASS score for both knowledge and practices were only 325 (19%) participants *(Table 25).*

Table 25. Total knowledge scores and total practice scores among participants

	Total Knowledge scores on ASD		
	Insufficient knowledge	Sufficient knowledge	Statistics
Practices towards ASD (*N*/%)			
Intolerant practices	485 (29.4%)	348 (21.1%)	χ2(1)=157.56,
Tolerant practices	226 (13.7%)	592 (35.9%)	p<.0001
Total	711 (43.1%)	940 (56.9%)	

Further analysis on demographics and total practice scores has shown that people are more accepting based on age, education and nationality *(Table 26).*

Table 26. Total practice scores across socio-demographic data

Socio-demographic data	Intolerant Practices	Tolerant Practices	Statistics
Gender (*N/% - out of total N*)			
Female	362 (61.8%)	471 (63.5%)	χ^2 (1)=25.52, p<.001
Male	257 (38.2%)	561 (36.5%)	
Age (*N/% - out of total N*)			
18-20 years old	66 (4.0%)	98 (5.9%)	χ^2 (8)=77.97, p<.001
23 -27 years old	82 (5.0%)	141 (8.5%)	
28-32 years old	68 (4.1%)	99 (6.0%)	
33-40 years old	85 (5.1%)	124 (7.5%)	
41-50 years old	127 (7.7%)	108 (6.5%)	
51 -60 years old	159 (9.6%)	109 (6.6%)	
61-70 years old	126 (7.6%)	77 (4.7%)	
71-80 years old	80 (4.8%)	48 (2.9%)	
<80 years old	40 (2.4%)	14 (0.8%)	
Education (*N/% - out of total N*)			
Elementary	23 (1.4%)	7 (0.4%)	χ^2 (7)=82.06, p<.001
Secondary	61 (3.7%)	41 (2.5%)	
High School	210 (12.7%)	193 (11.7%)	
Professional	121 (7.3%)	67 (4.1%)	
College	172 (10.4%)	108 (6.5%)	
Bachelor	155 (9.4%)	256 (15.5%)	
Masters	88 (5.3%)	136 (8.2%)	
Doctorate	3 (0.2%)	10 (0.6%)	
Place of Living (*N/% - out of total N*)			
City	304 (18.4%)	295 (22.6%)	χ^2 (2)=8.85, p<.001
Town	289 (17.5%)	208 (15.8%)	
Village	240 (14.5%)	169 (11.2%)	
Nationality (*N/% - out of total N*)			
Lithuanian	756 (46.4%)	769 (47.2%)	χ^2 (2)=5.6, p=.012
Russian	47 (5.7%)	30 (1.8%)	
Polish	20 (1.2%)	8 (0.5%)	
Finances per month (*N/% - out of total N*)			
EUR 400 or less	430 (45.9%)	267 (28.5%)	χ^2 (3)=14.98, p=.02
EUR 401 -550	91 (9.7%)	49 (5.2%)	
EUR 551-1000	40 (4.3%)	55 (5.9%)	
EUR 1001 or more	3 (0.3%)	2 (0.2%)	

There was a significant difference on the perception of ASD score based on the age group: Independence generation (Mdn=3, IQR=5), Transition generation (Mdn=2, IQR=5), Soviet Union generation (Mdn=0, IQR=4); Kruskal–Wallis test H (2)=56.43, p<.001, a pairwise comparison with adjusted p–value has shown that there was no significant difference between the Independence and Transition generations (p=.079, z=2.03, r=0.05). While a significant difference was found between the Transition generation and Soviet Union generation on their practices towards ASD (p<.001, z=-10.17, r=-0.25) and between the Independence Union and Soviet Union Cohort (p<.001, z=-8.59, r=-0.21). Showing higher practice scores by younger generation *(Figure 42).*

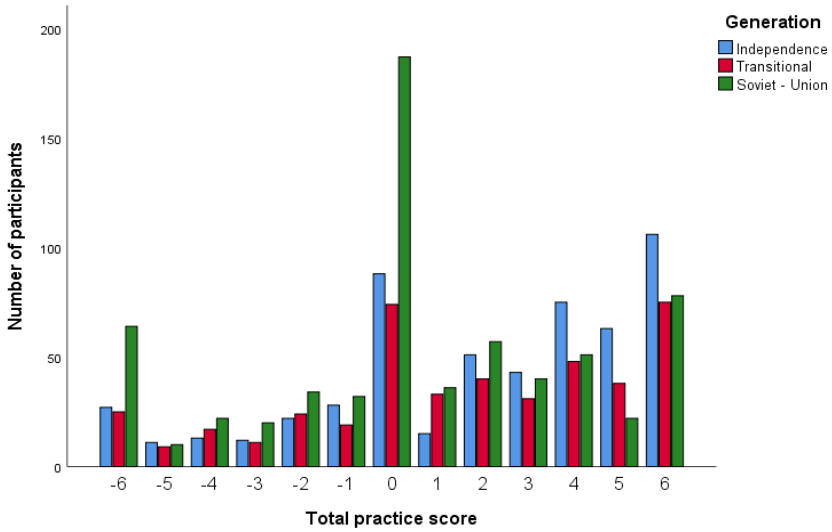


Figure 43. Histogram showing the total perception scores across the sample based on different generations

Further analysis has shown that there was a difference between gender and practice score H (1)=24.85, p<.001 *(Figure 43)*; between finances per month and practice score H (2)=2.40, p=.001, pairwise comparison of adjusted means showed the differences between the groups: 401-550 Euro and <400

Euro p =.030, 401-550 Euro and more than 551 Euro p <.001, <400 Euro and more than 551 p=.046 *(Figure 44)*; between practices score and education, H (2)=70.15, p<.001, pairwise comparison of adjusted means showed the differences between the groups: College and High school p =.001, College and University p <.0001, High School and University p<.0001 *(Figure 45).* There was no difference between practice score and nationality H (2)=8.66 p=.013 or place of living H (2)=6.189, p=.05.



Figure 44. Error bars of total practice scores on ASD between genders, with 95% Confidence Intervals

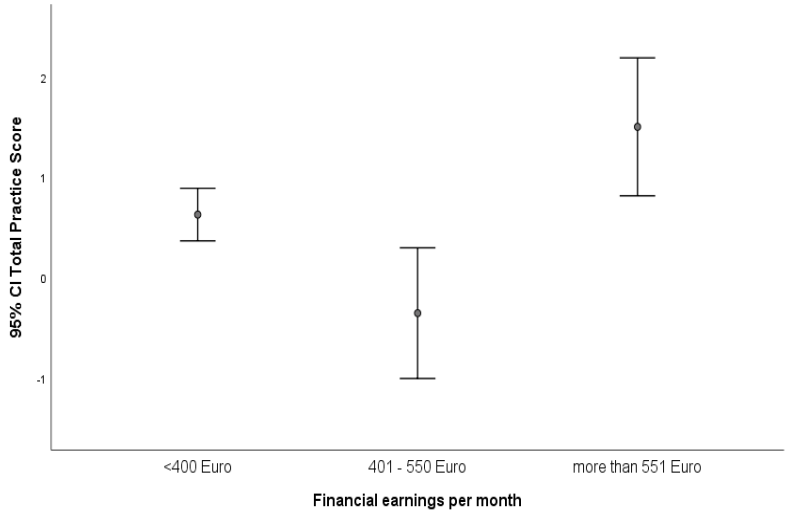


Figure 45. Error bars of total practice scores on ASD between salaries per month, with 95% Confidence Intervals

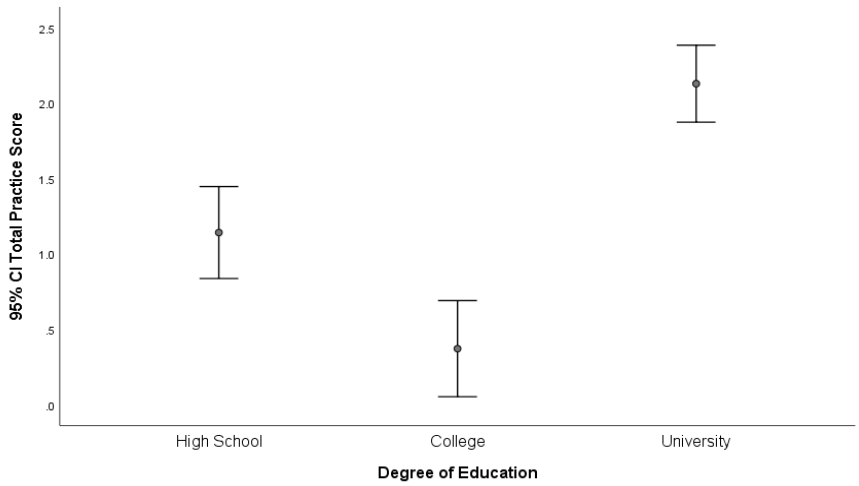


Figure 46. Error bars of total practice scores on ASD between degrees of education, with 95% Confidence Intervals

8.3.6 Logistic Regression

Finally, I aimed to build linear model for knowledge and practice variables, based on the bivariate analyses that were performed. The correlation analysis informed about significant relationships between the demographic variables Regression assumptions were tested before performing analysis. Linearity between predictors and logit outcome was assessed using scatterplots. Multicollinearity was checked using correlation matrices, there were no R value greater than 0.9 *(Table 27).* Influential outliers were visually inspected using Cook D - no outliers higher than 1μ. No violations of assumptions recorded, thus regression analysis performed. A logistic regression demonstrated if knowledge scores can be predicted by the practice scores and demographic factors (age, finances, degree of education, participant's gender).The analysed model 6 was significant with the highest loglikehood. *(Table 28).*

Table 27. Correlation analysis between the demographic variables and total knowledge and practice scores

	Correlations					
Variables	Total knowledge score	Generation	Finances per month	Degree of education	Participant's gender	Total practice score
Total knowledge score	1.000	-0.173**	0.206**	0.279**	0.082**	0.288*
Generation	-0.173	1.000	-0.202**	-0.073*	0.089**	-0.067*
Finances per month	0.206	-0.202	1.000	0.275**	-0.113**	0.090*
Degree of education	0.268	-0.073	0.275	1.000	0.027	0.135**
Participant's gender	0.080	0.089	-0.113	0.027	1.000	-0.006
Total practice score	0.293	-0.067	0.090	0.135	-0.006	1.000

Correlation is significant at the **.01, *.05

Table 28. Logistic Regression Analysis of 1651 participant's for knowledge score by different demographic variables

						95%CI for Odds Ratio		
Predictor	β	SE β	Wald's χ^2	df	p	Lower	e^{β} (odds ratio)	Upper
Constant	-0.2	0.25	0.61	1	.43	Not Applicable		
Gender (*Female*)	0.23	0.15	12.24	1	.002	1.51	1.07	2.13
Generations (*Independent*)	0.62	0.2	10.11	1	.001	1.27	1.87	2.74
Degree of Education (*High School*)	-0.98	0.19	26.77	1	.000*	0.37	0.26	0.54
Finances per month *(<400 €)*	-0.47	0.24	3.8	1	.049	0.63	0.39	0.99
Total Practice Score	0.07	0.02	12.16	1	.000*	1.08	1.03	1.12
Test			χ^2	df	p			
Overall model evaluation								
Likelihood ratio test			85.22	1	.00			
Goodness-of-fit-test Hosmer & Lemeshow			10.57	8	0.23			

**Note.SPSS.23.* Cox and Snell R^2 =.87. Nagelkerke R^2=.12. *p< 0.00001

8.4 Discussion

It is no longer a question of whether a person in Lithuania will meet someone with ASD but rather *when* they will meet one. This study showed that 74% of people had heard about ASD, indicating moderate to high awareness on ASD.

This study is similar to findings from other public studies that show 80% to 100% societal awareness on ASD (Dillenburger et al. 2013; Durand-Zaleski et al. 2012; Holt and Christensen 2013; Liu et al. 2016). Nevertheless, it is important to distinguish between awareness and knowledge. Even though participants were aware of ASD, their knowledge about it was poor; less than 29% scored above the PASS mark. In other studies, the trend was similar, as ASD knowledge scores had decreased drastically: France from 100% awareness to 64% of good ASD knowledge, United Kingdom from 89% to 53%, USA from 92% to 64% (Dillenburger et al. 2013; Durand-Zaleski et al. 2012; Holt and Christensen 2013; Liu et al. 2016). Of course, one must be careful, as the scales used in these studies were different ones.

8.4.1 Misconceptions of ASD

In this study 63% of people claimed that ASD is a neuro-developmental disorder and 29% agreed that ASD is hereditary – demonstrating that some Lithuanians understand that ASD has biological/genetic basis. However, some participants attributed the source of ASD to other causes: neglectful parenting (6%), or vaccination (10%). Similar results were found in other Western cultures (Dillenburger et al. 2013; Durand-Zaleski et al. 2012; Tipton and Blacher 2014). The study by Durand-Zaleski et al. (2012) found that French people attributed the causes of ASD to genetics (44%), parent–child relations

(22%) or environmental factors (i.e. dietary) (11%). The study by Dillenburger et al. (2015) has showed that Northern Ireland's public attributed cause of ASD to genetics (59%); parent–child relations (3%) and the environment (7%).

In this study, I have found that 16% of respondents who knew someone with ASD believed that ASD is caused by vaccination. This is not supported by the scientific evidence about causality of vaccines and ASD (Ahearn 2010; Chen et al. 2004; Gerber and Offit 2009; Madsen et al. 2002; Miller and Reynolds 2009; Smeeth et al. 2004). This study highlighted the harm of such statements and showed how families with ASD internalised such statements and became advocates against vaccination (Dannetun et al. 2005). In addition, I found that people who did not know anyone with ASD (11%) agreed that vaccination causes ASD. Studies demonstrated that the public tends to avoid vaccination due to the fear of getting ASD (Fredrickson et al. 2004; Huws and Jones 2011; McMurray et al. 2004). Therefore, this misconception exists in the Lithuanian population despite the wealth of evidence against it.

Approximately 9% of the population who were aware of ASD believed the statement: 'children with ASD usually grow up into schizophrenic adults'. This points out that the Soviet Union explanation of ASD as infantile schizophrenia prevails in the general public (Serapinaitė 2014; Lesinskiene et al. 2008; Puras et al. 2004b). It was found that this misconception is more prevalent in the older generation. Another misconception found among people who knew someone with ASD personally (13%) was that ASD children deliberately misbehave. This was reported in other studies showing that behavioural problems are perceived as deliberate among the general public and relatives of ASD families (Dillenburger et al. 2013; Durand-Zaleski et al.

2012; Liu et al. 2016; Tipton and Blacher 2014). Also, the findings showed significant differences between generations, and that this misconception was more common among the older generation.

The final misconception that ASD is caused by poor parenting (6%) was the least prevalent among the Lithuanian public. However, the generational differences were detected, showing that the older generation were more prone to this belief than the younger ones. This was lower in number than in a previous study in the USA where approximately 30% of people in the USA attribute behavioural issues of ASD to “bad parenting” (Chambres et al. 2008). However, one must be careful interpreting the findings that are 10 years old and different countries, the dissimilarities might be due to generational differences.

For both correct knowledge statements like “ASD is hereditary” and incorrect statements like “ASD is caused by MMR vaccination” there were high proportions of “I don’t know” (IDK) answers. These proportions appear to be higher than those found in comparable studies in France (on average 20% chose IDK answer) and Northern Ireland (35%); these differences suggest a delineation between the general knowledge on ASD in different European countries compared to Lithuania (K. Dillengburger et al. 2010; Duran-Zalieski et al 2012). Nevertheless, no additional explanation can be gauged as no further data was gathered to explain why Lithuanians chose IDK answers.

In previous chapters, parents also claimed that when faced with unsuitable behaviour, observers accused the child of being poorly raised. This begs the question of why there is such a difference between parental reports and the general public in Lithuania. The study by Chambres et al. (2008)

explained that when the US population was presented with problematic behaviour and were not informed about the child's condition, they attributed the behaviour to poor parenting. Thus, this could explain the difference between the reports, as participants in this study knew the topic of the survey, while in Chambres et al. (2008) scale questions were mixed (ecological validity) and aims could not be guessed.

I explored the relationship between common knowledge scores and demographic factors. The regression analysis has shown that these demographic factors were associated with knowledge scores: gender (male), age (41-60 years of age), education (high school), financial status (EUR 400 or less), and lower practice scores. The study by Dillenburger et al. (2015) reported that knowledge about ASD varied across different demographic categories in Northern Ireland. The participants were less informed about ASD if they were males, had lower education level, or were age 18-24. Similar findings were observed by Adli et al. (2017) in Malaysia in that women had fewer misconceptions about ASD than men. However, it also showed that people with higher levels of education were significantly more misinformed compared to others. This demonstrates that demographic aspects are different depending on the country and its cultural perceptions towards ASD.

8.4.2 Knowledge on ASD

Different demographic variables were associated with knowledge about ASD. In this case, gender was associated with knowledge on ASD. This supports the findings from previous studies that demonstrated women were more knowledgeable than men about ASD (Hutzler 2003; Popovich et al. 2003). The study by Chambres et al. (2008) also has found that men are

harsher critiques of problematic behaviour if they are not aware of a child's diagnosis.

The Independence generation was more informed about ASD than the Soviet Union generation. This supported the findings from parents' reports in previous chapters that claimed that the older generation is less informed compared to the younger generation. Also, Dobryninas and Gaidys (2003) claimed that the older generation in Lithuania is less knowledgeable about people with disabilities. However, Western studies supported current findings and reported that the older generation tends to be more informed about ASD compared to the younger one (Dillenburger et al. 2013; Durand-Zaleski et al. 2012; Tipton and Blacher 2014; Society 2017). I have found that age is correlated with knowledge of ASD and people of 51 years and above scored the lowest, while the younger generation (age 18 – 50) scored higher on ASD knowledge. Adli et al. (2017) showed similar findings, that the age of 50 years and above had the highest prevalence (43%) of poor ASD knowledge in Malaysia.

On examination of education and total ASD knowledge scores, I found that people with university education scored higher on knowledge of ASD compared to participants with a high school degree. Similarly, the study by Adli et al. (2017) demonstrated that people with higher education had better knowledge on ASD (92.7%). Findings by (Tipton and Blacher 2014) also demonstrated that total knowledge score and education had a significant relationship, $F=11.26$, $p=.001$, with a positive correlation from a low level of education (high school) to a high level (university degree). However, Holt and Christensen (2013) demonstrated that the public with high levels of education

(university degree) had a similar level of knowledge about ASD to that of professionals. Thus, education remained a contributing factor towards ASD knowledge.

Another element found to be significantly associated with ASD knowledge was financial status; people who earn less in the sample knew significantly less about ASD. Holt and Christensen (2013) claimed that individuals with low incomes are less informed and more prone to general misconceptions about ASD. Similarly, Adli et al. (2017) showed that those who earn more were among respondents who had good knowledge about ASD (47%).

8.4.3 The attitudes towards ASD

I have also found that attitudes towards ASD were similar to the other population studies (Dillenburger et al. 2013; Durand-Zaleski et al. 2012; Holt and Christensen 2013; Liu et al. 2016). Most participants (58%) were friendly towards people with ASD. However, higher literacy in ASD was not associated with more positive practices. Individuals that hold more positive practices towards ASD were more interested in finding ways to help people with ASD. This is supported by Liu et al. (2016) that identified Chinese teachers who had positive attitudes towards ASD were more likely to seek additional information about ASD.

Interestingly when it came to their personal attitudes 13% of respondents had negative opinions towards ASD, 38% were neutral, and the remaining 45% were motivated to help. Adli et al. (2017) showed that majority of the respondents (92%) feel sympathy towards people with ASD and were open to the thought of getting to know someone with ASD or were motivated

to know more, with the percentages of 91% and 72%, respectively. Only 14% of the respondents thought that people with ASD were dangerous. The National Autistic Society (2017) study of the general population in the United Kingdom has demonstrated that good intentions were not enough to instigate change and to bridge the gap between attitudes and behaviour.

Participants reported negative emotions like fear (23%) or hopelessness (37%) and shame (1%) if someone they knew was diagnosed with ASD. Only 12% of respondents were accepting of the ASD and reacted neutrally. Similarly, the study by Surmen et al. (2015) has shown that people felt pity towards people with ASD. Additionally, the National Autistic Society (2017) reported that the general public experienced fear (8%) when exposed to individual with ASD, as they find them unpredictable. Fear was lower among Lithuanians – only 2% stated that ASD people were unpredictable, which challenges the findings by Dobryninas and Gaidys (2003).

8.4.4 From Perception to Practice

I have found that 36% of respondents had sufficient knowledge and were tolerant in their practices. This demonstrates that knowledge did not increase tolerance among Lithuanians. In addition, when looking at the practices I found that total scores were significantly different among generations, showing that the Soviet Union generation are the most intolerant in their practices, followed by the Transitional generation and then the Independence generation. Similarly, in existing research, older generations were less tolerant towards people with ASD (Ryan 2013).

I found that there was a difference among the societal practices based on an ASD person's age. Lithuanians tend to be more comfortable around a

child with ASD but not the adult. This supports findings by Ryan (2013) who conducted a study among the communities in United States. She showed that 10% of respondents preferred not to have contact with a child with ASD while 35% of the participants had the same attitude towards adults. The study by Surmen et al. (2015) has found that (50%) of respondents who have heard about ASD would not worry if their neighbour was a child with ASD, while only 22% of respondents felt the same towards adult with ASD. On contrary, in this study, 60% of Lithuanians reported that they were comfortable with having a child with ASD as their neighbour, while 50% of participants said the same about adults with ASD. These findings were not surprising, because in Eastern Europe (including Lithuania) the relationships among neighbours are not that close, which was revealed in a UNICEF survey on child disability in Eastern Europe (UNICEF 2014).

Nevertheless, Lithuanians were uncomfortable at the prospect of having a colleague with ASD (23%) or a boss with ASD (39%). This shows the societal limitations towards people with ASD in Lithuania, compared to other countries. For example, Ryan (2013) highlighted that only 6% of the respondents refused to work with a person with ASD. Similarly, Dillenburger et al. (2015) showed that Northern Irish people thought that ASD people cannot do highly skilled, socially demanding, and responsible jobs, like doctors (42%) or lawyers (50%), but would think ASD people would be well-suited for lower grade jobs like shelf stacker (85%), labourer (71%), waitress (64%), or as artists (90%). In addition, it was found that - for all six questions - one third of respondents were not sure what they would do, showing that there is space

for positive persuasion about ASD. Especially, it demands the increased visibility of adults with ASD in Lithuania.

I have also found that media (TV, Radio and Journals) was the main source of knowledge about ASD for majority of people in Lithuania. This was in line with the Dobryninas and Gaidys (2003) study that showed media (80%) was the main source of information about disabilities in Lithuania across all different age groups. Scanning through the ASD articles on Lithuanian media, I found little information about adults with ASD (15min 2017; Rytas 2018). The study by Huws and Jones (2011) has shown that it is a similar problem in the United Kingdom, where the focus is predominantly on childhood rather than in adults. They concluded that the news coverage should be evenly distributed across different stages of ASD. In this study, I also found that schools contributed less than 1% on ASD knowledge. Thus this potential information resource can be used to teach younger generations

8.5 Limitations

The current findings present some important suggestions for the future. However, because it is a survey, the findings are by definition self-reports. They do not necessarily imply accurate positive or negative behaviours of the individual (Lloyd 1994). Thus, people express their attitudes but their public behaviours might be intentionally or unintentionally incongruent with their attitudes. Especially the fear of scrutiny or being judged by the interviewer because participant is unaware what the interviewer's opinions are on the subject and aiming to provide more socially appropriate answers due to social desirability bias. "Vilmorus" attempted to minimise these limitations by

reiterating to the participants that their responses were anonymous and there is no judgment about their choices.

Further to this, 15% of the respondents indicated that they had relative(s) with ASD, strengthening the possibility that the sampling was skewed toward representing the population with increased awareness about ASD. Hence, the findings from this study need to be interpreted based on these considerations. In addition, there was a high proportion of “I don’t know” answers which could not be explained or properly interpreted because no further data was collected. This must be considered in future studies when collecting data on general population knowledge and attitudes on ASD in Lithuania.

Finally the omnibus methodology has its own drawbacks

The results of this study contribute to the larger body of work concerning the knowledge, attitudes, and practices towards ASD among Lithuanian public. It has also presented opportunities to further this area of research. Establishing a greater understanding of the beliefs held by the public about ASD is not only important now, but will continue to be with the current prevalence of the disorder.

8.6 Implications

The implications of this study are evident; education of the general population is required. Teaching programmes should be developed, using a Lithuanian context (notably a post-Soviet Union context). The study by Durand-Zaleski et al. (2012) has shown that attitudes towards individuals with disorders are more benign than those expressed about mental disorders in general. Thus, it would be beneficial to build an approach that specifically uses

personal testimonies and raises the visibility of individuals with mental disorders who are living normal lives, as this is likely to be more effective than generic campaigns trying to de-stigmatise the disorder. For the future, it would be useful to use vignettes and different conditions (blind and ASD) in order to see if people's attitudes and practices change depending on the condition.

A lack of media reports about adults with ASD was reflected in this study. Thus, studies should be done on the population's perceptions about ASD through lifespan, to be able to tackle specific issues of intolerance in Lithuania.

8.7 Conclusion

This study showed that general public in Lithuania was aware of ASD, but there was a lack of knowledge about ASD (the aetiology and symptomology). Moreover, I found that there was gap between positive attitudes about people with ASD and actions to help and assist people with ASD. Even though there were positive practices towards people with ASD, the treatment differed based on ASD person's age (child or adult). In summary, current findings highlight the urgent need for increased knowledge of ASD in Lithuania. However, this study showed that increased knowledge does not mean changed attitudes. Thus, interventions aimed at increasing knowledge of ASD need to be based on practical grounds, not just facts and theoretical premises.

Chapter 9 Synthesised discussion

"*Somehow, it would not make sense to deny a wheelchair user access to public buildings while waiting that someday with the help of science, everyone will be able to walk. Thus, designing appropriate forms of support and accommodation is not beyond our capabilities as a society*."

Steve Silberman "Neurotribes"

There is a paucity of research studies examining how cultural values influence parental stress when raising a child with ASD (Deater-Deckard 2004). In addition, there are few efforts that have been made to address the differences in cultural values towards ASD and how they contribute to parental experiences in raising a child (Pisula 2011a). The aim of this thesis is to explore stress in the Lithuanian parents of children with ASD. As results demonstrate, Lithuania has inherited a negative perspective of mental health from the Soviet Union. The systematic exclusion of people with any form of disability (mental or physical) is still prominent today (Chapter 1). The exploration of parental stress in Chapter 4 informs that parents of children with ASD experience higher levels of parental stress compared to the Cerebral Palsy group or controls. These findings support the long standing results of parental stress being elevated in parents of ASD children. In addition, Chapter 4 shows that experiences of stigma are significantly correlated with high levels of parental stress, which highlights the importance of external factors that might play a significant role in parental stress.

These dynamics between cultural values and parental stress are explored in Chapter 5. The data indicates that "societal barriers" hinder parents

from accessing services (i.e. public schools) and are correlated with greater levels of parental stress. Parents reported arguing with local school administration and staff to obtain an appropriate classroom placement for their sons and daughters with ASD (Chapter 5). Previous studies have shown that a lack of integration of children with ASD into schools, and in society in general, was associated with higher future dependency (being raised by siblings or other relatives in the absence of parents) and usage of governmental resources (Zwaigenbaum et al. 2015).

The results in Chapter 5 show that most parents no longer worry about what caused their child's autism, instead, they are more concerned about their child's future. Parents are facing the idea that their child will "outgrow" the modest level of services available for their child in Lithuania. Most of them are concerned about the prospects of their child's adult life and the lack of services for adults with ASD in Lithuania. Parents highlight that one question cause's stress: 'What will happen to our child when we die?' The study illustrates that many autistic adults are unemployed and struggle to get disability payments in Lithuania (Čekanavičiūtė 2011). The results also inform of a shortage of services and support available for parents of ASD child in Lithuania (Chapter 5).

Consequently, medical and educational groups emphasise the importance of services and support for parents of an ASD child (Chapter 6). Past studies have indicated that social support (both formal and informal), can serve as a buffer against the feelings of stress that are usually associated with parenting a child with ASD (Ekas, Lickenbrock, and Whitman 2010b; Lu et al. 2018; Sipal et al. 2010). Professionals (medical and educational) working with

families who have a child with ASD should be made aware of the ways in which their services can potentially lower the stress levels of their patients, especially stressors related to parenting a child with ASD. A previous study by Sipal et al. (2010) has demonstrated that professionals should also encourage parents to seek out more informal sources of support. They should be knowledgeable of the types of informal support that exist in their client's community (e.g. parenting support groups) and recommend involvement in such activities (Sipal et al. 2010). The results in Chapter 5 illustrate a lack of direction and a systematic approach when tackling ASD symptomatology. They also inform about parents feeling alone and left behind, as professionals have not provided information about the services available to support ASD children and their families. At the same time, professionals complain about a lack of resources (time & money) to assist parents with services post-diagnosis. They are hoping for governmental input into the psychiatric services such as the production of booklets or manuals to share with parents about services that are available. In addition, both parents and professionals complain that services are less readily available to parents in rural areas of Lithuania. Previous studies have shown that informal support from families and friends is reported as more beneficial on a day-to-day basis, especially for families that struggle with access to formal support (Lu et al. 2018; Bonds et al. 2002; Rutstein 2014). For example, friends can provide respite when needed, and help with the daily childcare responsibilities associated with raising a child with autism. Nevertheless, it requires more professional training for GPs to be aware of child's psychosocial development not just physical, so that s/he would be referred on time. In

addition there is a need for training how to interact with ASD children during the visits and how to support parents in this process.

Added to the above, parental stress is reported to influence family relationship dynamics. Chapter 4 illustrates that there is no difference between relationship satisfaction among parents of children of ASD or TD children. This is inconsistent with the existing body of literature (Bluth et al. 2013b; Hastings 2003a; Sim et al. 2016). However, upon further exploration in Chapter 5, I discovered that the spousal/partner relationship plays a significant role in parental experiences. Parents stated that conflicts and a lack of time increase parental stress. Additionally, parents must decide how best to provide care for their child, both medically and post-diagnosis. Making decisions about the costs of certain services compared to the necessity and availability of these services led parents to additional disagreements within their relationship. However, agreement on roles and household responsibilities allowed the relationships to grow.

Parents also discussed a decrease in quality within their parent-to-child relationships, as well as adopting poorer parenting practices (Chapters 5 & 7). Parents reported worrying about their TD children and their relationship with them. This led me to explore sibling experiences of growing up with an ASD child. The data informs that siblings experience stigmatisation and worry about their ASD sibling's future. They also reported the occurrence of conflicts between them and their parents due to expectations and a higher level of responsibility. Thus, to make the parent-child relationship as successful as possible, it is imperative that professionals find ways to help alleviate the heightened levels of parental stress associated with arguments with a TD child.

Experiences of stigma are reported throughout quantitative and qualitative findings across all of the data chapters. As a result, a survey on ASD knowledge, attitudes, and practices was conducted. Chapter 7 demonstrates that the Lithuanian population lacks knowledge about ASD and excludes such people from work, school, or any other public places. These societal values are highly linked with parental stress. The perception of ASD being a disorder that needs to either be isolated or cured is still prominent in Lithuania. Past studies have demonstrated that this narrative is not confined to Lithuania; similar positions are found around the world. For example, research primarily concentrates on the potential causes and risk factors of ASD, which reinforces the idea of ASD as an anomaly; a distinctive problem of modern times that should be solved by a discovery of the cause and the cure of this disorder. This is especially true when you observe the amount of money that is dedicated to find the cause or cure of ASD versus the amount that is directed to the support for - and integration of - such people into society (Pellicano, Dinsmore, and Charman 2014). To conclude, as researchers discuss the arguments of vaccination, families with newly diagnosed children engage in a very different conversation about the difficulties of navigating in a world not built for them (Chapters 5 & 6).

From the parent and sibling reports, I discovered that many of the challenges they face are not the “symptoms” of their child’s autism, but the hardships imposed by a Lithuanian society that refuses to make basic accommodations for people with cognitive disabilities. The notion that the cure for the most disabling aspects of autism will never be found in a pill, but in

supportive communities, is one that parents have been advocating in Lithuania and across the world.

9.1 Implications for Practice

Before addressing any issues related to ASD, it is crucial that researchers and the Lithuanian government conduct an epidemiological study to know the prevalence of the disorder. As a result, this will inform about the actual burden of the disorder (not just estimations based from other countries prevalence data) and shed light on the needs of all individuals with ASD (not just children). In other words, this study will help in designing a better pathway to care through-out the individual's life, when the country knows the quantities of individuals with ASD not just estimations (http://pazangosprojektai.lt/uploads/images/ASS%20analiz%C4%97.pdf).

The present study chose to investigate parental experiences in raising a child with ASD. The findings of this study indicated that support (from friends, family, professional organisations such as schools, paediatricians, and society) plays a significant role in decreasing parental stress. These findings support the importance of clinicians not only providing direct services for children with ASD, but serving as sources of support for the families as well. When working professionally with families raising a child with ASD, it is important to engage them in the management of the child. The availability of professionals (medical, therapists, and educational) and their encouragement of seeking out alternative means of support can lower the levels of parental stress, which is associated with a better overall outcome for the child with ASD (Rutstein 2014).

According to parents and medical professionals, there is a need to develop services and psycho-social treatment for children with ASD, which currently is only available in private sector for families that can afford it. Effective interventions during early childhood may ensure that children with ASD reach their neurodevelopmental potential, consequently reducing behavioural and communication difficulties that parents face when raising such a child (Magan-Maganto et al. 2017). Current evidence-based interventions to augment behavioural and language function in early childhood include behavioural programmes and social skills training (Hwang and Hughes 2000; Koegel et al. 1998; D'Elia et al. 2014b). The access of such programmes for parents would provide a sense of direction and assurance (Zwaigenbaum et al. 2015). The findings from this thesis points to the need of increased number of diagnostic and treatment centres in Lithuania. Parents have reported that times is plays an important role in their experience of stress. They have reported that their stress levels rise before the time of diagnosis and after when there is the least support they experience. As a result, Ministry of Health should decrease the time that parents have to wait anxiously to receive the diagnosis. As current findings have shown that the waiting time after referral is 6 months to a year in Lithuania (Diržyte, Mikulėnaite, and Kalvaitis 2016). In addition, increased number of treatment centres would provide every family an equal chance to support their children. Private sector treatment puts a strain on the family finances and discriminates against lower income families who cannot afford those treatments (Muiznieks 2017). Also, lack of treatment centres puts the burden on the parents to find professionals themselves and it becomes the logistical nightmare for parents living in both urban and rural areas as

professionals are based in different/distant locations. However, the public treatment centres would eradicate these problems and allow the child with ASD to receive a concentrated treatment in one place.

The findings also inform a lack of material about ASD among medical professionals postponing access to diagnosis and prolonging the uncertainty among parents. The findings demonstrate a lack of knowledge among paediatricians about ASD. They are hesitant to give information and even inadvertently delay access to diagnosis. The study by Heidgerken et al. (2005) shows that general practitioners served as gateways for access to diagnosis for the families, hence it is important to efficiently provide relevant and adequate information even before diagnosis for parents. The creation of educational programmes about ASD that provide concrete materials and direction - not only about ASD symptomatology but also about early interventions for the GP - may close this knowledge gap (Rhoades, Scarpa, and Salley 2007). The Lithuanian Ministry of Health should develop guidelines for medical professionals working with ASD. The recommendation is to look at guidelines from other countries, e.g. the NICE from the UK or A.L.A.R.M from the USA, as these countries had reported similar problems in the past and used effective ways to manage them. This systematised approach of having national guidelines has delivered significant changes for the ASD community in the UK and USA (Autism Speaks, 2011; National Autistic Society, 2009).

In particular, research has shown that transitions can be especially stressful for a family with an ASD child, as they are paired with more uncertainty than with TD children (Pang 2010). For example, starting school for the child is one of the key aspects of parental stress. Consequently,

therapists should concentrate on these crucial changes for families of ASD children, and work on potential resilience factors to reduce parental stress.

The current research also demonstrates the necessity of policy development with regards to educational support for school staff. It was found that educational problems (such as a lack of teacher's knowledge about ASD, resources, and skills to support parents) lead to arguments between the school administration and parents. Hence, national access to resources and training provided for teachers and school staff is a necessity in Lithuania. The Ministry of Education should provide training for schools (both administrators; teachers and parents) in the steps of integration of such individuals in general schools in order to reduce the arguments that appear between the ASD parents and schools. Also this thesis has demonstrated the need for teacher assistants and specialists i.e. speech and language therapists in general schools. This would take the burden off the teachers and would form part of a therapeutic intervention that could be accessible publicly, i.e. reduce the treatment costs. Thus, the need to increase funding for schools, is an important first step that must be taken for them to be able to afford these services, which were named by parents and teachers in this thesis.

The high reports of stigmatisation conveyed throughout this thesis suggest that immediate attention should be given to raising awareness in the general public and decreasing misconceptions about ASD in Lithuania. The government should concentrate on providing campaigns to de-bunk myths about ASD by starting educational programmes in schools, as is common in other European countries. For example, in the UK there is the programme by "Autism Education Trust" used in British public schools to inform students and

staff about ASD and equip them with tools to support their peers/pupils with ASD (https://www.autismeducationtrust.org.uk/training-programme/schools/). The adults can be reached with awareness campaigns through radio, television and newspapers as it was shown to be the most common way that Lithuanians heard about ASD.

Finally, marital relationships do not appear to be affected negatively by raising a child with ASD; on the contrary it may strengthen the relationship. However, potential risks factors including disagreements in parenting, a lack of time together, and a shortage of respite may lead to marital discord in families. These factors should be further explored and considered when working with ASD families.

9.2 Limitations

I concede that my personal experiences, nationality, and biases will unavoidably influence the study that was conducted. Nevertheless, a conscious effort was exerted to control these biases and perceptions in order to avoid influencing the participants. Clear and systematic procedures were followed for the collection and analysis of data. My professional experiences benefited the study as I had insights into the situation of mental health in Lithuania and the structure of mental health services, and could relate not only as a researcher, but as a participant. Moreover, my nationality provided easier access to the participants, as I spoke the native language of the participants and had been working professionally with children and their parents as a developmental psychologist in Lithuania before my PhD. None of the parents or professionals interviewed were known previously to me.

9.3 Future Directions

As the scoping review indicated, it is important to determine the burden of ASD in Lithuania and increase interest in ASD among researchers, so that information would reach the general public and governmental institutions. Thus in the future it is important to conduct an epidemiological study on ASD prevalence in Lithuania. This thesis has informed about the factors related to parental stress. Thus further research should aim to study if changing those factors would actually mitigate parental stress in Lithuanian cohort. Specifically associations with parenting aspects like career and employment changes, financial strains, and the evolving parental roles. These factors may be relevant in understanding parental stress. Furthermore, studies should concentrate on the positive factors of raising ASD child rather than the deficits and provide a framework of successfully managed stresses and resilience factors.

Researchers should investigate methods to increase access to information and resources, build supportive communities and foster training for medical and educational professionals. Hence, well designed research studies that target appropriate practices in community outreach, interventions, and parent support groups could be used to substantiate the conclusions derived from subjective reports from parents, professionals, and siblings. One potential quantitative research design is to test the efficacy of Lithuanian parent support groups and compare it with parents not receiving any parent support. The dependent variable of the design would examine levels of parental stress and efficacy of the increased levels of informal and formal support. This would help

explore potential intervention strategies towards parental stress in parents of children with ASD.

Further research on the influence of resilience on parental stress in ASD families in Lithuania must be investigated. Research indicates that family life generates the experiences of stress. In the qualitative results of Chapters 4 and 5, I found that if the quality of life was low, parents reported high levels of stress. A low quality of life consisted of isolation, conflicts, and exhaustion for parents, while a high quality of life consisted of integration, support, and adequate coping strategies. Thus, family quality of life, coping strategies, and support received must be further explored in a quantitative methodology.

In addition, the research should also consider the siblings of children with ASD and potential interventions that can support them. Siblings have reported negative experiences of growing up with an ASD child. Consequently, understanding how these experiences affect the siblings' mental health requires further investigation. Accordingly, it calls for a larger-scale quantitative study on a sibling's mental health while growing up with an ASD child.

Finally, future studies should investigate the experiences of adults with ASD and their families to provide a broader picture of life with ASD in Lithuania. It is clear that parental fear for their child's future or uncertainty of their child's adulthood life create significant stress and anxiety in both the parents and siblings of child with ASD.

9.4 Conclusion

Since it is unrealistic to eliminate all stress related to parenting for this population, it is important to begin to devise and access methods for protection against the negative effects of the parental stress. The outcome of this study

is to bring to light the cultural and external factors of parental stress and provide information about the situation in Lithuania. The main suggestion is to provide support for families through direct contact with therapists to answer questions. Another suggestion is to help parents identify forms of informal support such as family and friend networks or support groups, which should be regular components of all services geared towards families raising a child with ASD in Lithuania.

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Appendix A. Parental Data from Demographic Questionnaire

Variables		ASD	CP	Typical
Family member with neurological disorders (*N, %*)				
	Yes	18/13%	13/12%	7/5%
	No	115/87%	93/88%	131/95%
Does child have epilepsy (*N, %*)				
	Yes	21/16%	28/26%	0
	No	112/84%	78/74%	138/100%
Does child have learning disability (*N, %*)				
	Yes	58/44%	49/46%	0
	No	75/56%	57/54%	38/100%
Does child have anxiety (*N, %*)				
	Yes	76/57%	48/45%	0
	No	57/43%	58/55%	38/100%
Does child have tantrums (*N, %*)				
	Yes	48/36%	23/22%	7/5%
	No	85/64%	83/78%	131/95%
Does child have aggressive episodes (*N, %*)				
	Yes	50/38%	10/10%	5/4%
	No	83/62%	96/90%	133/96%
Does child have attention problems (*N, %*)				
	Yes	100/76%	48/45%	8/6%
	No	33/24%	58/55%	130/94%
Does child have language deficit (*N, %*)				
	Yes	121/91%	65/61%	2/2%
	No	12/9%	41/39%	136/98%
Pregnancy (*N, %*)				
	Normal	101/76%	81/76%	122/88%
	Complicated	28/21%	22/21%	14/10%
	Very difficult	4/3%	3/3%	2/2%
Child Birth (*N, %*)				
	Normal	82/62%	52/49%	121/88%
	Complicated	47/35%	43/40%	15/11%
	Very difficult	4/3%	11/11%	2/1%
Any complications after birth (*N, %*)				
	Yes	30/23%	58/56%	11/8%
	No	103/77%	48/44%	127/92%
Support from government (*N, %*)				
	Yes	88/66%	72/68%	12/9%
	No	45/34%	34/32%	126/91%
Support from relatives (*N, %*)				
	Yes	94/71%	76/72%	60/44%
	No	39/29%	30/28%	78/56%

Variables	ASD	CP	Typical
Support from friends (*N, %*)			
Yes	51/38%	40/38%	33/24%
No	82/62%	66/62%	105/76%
Parenting methods when child misbehaves (*N, %*)			
Leave the room	16/15%	19/23%	11/13%
Parenting/punishing instantly	29/27%	22/27%	50/60%
Parenting based on the child's needs	55/54%	37/45%	13/15%
Pray	0	0	2/3%
Other	4/4%	4/5%	7/9%
How much has your relationship change since having **this** child (*N, %*)			
Did not change	70/67%	39/48%	82/98%
Partially changed	19/18%	29/35%	1/2%
Totally changed	15/15%	14/17%	0
How much you agree on parenting methods with your partner (*N, %*)			
Totally disagree	17/16%	16/20%	8/10%
Partially agree	44/42%	38/46%	43/42%
Totally agree	43/41%	28/34%	32/48%
How much time do **you** spend with child during **weekdays**? (*N, %*)			
1-3 hours	33/31%	16/20%	41/49%
4-6 hours	45/43%	25/30%	32/39%
7-10 hours	14/13%	12/15%	3/4%
<10 hours	12/13%	29/35%	7/8%
How much time do **you** spend with child during **weekends** (*N, %*)			
1-3 hours	0	2/2%	8/10%
4-6 hours	5/5%	6/7%	33/40%
7-10 hours	11/11%	15/18%	23/28%
<10 hours	88/ 84%	59/73%	19/22%
How much time does your **partner/husband/wife** spend with child during **weekdays** (*N, %*)			
0 hours	13/13%	14/17%	2/2%
1-3 hours	42/41%	26/32%	48/58%
4-6 hours	34/33%	20/24%	23/28%
7-10 hours	6/6%	7/9%	7/8%
<10 hours	9/7%	15/18%	3/4%
How much time does your **partner/husband/wife** spend with child during **weekends** (*N, %*)			
0 hours	7/7%	9/11%	1/1%
1-3 hours	2/2%	7/9%	13/16%
4-6 hours	14/13%	10/12%	28/34%
7-10 hours	15/14%	18/22%	21/25%
<10 hours	66/64%	38/46%	20/24%

Appendix B. The Interview Questions Used

Domain	Question	Probe Questions
Child Domain	Can you tell me about your son/daughter	His/Her characteristics? His/Her interests (*Use this as an open/warm – up question*)
	Does your child have any health concerns	Comorbidities to other disorders
	What are strengths of your child/as also weaknesses	Capabilities, personality
Family Patterns of Interaction	Can you describe a typical day for me?	Probe: Family, community
	Tell me about your relationship with your child.	Describe how you typically communicate with your child?
Autism Domain	What was your initial reaction when you were informed of your child's autism diagnosis?	What were your thoughts, feelings?
	Were you aware of what autism was? If not, how did you inform yourself on the diagnosis?	Where did you find more about autism?
	Did you receive any support from the practitioner? Where there any follow –up appointments?	Occupational therapist, respite, speech language pathologist. If no why not?
	How did you find meaning and acceptance in having a child with autism?	at what point did you accept that your child will be "different" than other children? What triggered that response?
Autism Domain Continues	How did this diagnosis change your expectations for your child?	Future of the child, his capabilities, your dreams for your child.
	How did having a child with autism affect your daily routine?	Were you able to work full time or did you have to give up your career plans to care for him/her in the home?
	What stressors, if any, have you experienced raising a child with an autism?"	Behavioural problems; language impairments; lack of social interaction; unclear future.
	Can you describe the strategies you have found most effective in dealing with these stressors? Have any strategies been ineffective?	How you deal with behavioural problems, language impairments, lack of interaction and etc.
Marital Domain	Has your child's autism caused stress on your marital relationship?	View of your partner, roles of the family.
	How were you two able to stay strong as a couple and help support one another through this?	Coping techniques used by the spouses
Support Domain	Where you supported by extended family (their initial reactions to your child's diagnosis).	How were you supported/not supported by the extended family?
	Where you supported by your friends or community?	How were you supported or not supported by the friends or community?
Support Domain	How people react/not react towards your child in public?	Staring looks, critical comments or opposite, understanding and welcoming.
Advice Domain	What advice can you give other families who are raising a child with autism?	

Appendix C. Parental Interview Data - Emerging Categories Based on Exerts and Units of Meaning

Category	Examples/Exerts	Units of Meaning
It was so sudden	MC5 “But when he was one and a half years it became difficult. Maybe I didn’t want to acknowledge it for myself that, maybe something will change. The sudden regression had started.”	109
	FC4 “He began counting, and then after two and a half years, little by little, he became silent. And now he begins to speak again. So, like… (a long pause, he was thinking). Hmmm… I don’t know…it was regression.”	
	FC9 “Until then everything went smoothly, sometimes even better than his peers. Then, after the vaccine, we noticed that something was wrong, the child stopped talking, only said a few words.”	
	MC7 “Suddenly all this retrogression started, odd behaviour. And after a year, when he totally left... And all of this, started.”	
	FC10 “And later he somehow, when he was almost two years old. He then even stopped saying those words which he knew. Well we thought, what this is…”	
Lack of knowledge among the GP	FC2 “And we saw that he is... he started to walk later. But all the time we heard...from our GP... how to call it... consolation or not, this appeasement, that this is a boy. Boys tend to develop slower, don’t you worry. That boys don’t speak, and start to speak later on and everything is going to be alright.”	117
	FC3 “So this was the probably the biggest problem, that our family doctor said that he will start, will start, everything is fine here. Even though he was hard to control and was walking, I mean, from corner to corner, all being restless, this was ‘problem’ [shows in quotation marks] only to my wife and me, apparently.”	
	MC4 “She [refers to GP] didn’t know herself what autism was and just suggested to go to the child development centre. I understood it was shocking to her as well…”	
	MC5 “Yes, it was a family doctor. She also has children - boys. So again, I say, that he doesn’t speak. And she says that it is a traditional...that boys start speaking late...But again, she didn’t evaluate his speech…she just assumed.”	
	MC6 “I am actually pretty angry with these Lithuanian specialists, that we have wasted a whole year and did not receive the real diagnosis. I mean, simply, that those specialists, who are in those common practice institutions, they are not competent, in a way, that at least would send you somewhere to examine yourself, would offer to examine, somewhere	

Category	Examples/Exerts	Units of Meaning
Lack of knowledge among the GP	deeper. So yes. So, I feel very sorry for that year, because I would say that it was critical year, between two and three years old, which we practically lost."	
	MC7 "Yes, and... I guess, that family doctors usually are faced with runny noses, coughs and all the panics of mothers which mostly are not justified or proven. So, my case was the same. I say that my son is looking in the weird angle. And she tells me, "maybe he watches too much of the TV. It's no big deal, don't worry…"	
	MC8 "Doctor, of course, said, let's wait, let's wait. Half of year went by, centimetre, another centimetre [shows child growing]. And every half of year like that. And later we started to get worried… we wanted answers."	
	FC8 "The doctors said something, but most of them have never heard about this, maybe only neurologists, but others not, and you say that this is an autism syndrome, and they look at you like they don't know and need to look into this additionally. So basically, we sometimes know more than the doctors."	
	MC10 "I remember even when and how. Before we didn't pay special attention because even doctors would do check-ups like this: "everything is good just doesn't speak for some reason, but it happens so that boys start speaking later."	
Partner's denial of the diagnosis	MC6 "So maybe it was more with my husband with his denial. He was also trying to persuade me, but it was already very hard for me to tell myself, that no, everything is okay, there is no problem."	43
	FC2 "Well... At once, my wife does not approve... Let's say... For this direction, that we need to change child's brain. And to concentrate to that... I tell you, she is like…like person with the medical education, she had her opinion that we cannot change, and it is not..."	
	FC3 "…it was difficult for my wife, it was, maybe she doesn't want to admit. But it really… she could not accept it."	
	MC4 "When dad got hospitalized in the child development centre, because I was working, he was arguing that the child was normal, but somehow they still wrote ASD…and it took him awhile anyway."	
	MC8 "Surely, maybe at the beginning I looked at it differently. I wanted to prove him that she will be different. That she only now has this diagnosis, but you'll see she will do what will do. He says, accept it. I still hadn't accepted."	
	MC6 "Of course I knew. All parents know, they are simply scared to admit it, and to say. All parents have internet these days. All of them know how to read. And if parents care, they	

Category	Examples/Exerts	Units of Meaning
Partner's denial of the diagnosis	will show interest since already one and a half years and one years, if they will see, that something is wrong...it took a while for my husband to accept it…"	
	MC7 "And it was one of these cases, when you don't even want to think that there could be something wrong. And... Maybe he was sick, spent a lot of time at home, and got depressed. Little of what. Maybe nothing... But later you realize that, that is not nothing. Then my parents saw that, and told me, - 'Something is really wrong.' And you realize that there is no place to hide anymore."	
	FC1 "I knew this from common knowledge. I saw this on TV, these situations, and I have been to the child development centre before. For work. And it was not new for me, maybe my wife, was more in denial and shock."	
Discovering about ASD before diagnosis	FC5 "We knew, but not as deeply, we just had an understanding. This this something you cannot control or cure, this is something you get, a way of life. You don't go deeper if it doesn't concern you, what is good or bad. We did not know there was a broad spectrum or something like that. You don't care because this doesn't concern you."	42
	FC1"[Did you know what autism was before?] ...No, I did not and I did not care. It was not on my radar, thus not interesting to me…"	
	MC5 "I have read about it. In university I had a class of special education basics. Back then, I had no children, I was not married. So particularly about autism we were talking in the class and we had assessments of this topic. So I have read about it. But I didn't know that they are different and of different levels."	
	FC7 "Very little. I've seen the movie called "One Flew Over the Cuckoo's Nest", I have heard that autistic children can be very gifted. [How much of what you've heard before was actually true?]...Zero percent."	
	FC8 "It was just, so to say, when the suspected this, I immediately started looking for something on the internet, everywhere, but we did not know the answers yet, and we got them only later from the specialists but before that I have never heard about this and nobody told us it could be this...autism."	
	MC6 "So the reaction was like, that I was expecting this, because I was already, I tell you, it was, I was determined to myself, so, so this for me was only confirmation from the competent specialists, that that is that. So I mean, what kind of thoughts. Thoughts like, that everything is not like you expected to be, and there was everything, what can I say."	

Category	Examples/Exerts	Units of Meaning
Discovering about ASD before diagnosis	FC9 “As I mentioned, we had some information from before… But we got some more, however, the information is always quite controversial, you need to sort it out yourself, that maybe this or that doesn’t suit you.”	
Disability label	FC2 “What kind of reaction? We started to look for information… Am…The reaction was more vibrant not to the diagnosis itself, that child is with autism spectrum but we...[...] found out, more precisely we got a document, that our child is disabled and that this form of disability is severe. So that was...the most difficult and stressful time...This disability is a stick. Stick with two endings and how to put this... This... That ending is hurting us. And I think that one of the reason, let’s say, why our child was not accepted to the first grade at X school, is that, we were already with this certificate. Came there marked with this huge problem.”	53
	FC3 “...There were not much information there about the disability. And we didn’t need to. I did not want to…Considering them as disabled is too harsh, they really are able. We...uhm… this disability, they make it like… you know...incapable.”	
	FC5 “It is a word. But firstly there was no need to look for the benefits, and there barely are any. You get some money, but I don’t think there is enough. They wouldn’t have helped me, because I think it is as much money as some brand new toy costs…So I could buy such toy during a holiday, but I… I did not give too much thought about this, because it doesn’t give me any benefits. Of course, the label and some words hurt me as a father, because you get this different acceptance of the society. Like somebody with leprosy or something like that…”	
	FC9 “I don’t know, I think this is normal, it is worse for the adults, because the child has disability but the adult’s person gets the evaluation to work. In addition, there is no methodology how to take it seriously and actually evaluate everything. He has hands, legs, and a high intellect, it means such person can work.”	
	MC10 “*interviewer*: How did you deal with disability aspect? Did you get the diagnosis and went to fill in the documents for disability? *MC10*: Not right away *interviewer*: Did you have to go through this too? *MC10*: Not right away, yes, yes, had to go through this, and it was a big compromise, and in the beginning I thought that we won’t do this. Later on I heard others opinions, how it is	

Category	Examples/Exerts	Units of Meaning
Disability label	help for your child and you have to try to help and use the help. So yes, later I understood that I will try to use it and do something extra, and we did what we could, and still are doing."	
	FC10 "At the development centre they told as that. Someone even gave us advice, to get the disability as fast as possible. You will be able to get benefit for the child. Another thing that this is also... I don't think, that we are alone here like this. Many parents with autistic children goal is to as long as possible not to admit, not to take the disability, because you have hopes that soon something will change. We will do something, and after some effort situation will change and it will be better. And parents are resisting to that because they know really well, that this disability is kind of verdict for their child. It is like written off person here at us... And that is why many parents are resisting, to process the disability."	
	FC4 "Many parents with autistic children have a goal. It is to as long as possible not to admit, not to take the disability, because you have hopes that soon something will change. We will do something, and after some effort situation will change and it will be better. And parents are resisting to that because they know really well, that this disability is kind of verdict for their child."	
	MC4 "So he has severe disability, meaning he has high special needs... so... in short, during this year... on the July we got this diagnosis, that child... well from the appearance somehow healthy, everything is fine with him, not in wheelchair, not...am... I mean, doesn't look like... and then this severe disability...it was a rejection straight away."	
Adaptation in daily life	FC3 "We are spending time like all the other families. We go to the store, to the party, everywhere... Where it is safe and pleasant for all of us. Because... yes, sometimes it gets you tired. Sometimes you get nervous, you just simply need to learn...learn to live together."	144
	MC5 "It was difficult until he was five. You have to think about each trip, what he will be doing, what can you give to him, because he will have trouble sitting in one place.... <....>Until six or seven there were really a lot of problems. You had to think carefully what activities you will provide him and interest him. He would sleep rarely. A tablet or some cucumbers, food would keep him busy a little bit, but it still was a big trigger, because there were no problems with our daughter. She never had any problems and we can take her anywhere."	
	FC5 "Well yes. It changed. It needs a lot of fuel. So yes. There are such things, where you have to adapt to the diagnosis."	

Category	Examples/Exerts	Units of Meaning
Adaptation in daily life	FC9 "…why I did it, for what it was, what was for lunch, why shops, it was impossible because it was great stress to him. Any kind of going to the shop was like, maybe, more stress for himself, we try to pull him all the time, but he, there was no participation no interest from him."	
	MC9 "Practically with relatives. It is so, because when we go somewhere as a guests or some guests come to us, child is hyper active and I can see that he irritates other people, he constantly is running around, take other stuff, puts it away, breaks it... it is always, you can do that, cannot do that, running around slams the door, turns light on and off, he is restless. Thus we will be told to calm him down but I realise that in these situations I am not able to calm him down. I only can leave, because if I yell at him or put him in the corner it will only make things worse..."	
	MC10 "First of all, shopping was, pretty difficult thing, because he constantly wanted something what we didn't give him or we would say next time, then he would throw a tantrum scene, but you learn how to cope and change patterns in life."	
	FC10 "Let's say, shopping or going somewhere, is totally different, then it is with regular children. It is because, you cannot go to the concert with this kind of child, for example. Or at the shop. Now we can say that it is within the normal limits because you are able to control the situation at the shop and you adapt to the situations."	
	MC6 "So we think like, will we really be able to do that and if we really won't get any troubles. So sometimes it is like that, that we are refusing or somehow solve this thing. So there little of this thing, because there was this time, that there was this little problem of behaviour when we went there as a guests, so later it is simply complicated for everyone and us and child and for those around. So... we stopped going to the parties that to avoid him meeting strangers"	
	FC7 "About the guests. When son is at home, we try to have only these people, as our guests, with whom he is familiar with, because otherwise he gets out of balance, reels and then it's hard for him to fall asleep..."	
	MC7 "Also to go somewhere well... and for us, to look that he wouldn't take anything. Anyways, it's an unfamiliar place, so that he wouldn't steal something. Anyways, it is not the most pleasant thing. To go somewhere... There are limitations with having our visiting guests."	
	MC3 "I understand. Perhaps I won't be able to name them all, without giving more thought. But first one is, that you cannot <...> Have a normal life. In a sense that you cannot go to	

Category	Examples/Exerts	Units of Meaning
Adaptation in daily life	the cinema with your child you cannot call grandmother and suddenly leave the child with her, when you thought of something and need to leave."	
Isolation	MC8 "We just go to visit our friends less than before, because it takes a lot longer to get ready with her, put clothes on, undress, and then you constantly have to look after her so she wouldn't break anything…so it is more stressful than before, thus for everyone's sake we try to avoid this…"	64
	FC1 "Until he was six he used to run away all the time, you had to hold him by hand. And it happened that our habits got smaller. We don't go anywhere, we don't do anything, and if we do it close to our home. Guests are very rare. So that was the change. Before that we loved to go on trips, travel, do something. So now with him is just… you don't want him to be upset. Less stress, less tensions, less psychosis and so there is barely anything left."	
	MC4 "The routine is because we cannot go anywhere, even if we go to the village, of course it depends to which side we go… We go to our friends; we don't have our own. <…>We can go where they have a big pool, so he can spend a long time there. There is a tractor in another place, he can sit an hour there… To go to the cattle, the chicken. If there is nothing they sit in the car and drive around. He doesn't want to go to stranger's houses, so we have to decide who will take care of him while at the guest…"	
	MC6 "We have flown, when he was still year and four months old, and we didn't know any of diagnosis yet, and everything seemed normal to us. So everything was fine, but since then we haven't flown. Now if we are going somewhere, we are driving by car more. So yes, we do not feel so free. In a sense, that we could like, let's do it and then do it. Else we are thinking about it all the time, and I think we will anyway try it someday. Just we cannot make our minds about it, because we would then want some shorter flight, where there wouldn't need so much time..."	
	MC9 "Because of the children. Because it is scary to go to new place. With two children. Our little one is five years old, it was also scary when he was even younger, when two children and one of them is little and another is with autism, it is really hard to go somewhere and look after them. Kid gets confused in unfamiliar surroundings, tends to become more willing to run away and that is really scary, and if we have even one day of holidays it's a nightmare for us, because child becomes restless, and it becomes running around and fuss for us."	
	FC9 "Since we cannot really leave the kids and the circle of friends got smaller, we live by a structure. It is difficult for others to understand this, you would have to arrange visits or	

Category	Examples/Exerts	Units of Meaning
Isolation	meetings a lot earlier and so on. We really limit ourselves in such situations. Our kids don't really like big companies and we decided to avoid them. If there is a bigger company we try to stay there shortly or to avoid them in total."	
	FC4 "Going somewhere always ends up with me spending all the time with my son, and we get into arguments with my wife… She says let's go out somewhere, drive to our cottage, somewhere… And I tell her wait, you will be sitting there, eating your barbeque, and I will have to sit with the kids? Where is my rest? I work, and I will have to sit there with the kids, no… [Gets upset]. Of course we do go sometimes, but it is not rest for me…"	
	MC4 "There is nothing easy with my son. Maybe we really became closed, because wherever you go there are always hysterias, tantrums, and discontent. Until he was six he used to run away all the time, you had to hold him by hand. And it happened that our habits got smaller. We don't go anywhere, we don't do anything, and if we do it close to our home."	
	FC10 "So that is how it is. I don't say that that this life has changed a lot. We, we still have more or less stayed the same as we were. What we had afforded ourselves with, it was stayed until now, and we are still trying, I mean, we bring our children and try, but it is just that it is not that simple. I mean, how it would be without this diagnosis. I mean. I would be lot different...a lot easier...a lot less stress..."	
Lack of support	MC10 "For a few times, we tried to go to some kind of concert, but that's impossible. Because he does not remain there. He doesn't sit. Or he may, if that is the concert where you need to listen to the music, start making these sounds...Am... Or shout something loudly. And then, you are certainly, making a difficulty for others to listen to the music, and thus you have to stand up and leave….there is nothing that would allow people with special needs kids to enjoy activities together, there is little help available."	76
	FC1 "They could do more for the kids. Because now I know a lot more kids like my own. You need to invest more in them. You can teach them to be fully functioning people in the society. But in the governmental institutions they just give you a stamp and that is all. They won't tell you what to do and where to go, especially for the parents in the provincial areas, there are no chances."	
	FC2 "When we received the diagnosis, we were not offered any service by no one…they just this is who you are and now go live with it."	
	MC5 "You see, here are only pictures. I ask where I can get them. "Search on the internet". Of course that was about 4 years ago. He said that I have to work daily. I asked him, how?	

Category	Examples/Exerts	Units of Meaning
Lack of support	I said, I would like to have your specialists' help, maybe I could privately go? Pay extra money. He didn't say that people are waiting in the queue. So, mommy, go to work. Ok, I will work, so on? So on? How to work? So again... I somehow very clearly remember the shock and no help…"	
	FC5 "Nobody gave us any help; I don't know how it is right now. I still ask sometimes this pedagogical psychology… services"	
	FC7 "We wished for some help...Some kind of specific plan what to do next, I didn't see. I was simply offered the repeated evaluation after half-year. In case that everything might change, that was it - you just go and live your life - no direction, no support."	
	MC7 "So nobody gave us a booklet, or a guide what to do next for this matter that we would see straight away - we can go there, consult with this person, and etc. We had to start with the burden and the question whose fault is that and what to do next we had to figure out all by ourselves. And you know time is precious at that point and I feel without that help you waste a lot of it trying to figure out what to do next?"	
	MC8 "They told us that we have to get the disability, and that's it. Then I went to our GP, I asked "doctor, so how is it? We have this disability now, but we need nursing services, because girl, requires a lot of attention, I do everything for her" She said - nothing you cannot do about it, wait for help five years, because child is not five years old...so here it is the support in Lithuania."	
	MC9 "Of course it is disappointing. We too tried it for year or two, drew, glued, read, printed, photographed. How much time did we waste, and now there are PEX's sets of these cards published and when I saw them I almost started to cry, because all of these methods and techniques were invented long time ago, and I lost two years by inventing the bicycle, while this method is already there. Of course it costs to buy these cards. It is all clear. But you practically get it from private sector. All of the services which really helped me and was in use for me practically all of that we got from the private sector. No public help available…"	
	MC10 "Because usually they tell you the diagnosis and leaves you with the diagnosis. And because they don't give any prognoses, this allows parents fantasies to go off, everyone probably fantasies as they please. As there is no direction when you leave CDC"	

Category	Examples/Exerts	Units of Meaning
Emotional roller-coaster	FC10 “That’s why I say, it is some kind of despair, because doctors say nothing and they don’t say that they can help us. They say that to achieve something is only possible through behaviour therapy, that there is no treatment. Then... Then you accept it and start to work with it <...>, as much as you can. You try to find the way and get that help for your kid.”	86
	MC5 “Well, these relapse, like we talked... This relapse, maybe I would say... Appears due to the tiredness... At least for me. The angriness phase shows up…it was especially true in the beginning of the diagnosis…”	
	FC3 “It is internal. This internal fight between yourself... If it is now that I am always worried about what the future will be like... during that time these worries were even bigger. Especially, when you attend these classes and there is this difficulty, he doesn’t want to go, to do his works, and resists, and all the point of this... Like the biggest misery...in the beginning it was just emotionally draining.”	
	MC7 “Hmm… It was really difficult period. I was left alone and didn’t have with whom to share, about all of these thoughts. And <...> to share about anything. You just simply cannot believe, that it happened. You realize that it happened, but you don’t want to live by that thought, that you will wake up and this is only a dream. Maybe soon, soon, soon... He will just simply start speaking. And everything will be alright. And... I was told that getting further, he will fall behind more. And it will be like that... And you look, and think, that it’s some kind of nonsense. You realize, but you don’t want to. You don’t want to... That here... It is very, very scary.”	
	FC9 “You see, it might be this, this... It’s hard to tell why. Just because of this nervous tension. Because of this, again, feeling of despair, when you think, especially in the beginning: ‘How this is, how complicated... How difficult...’Sometimes you get tires of all these thinking and from this fatigue you want to cry, and... I guess probably, it is mostly because of that, when you get tired... These difficult moments, when you don’t want to go nowhere, just want children to sleep. And you don’t want anything...”	
	MC9 “Help mother not to tumble down into pieces, because she is under the stress, how to deal with this stress, how to live on, meet with other mothers, to show that it is possible, to show it, as usual...I think mother is broken into small pieces and left. The time is taken from her. Until she will fix herself psychologically, during that time they could already be working with child, and the time is taken away. And it is emotional roller-coaster - this journey.”	

Category	Examples/Exerts	Units of Meaning
Emotional roller-coaster	FC7 “Obviously it was that worry that when you hear the news you have natural reaction, it was, again depending from the age, education and etc., even more normal reaction but of course those 10 years ago autism was not even on the radar at all only now the education is getting more normal, but then it was like receiving the news of death sentence...it was just emotionally draining- you just get sucked into it.”	
	MC10 “For me, right away, we had to do something, we could not just sit. Something had to be done... you read, read... what can we do...First weeks were totally sleepless. You sit and read, read... And the more you read, the more you go to the despair. That, however, only minority grow up as independent people. You read, read... and they I say, only worse and worse. Depression was terrible. I just felt like a ton of bricks felt on my chest.”	
	MC3 “First... first week really went with thought, why us, why this is happening. Because again there nothing like this in our families... simply this, how to say this...Nothing would help, it was just - free falling into this abyss and then trying to catch onto something - that how it felt in the beginning. This... I don’t know how to call it. This. This period, when you are angry with everyone...and just frustrated.”	
	MC8 “Certainly there are moments, where most likely like every mother has challenge with child difficult as her [talks about her own child]. And it seems like I cannot take it anymore, but then new morning dawns, and then again from the start and sometimes it is like encouragement for me...sometimes it is a struggle, it was like that from the beginning…”	
Losing “normal child”	MC4 “We were happy, then we found out and we couldn’t accept this, because it was shocking, overwhelming and just full of doubts and self-blame. Plus, it was very difficult for my husband, and you know men don’t show their emotions but I can hear him cry at night.... but now when we learnt to live in this reality and everything is done, we can now accept the life what it is.”	52
	FC4 “Anyways, I disagreed until he was four, four and a half. Then little by little I realized he might be slightly autistic. I didn’t want to agree. But reality kept creeping in and then I had to accept it - there was denial and then the worry started, I had to give the idea of him ever being normal.”	
	MC8 “Although, as I said, my husband, he accepted it right away, that child will be different. I still was tearing myself, as I said, I am still going to do something. I was going through everything to make her as independent as possible… I just could not accept her being different - emotionally it was sooo difficult, I was just upset and shocked.”	

Category	Examples/Exerts	Units of Meaning
Losing “normal child”	FC1 “There is this question, because you have these illusions, how I will share my life with him. You know you build dreams, that this will be a man, you will go to play basketball, you will play something else, go running, and we will be kicking the ball…and suddenly there is none of that left... you are baring these thoughts far away and forget the ‘normal’.”	
	FC3 “So these expectations here... well to come back to, how I was imagining son’s future. There will be chicks, and will be in school, and friends, and when sixteen I will need to catch him and bring him home by his ear and... And…wedding and studies and graduations and everything else. I mean, this typical childish... that to go to kick ball... these regular typical things. Expectations now... Because you already have accepted that, understand that already... how to say this... You have to accept that all this ‘normal’ things might not happen…”	
	MC4 “*interviewer:* Why didn’t you want to agree? *MC4*: Because he was the normal healthy child, always on my hands, that’s all. My baby boy I did not want to agree that he is different that he is not healthy.”	
	MC5 “Your child is like every other child, he was growing healthy, there were no changes in life, everything was normal, but something was happening inside him <…> And I struggled to accept that he will not be like everyone else.”	
	MC7 “This thought that, all of the friends, with their kids. You can see these poems, celebrations at the kindergartens and else. These typical stuff when a healthy child grows up...And you realize that you will get nothing, similar to that. And how will you live? How will...? Won’t speak? Then what he will do? He won’t be able to have friends? Then...what?”	
	MC10 “You have this ‘white’ jealousy. You see this child running around, child like mine. One boy was born at our neighbourhood, week later then my child. He, is talking already while mine is still silent. When you have what to compare with. That does it. Mine is still not doing this. It is certainly hard. It is hard and you are jealous, that it is like that. I don‘t know how to accept it.”	
	FC7 “It didn’t change; it still was there. This idea of him being independent, healthy person. It is not possible and sorely understandable, that it will never happen. And it took a long time. Probably only now... 10 years maybe, so that these expectations would meet the opportunities. And I stop wishing to be normal.”	

Category	Examples/Exerts	Units of Meaning
Losing “normal child”	FC8 “So now we know will always have a child at our home, and these are only expectations we have. You think that one day your children would leave your home and do something of their own, but this won’t be the case. You won’t be able to live alone and do whatever you want, no, you will always have a small child at home who will need constant attention.”	
	MC8 “All of that, as I have these expectations of the child, so I wasn’t able to physically achieve that. So yes... Or to go somewhere. All of that, how I have imagined the life with a child, it was not there, it was not typical and it will not be typical - it took me long time to accept it.”	
	MC10 “And maybe then it was a very strong experience, that all the expectations... like a soap bubble exploded, exploded that whatever we thing and envision can be completely different. In regular situations we would have great expectations, with a healthy child.... And now I’m thinking, so what we all have expectations and it’s not a fact that they will come true, so yes, now I think about it differently. I had to give the idea of a ‘normal’ child.”	
Family Roles and Parenting styles	FC9 “Aaa, I think still it is my wife, if we don’t include the driving around, because the older one is back around two o’clock. *Interviewer:* Yes, the distribution of work who does what? All the same nothing change. We have this distribution as we did in the beginning despite the child's disorder... It did a little bit, but not directly. It is difficult to understand that I cannot communicate with my son as well as she can. And automatically I get upset the she tries to have the same expectations (laughs) for herself and me. I think she has a God’s gift with communicating with children, she has no specific education, she just feels how she needs to talk to them, what she can do, and I don’t have this.”	231
	MC9 “I think my husband’s is more standard, more like from the Soviet times, what I notice from him is not incentives, not motivation but on the contrary, criticism. ‘You didn’t do it right, this not good, here you wrote it wrong’ and I can see, that he does not even realise how it can be, how they perceive it, but he cannot stop it, comments from him all the time. I tell him, and I hear it from aside, just no and no. Don’t push the table, don’t do that, not that one, and for me, I try to do it more from the positive side. Maybe you could move aside, lets underline these letters with green, where he writes it good I try to compliment him. For him it looks like child has to do everything right, for me it looks like everyone deserves a reward, and I try to tell them, you play nicely, sit well, you are awesome you ate it right, here are rewards for you, but for him it seems like there is no need for rewards that they	

Category	Examples/Exerts	Units of Meaning
Family Roles and Parenting styles	must do so, that good behaviour is itself comprehensible, and that bad one should be noticed, and vice versa for me, so for this we are mostly arguing about."	
	FC7 "good question…I think that 99% yes, it happens sometimes that when both are aiming for the best result, you personally see the situation a bit differently and interpret it differently, for example one of us thinks that maybe it is time to say no, while another one maybe thinks that it is time for peace."	
	MC4 "My husband and I were arguing, I told him he needs to understand what school is, and it is different, and not that he would stay on the swings all day. He could do that the whole day. So I told him it has to be like that, if it doesn't work after the first year we could go back, but then there even was the same bus…"	
	FC4 "No, we are different… Sometimes the arguments with my wife gives them the basis… They know if one doesn't let something, the other one might. The kids are smart."	
	FC1 "There is some anxiety… Because you… He is always screaming or angry, being messy. It doesn't give you joy in the family. And we would get into arguments, but we still support each other and move forward. We really communicate and support each other, and try to have one strong positions, so that it would not change. We have agreements what behaviours are punished, and we never show him submission. We have to support each other no matter what. But we do have negotiations. We encourage him [the child] if to give him a phone or not…and we communicate. It is not like we always agree, wife is more submissive and I am more strict."	
	FC3 "So yes, and there are strict moments, that I need to pull him by his hand, I need to bring him to side, I need to tell him something strictly and angry. I guess this is normal. We do not apply physical punishments, but sometime we need to show, that we are parents and that he needs to listen because that is dangerous. We always show him what is dangerous, we clearly show it to him, and that he shouldn't do that. He shouldn't and that i it...Maybe I, to be honest, look, that I am stricter... With these raising of voice and with these... Well, how to say this... raising my voice, strictness, that is if we go, we go. You take him by the hand and you bring him. If something is wrong then you pull a little stronger…"	
	MC3 "Roles. No, there is mother and there is father. And that's it that is the roles in the family. I would just say, that father's role is bigger, because he is the driver of son's, he brings him to the kindergarten, and they have this morning routine together. That is their time."	

Category	Examples/Exerts	Units of Meaning
Family Roles and Parenting styles	FC4 “No, she is like… the nursing, right. She is taking all the credits herself, that she is the main, and that is why I am mostly angry about. She has advantages, she is at home the whole day, cooking or something. I tell her wait, I also sit and cook the soup and I don’t get exhausted, and I manage to clean up the house. But she takes all the credit that she spends so much time in the kitchen, has no personal relaxation time… And there is always a lack of money…and nagging.”	
	MC5 “I don’t think that they have changed. I would even think that... Of course, it comes with time... Of course, there were various situations, but... Somehow we... I think we managed to keep husbands and wife’s roles separated from the roles of mother and father. Mother and father are for children. Husband and wife are for us.”	
	FC5 “You see, the wife was more into raising the kids, and I was fine with it, it was acceptable for me. Therefore, she began doing the schedule very early for the older daughter, so she would know how her day is going to look like, to let her understand everything better, I more followed her ideas…”	
	FC7 “Like these options… I am telling you this is a rare example. And then different teams occur – like these considerations, or anything else. But anyways we have to say that maybe it is my secondary position here in this whole process and I help with whatever I can, with whatever I am asked, and view it as necessary, then I say what I think and we put the parts together. Essentially I am telling you 99, 9% I think it coincides, I feel that way and it seems we agree most of the time.”	
	MC7 “But that is very acceptable to me. I like that and accept it very well. That I am, let’s say... I am buying food, pay for services, I look that everyone would have shoes and clothes. And he takes more of responsibilities at business and money.”	
	FC10 “Perhaps my wife’s approach towards upbringing of the children is little freer, than mine. But I notice that I start to think, that... Because I see, that it really gives results. How to better describe this difference of ours...<...> What concerns the school business, it concerns our older son more. That, for example, not to demand these good results from him, but just go to school, go to school to take knowledge <…> We sometimes have different approach on how to dress up the kid. Because my wife dresses them too warm. She thinks that me, not enough. So these kind of, you know... It is not general view on upbringing of the children.”	
	MC10 “From a different side, sometimes we would get into arguments, just because of particular moments, actually sometimes it would seem that we completely can’t agree,	

Category	Examples/Exerts	Units of Meaning
Family Roles and Parenting styles	completely can't agree and I think that we can't even talk about the topic, would even think that sometimes it's easier when husband leaves, sometimes I think that maybe that is easier, because we are completely unable to agree on something, but later that thought passes and I understand that this was just an emotion, emotional moment."	
	MC10 "I do house chores because all of us eat at home. Husband and children eat lunch at home and the child comes home from school sometimes to eat with me or grandmother, but I need to prepare food and sometimes I help my husband out with his work because I'm currently I am actively looking for a job."	
	MC5 "Sometimes my husband...There are such moments, but then we sit down and talk. Of course there are, some disagreements...because... Especially about the older girl... As I say, he kind of had Soviet view... For example, you are so foolish, you can't do it. You can't write this... I sit beside him and say, that he should support his daughter and be less strict."	
	MC6 "Everything, everything is fine. We agree upon the kids. I cannot say that there are these big differences. Well perhaps, perhaps I am more forgiving one. I am more of this mother, and father is maybe stricter. Good...I mean, sometimes it happens that we do not agree on something, but we have agreed on this strategy between ourselves, that if you feel that you are wrong, then you descend and in that sense that who has said it first. Maybe sometimes you don't wish to do so, but you accept, that it will be like father said, or like mother said. So well, well we are trying to stick to this united kind of, united principle."	
Child characteristics: Tantrums	FC2 "I don't know, if you can call this getting out of track... When there is a moment for the child, how to say this... some kind of anger ... like...moment. He doesn't agree, well... well how to say this... Adults, if for example you are having a discussion with the voices up, you might go away, separate, close the door... Child like this with ASD... First of all, he is not able to discuss like we do. Let's say sometime we may discuss, maybe he is not always allowed to go somewhere... thus, he express his frustrations and sometimes he pinches, for example, someone's hand... or throws a tantrum."	89
	MC4 "Well he is selfish. Of course, he needs attention if he wants something. A regular person can say what they want while he cannot, so he becomes angry, demanding, he begins screaming and breaks everything."	
	FC4 "He would probably take you down, push you… If you are not physically strong. And if you let him, he will continue to do this. Older teachers, they restrain him and the	

Category	Examples/Exerts	Units of Meaning
Child characteristics: Tantrums	aggression goes away. Then he goes to apologize, or… He wants to reach his goal, his goal, whatever he wanted and initiate this tantrum… That is all."	
	MC5 "I don't know. Well, what is it? There is... There is, so in general such situation comes up. For example, if he was sleeping badly, he's tired or his schedule was too intensive... Then, even my smallest incontinence, a slightly raised voice could unbalance everything, and he can throw a tantrum there...or he threatens to beat me. Sometimes he even hits. So the example of such moments is when you are exhausted, the child is exhausted and you try to make him go to sleep."	
	FC5 "Our son threw a tantrum and we asked the personnel to put back the colour it was on the flight before, but they didn't. And go to hell. So we played with him maybe half an hour until we calmed him down, it was stressful to all of us."	
	FC7 "What I had in mind, concerning health... I meant that, probably just that there was a lot of hysteria and a lot of these 'tantrum', how to say – attacks. Purely these behaviour, hysteria I guess in Lithuanian. So all of these things and also not sleeping, laughter at nights, peeing in his pants and etc."	
	MC7 "When it used to be that you wouldn't know what to do anymore. He screamed all the time. I couldn't take it anymore that was it. So, let's say he would start it in the car, I would get out of car, would stand there looking at him. He would scream until he would fall asleep."	
	MC9 "Angry with me, but clearly releases his anger at everyone. He becomes restless, then things start to fly around the house. As he does not know how to express himself, thus he simply gets attention or else, but he has this very strong way of protest, which stresses me."	
	FC10 "In few words, when he is protesting against some kind of activity, then it also happens that he starts to scream, then he screams loudly. He might roll on the ground or bite himself. But it is only biting, there was nothing stronger or more vivid manifestations."	
	MC10 "When sometimes, he is angry, because he wants to tell us something, but because he is unable to do so, unable, thus becomes angry. Later, he would show his dissatisfaction in this manner, he would bite me, and really hard, so hard that I would be all blue, during the summer season I couldn't wear revealing clothes, it was very uncomfortable."	

Category	Examples/Exerts	Units of Meaning
Child characteristics: Tantrums	MC6 “With his behaviour problems, well that is there, yeah... I have somehow not mentioned it. How it is with these behaviour problems. When it is either his waves of anger or when the hysteria starts for no good reason. Then it is difficult. Well... It is especially hard at the beginning, because you don’t know what to do now, what actions to take.”	
	FC3 “I mean there is total mess... If, we say no to something, he screams. Then we are screwed. And he can just be uncontrollable, thus we learnt to scream back and it made him realize that this is not going to be the case and he will get screamed back.”	
	MC3 “To be angry... well angry. Not angry, but rather to express his dissatisfaction. He does it very well. You couldn’t say that we are fighting that, but sometimes we do…that his behavioural issues like tantrums and screams and kicks and etc.”	
Child characteristics: perception of danger	FC2 “Someone has to be always around, of course... how to say this...aa... It might be that nothing wrong would happen to him, but we cannot take this risk. Make some kind of experiment. There is always someone near him…as he does not have understanding of danger.”	103
	MC3 “Yes, sometimes you have to be strict. But there are limits to that, in order for him not to get on the street or to start cuddling an angry dog. Yes, other children who are not autistic may also run to the street, but he is more likely to do so. Or to stop in the middle of the street.”	
	FC3 “In majority of time, well I need to hold him by the hand, because there is that desire to run away, not looking for the cars, or, or, or... so this is a form of weaknesses, incomprehension that big accident might happen.”	
	MC4 “He is a big boy now, but when he was smaller, it took a lot of time to explain that you need to cross the road when there are lights... And really if he needs to cross the road, he can start to run, we run. He holds my hand and we feel one another, I try not to let him go...as there is still lack of that perception of danger…”	
	MC5 “…and my child does not have perception of danger, he just does not understand it, thus you have to keep an eye on him... You don’t know. We had an accident… Maybe the year before he went to fish to a pond and felt in, the neighbour almost got him...”	
	MC7 “…it is complicated because he does not understand dangerous situations and you need to have lots of rules, like don’t do this, wait here, come now and etc. it is exhausting…”	
	FC8 “…she needs help and constant supervision as she does not comprehend things, so her perception of danger is non – existent, so you need to be with her constantly.”	

Category	Examples/Exerts	Units of Meaning
Child characteristics: perception of danger	MC9 "…running around, him running away, hyperactivity, because he might get into trouble, he might get through window, yesterday two times... He got on the chair in the balcony to look through the window...I'm also worried that he is throwing stuff through the window and there is no understanding of danger for self or for others."	
	FC9 "…impulsiveness, the lack of patience and understanding of danger, he just does things out of urge and you have to watch that he would not hurt himself."	
	MC10 "Being by the water also makes me feel worried. I constantly have to keep an eye on him if we are on holiday somewhere, during summer we go by the lake to swim, we need to keep really really, really close eye on him. There were few occasions which I can't forget because I talked a minute too long with friends when we came to visit friends. The child was at the house; he was really close. I was speaking with my friend and my husband also was near me and I thought that he can see the child and a minute passed, where is the child? No one can see him. We left the house, I ran to the lake right away, because of the small hill you couldn't see and I found my child getting out of the lake, all soaking wet, while still wearing clothes. Did he fall in or did he try to swim I don't know? He didn't tell, show, but we were in great shock. And it was just a minute…after that I'm always like: 'Where's the child? Where's the child?'. I look really worried and can't be calm but there's a reason for that, he does not understand danger."	
	MC6 "But in general I am worried about a lot of things. I am worried about all these things with which we have difficulties, because there are plenty of them I mean. Just sometimes you feel that you cannot leave him alone, he is sort of fearless and does not understand - what is dangerous."	
	FC10 "…perception of fear - let's say, if it is a crossroad or a street, you cannot relax while going with him on the street, he might suddenly run way upfront 50 meters from you. And I already know, that in the park I can freely let him do that, because as he starts to run and after approximately 50 meters stops, stands, looks up to the sky. And when you go on the street you cannot know what will get to his head."	
Child characteristics: communication issues	FC1 "He doesn't talk much about history or when he needs to describe something. It is difficult to get the words out of him. You really need to… If he is in the mood he can tell something but not very consistently, and he will never tell you how he feels, you have to guess it."	153
	FC2 "Well I don't know... and there is this one thing... how to put this... Well he does not have this big need for...communication... these things, I realise, are related, when he	

Category	Examples/Exerts	Units of Meaning
Child characteristics: communication issues	doesn't want to talk, then there is no need to talk…there is no need to try... I am trying to highlight, that we need to stimulate communication, improve it, so that he would be able, I mean, express his worries, needs and... And…again, I know, that in this way we reduce the chance to get into unclear stressful situation for the child... So then...then... In that case live is easier and sweeter. So he is able to communicate, I am not sure if well enough, at this age or it was possible to do it better or not."	
	MC3 "Namely, verbal communication is probably his biggest problem. Which is the outcome of this not motivated behaviour. This is my opinion...that scares me sometimes the most is if... I am most concerned if he understands, for example, that I love him. Does he realize that? Does he realize that I am not bad? Why should I be bad? Maybe these are the questions that other moms have too. But sometimes moms have to be bad moms…Because he was in pain, and he was feeling bad. And until you sit down you are unable to see. Thus sometimes it is scary that he might not tell when his belly hurts, and he might have appendicitis, or his head might hurt, then how can you know that his head hurts? Those are my worries."	
	FC3 "So his weaknesses would be about the speech, about, I mentioned this feature of the character, that... he doesn't want to accept, for example, that we are going to sleep, therefore mother and father gets to be screamed on, but we understand that... as inability to say no, because if he could say no, he wouldn't scream. I am worried very much about the speech. One of the biggest thing that I would like is, that he would know how to say where it hurts, and would be able to name at least five places to tell where, because it is the scariest thing, when you don't know what does it hurt in the child."	
	MC4 "I don't know the weaknesses, just the weaknesses… When he cannot say something, I cannot help him. I don't know otherwise, he is just a different child, because he doesn't speak..."	
	FC4 "Mostly we try to make him speak in sentences, not just single words, but sentences. And as I am saying, he is smart. We need more discipline, maybe we can achieve more and he can finally talk."	
	FC5 "The weakness is a lack of communication, the language itself. He doesn't have a vocabulary. It is not wide and does not allow him to speak fluently, and since there is no such wide vocabulary, there is a struggle to understand him…Thus, it gets frustrating sometimes…"	

Category	Examples/Exerts	Units of Meaning
Child characteristics: communication issues	MC6 “In general, we are having a hard time with all of his development. There are problems with his speaking, he is able to speak some words, he has passive vocabulary, is not little but this kind of usage is very little. So, and I am worried when let’s say when I leave, because I know, that he doesn’t have feeling of danger, that he might stray somewhere and I mean there is also this anxiety and all the time this supervision. So yes, and in general, as I have mentioned, what is missing the most, what is wished the most, that is this [comprehension]...I would like that sometimes he would understand my feelings, that he would be able to show what he feels.”	
	MC7 “Well, certainly, total absence of his verbal communication. Any kind of... It aggravates everything...Probably it is hard to express their emotions and everything else for people with autism. Well but, it is really difficult when you cannot know if he is scared, or cold or he is hurt somewhere, or he is... If he wants anything, is upset about something, something frightens him, worries him, so... This is the biggest fear. And fear... captivates us. And this frustrates him and bad for us. This absence of verbal communication is scary.”	
	FC7 “See, when a child cannot speak, what weaknesses can we talk about? That’s just how he is, he cannot talk, so he just simply cannot express himself. And our friends would ask us will this one ever speak or not, you know… We also focused on this task primarily, as without it we have multiple problems – understanding, pain, and etc.”	
	MC8 “The major disadvantage is that child does not speak and we need to guess what she wants. That is a difficulty – language and cognition that she does not comprehend and speak. Weakest spot. ye ye ye, that minus is the biggest, and is our problem. Because sometime, I tell you, you cannot even know how to help her, because when the child doesn’t feel well and if it hurts and you don‘t even know…”	
	FC8 “No, we got used to this, she will not start talking, so let’s find another tactic. If there is something wrong, you begin to offer something to eat, show the belly, or something. Once she was being disturbed, we could not understand what it was, we touched her ear and she moved her head, so it turned out to be an ear infection. And after this one time we know now that you need to touch her ear and have this whole procedure, you go through it, and you try to guess. You might be lucky, or it turns out to be just boredom, so this is a challenge, but as I mentioned, we got used to this. She will never tell us she is hungry, something hurts or she wants to go outside, nothing will change and we need to adapt to this…”	

Category	Examples/Exerts	Units of Meaning
Child characteristics: communication issues	MC10 “Talking about weaknesses, sometimes he can face a lot of difficulties expressing his emotions, because he is unable to speak, usually its inadequate behaviour.”	
	FC10 “When sometimes, he is angry, because he wants to tell us something, but because he is unable to do so, unable, thus becomes angry. Unfortunately, unfortunately there is no communication with other children. But this is a general trait. There is nothing can be done with that apparently. It will either change or not...”	
Reconciliation	FC2 “How to say this, already eight years… more than eight years… we live like that. How to put this… we are trying…get out of the clutches of autism…So already eight years. It is not going easy, but it’s going on. We accept what it is…”	42
	MC3 “Well this acceptance comes and goes in waves...I understand that this diagnosis might fade out and I mean that everything might fix... But somehow now, like at this time again... I don’t know, maybe, this autumn, autumn depression came by and simply it becomes hard to live with it.... Somehow again... maybe it will get better during spring. We will say that everything is going to be fine then.”	
	FC3 “Well and this acceptance, I say. These phases happened so fast that I cannot even remember it now. But this acceptance was also, relatively fast process, when you just simply sigh... well... well what? It is as it is... And we will have to live with that.”	
	FC4 “…even now I think he is healthier than me or anyone else. He knows how to use his brain, the disabled ones can autistic people can, they are very mobile. And that is all, I don’t think… he can take whatever he needs, he will achieve, and I don’t think this is a problem. I can’t imagine what problems there could be, and even then, he will try to handle them by himself, because he won’t have any help, I just don’t give up and I know he will change and I will not reconcile to the idea of disability and autism”	
	FC7 “But…In general, it is more calm now. There is much more acceptance now. You accept it as it is. I don’t know if I have answered this question... You realize that, look, you already not angry with yourself, nor with the world, that this had happened. It wasn’t like that I woke up and accepted that. It was a long way, but we are here now and I am very happy.”	
	MC7 “I don’t know; it was really interesting. For about 6-7 years I was saying that I, surely, will never accept that he is going to be autistic all his life. And I didn’t, for a single bit. It was bothering me and I was scared. And all of that…but know I accept it as part of us, our family and autism is not a penalty or judgment anymore.”	

Category	Examples/Exerts	Units of Meaning
Reconciliation	FC8 “it is just that there is no way out, there is no need to be upset or something. You can do whatever you want, pull your hair, but nothing will change, so there is no need to be upset, and do something, you just deal with that. This is going to be this way now. You reconcile with this situation and you adapt your life from that point in time.”	
	MC8 “Most likely I did not accept that as I say I did. But maybe I am trying to close that page and open a new, white piece of paper so that I would get used to it, that nothing is wrong with my child. And we are trying to make it for her, so that her life would be easier...Probably no mother will accept this diagnosis as it is. That this child came to the world being special. Not like that and, as they say, only strong people are given this challenge.”	
	FC1 “We reconciled with the fact. One thing was that both I and wife had to get reconciled with this. You have to understand it will never be like it is for others, it will be different. I mean, your son will be a complete person, but he will be different. You cannot run from it, that is the difference and then you reconcile with the given…”	
	MC6 “Yes, I mean, this acceptance you know it’s kind of, kind of conditional. It was not like, I needed half of year to recover, but it happened right away, I mean, we instantly went, took what we could take and instantly did what we could do. So…”	
	MC10 “Some people helped me by giving advice and recommending books on how to find inner spiritual peace. I really had to work a lot on myself in order to accept everything the way it is and even rejoice in some of the moments. Well, life is really multi-coloured and we can really be happy even in situations like this.”	
	MC5 “Well, autism is a great lesson of life. It teaches you, as a person... Of course, if you accept this lesson. It teaches you to look to the world from the other perspective. You understand that everything is not so easy in this world. If you accept it as a teacher, you are able to personally improve. That‘s it.”	
	FC5 “I love my child no matter what. The next task was to make him independent. It was my goal to figure out how to give him this...So this was my new challenge. Thus asking why, why me, would not give me anything, you accept it what is given and you try to make the best out of it.”	
Stigma and rejection	MC10 “One time, right after the first diagnosis I experienced major stress, we went to visit the sea and we stayed in a recreational cottage where there were few rooms, like a guest	204

Category	Examples/Exerts	Units of Meaning
Stigma and rejection	house. And the whole evening the child [refers to her autistic son] screamed really loud, he demanded a cartoon, I did not want to turn it on and I don't know an hour maybe an hour and a half, how long could he have screamed in the evening. The next morning the owner asked: "Why your child did scream so loud and for so long yesterday?" I told him that he wanted to watch a cartoon and I didn't allow him to watch it. He screams, happens. 'Mmm'- he said 'maybe he is unhealthy, because we had one mommy with a child, he also always screamed and screamed, disturbed other people and it turned out he is retarded.' I was shocked."	
	FC1 "There are millions of critics, but I look at it normally. This is a normal reaction when you see something you don't normally do. Women react more sensitively, oh someone looked, oh someone mumbled. I think this is normal, if the child is having tantrums on the floor of a supermarket, is rolling around. It is normal you will be looked at. So why be surprised or something, not everyone knows and it is not important for everyone. It is important to those who have encountered this or have a child like that. Everything is simple for me, and I don't judge the old ladies, or something… It is a normal think. You cannot run from this, and all of us…"	
	FC2 "Am... how to say it... aaa... These kind of kids... In the eyes of society…well…they are identified as not normal. Well…with some kind of development disorder. So…then... our goal is to get out of these clutches of autism to the group of normal people. And for now, let's say that, parents are still alive. Still some twenty, thirty years going to pass, but still... So to add to my wishes…So…It is not enough to only work with your children, but as well to work with society, in which we going to leave our children. To change the attitude a bit. So I do that myself. I am trying..."	
	MC3 "But if needed, I would say, because I am not ashamed. And stares happen, looks happen, sometimes they watch, sometimes they whisper something. People notice. People notice everything…They are afraid; people are afraid... I guess, that people are afraid and timid. If people would be more daring, perhaps they would ask or else... When I think, I would boldly ask, like I had not even one mother, asked, even if they were strangers, somewhere, how you are doing."	
	MC4 "What about the society? It used to be that in the shop he would fall down and scream, but when he grew up he understood… people would say oh what a child, look at the mom. I replied that he has a disability group, what are you looking at? Then the rest would pay no attention. He has the certificate, he is like that."	

Category	Examples/Exerts	Units of Meaning
Stigma and rejection	FC4 “No they talk a lot about those autistic children. Before that, as the CDC head of department said, until eighteen the child was just stupid, and after eighteen he is either locked in the psychiatric institution and loses his disease history, or he gets better. There were autistic people here for a very long time, but nobody wanted them. They are not interesting...When you see foreign TV shows, how they have a different approach to people like that. The support from government for older people, financial help, pensions. Look, these pensioners come to visit us, to relax, they walk around like they don’t care. And our pensioners cannot do that. They go to a store and count the cents to have enough to pay for the apartment. Is this a normal country? I am telling, a country of ‘idiots’. I have a friend in England. She says she has rest, and if you are like that they let you through first. You won’t have any accusations that you are not waiting in the queue. The doors are open there. And people here are like “I was standing here” (imitates an angry person). The level of development is different… That why I am saying, retards.”	
	MC5 “Yes, we do have a problem with him. Problems not only within him, but also with his social inclusion. Yes, here in Lithuania. I think that strengthened it. Because of course us... Well, it is difficult to talk about it, but we talk. And we... You know, we have to walk side by side. Lithuanian society does not understand what it is. They think that autistic children are uncontrollable and unsound. The Lithuanian society does not have understanding what autism is and what kind of spectrum it is, what is good or what is bad. You ask any of the people and they will tell you their imagination or information for the movies or a stereotype which has nothing do to with the diagnosis.”	
	FC5 “Of course, the label and some words hurt me as a father, because you get this different acceptance of the society. Like somebody with leprosy or something like that. We went through the societal acceptance for a long time, because there were many accidents where his coming would be… In an activity or somewhere a pedagogue or a director, I don’t know how to call them, or instructors, they don’t know you but call your kid bad, misbehaved, ill-mannered, and impolite or something like that. He doesn’t act like they want him to. So there were many offensive things, but they make you stronger. It is important not to…. not to allow them to act this way and if you see a conflict it is better to avoid these places. It is better to go to another place or find another way. And you feel vulnerable, irritated or something, and you don’t want to grow this negative emotion. We learned to live this way.”	

Category	Examples/Exerts	Units of Meaning
Stigma and rejection	MC6 “Well I don’t know, somehow. You know there are even worse reactions from the strangers. You encounter everything in Lithuania, with a lot... well I will say that in Lithuania, there is little of tolerance for different people. There are, there are relatively few people with this kind of tolerance and, and, and many of those, where you feel and, and from the children you feel...I wish that there would be more tolerance from other people, and this understanding, that they would accept more, because we have done nothing bad to this world. It happened, it happened, so I worry when I die and leave my child behind to this environment...”	
	MC7 “You would see people and there was people, who had heard about it or seen it, or lived somewhere. The child is simply like... Person grows up, who doesn’t speak, or is not capable of something - then people call him retarded. Like this popular expression, in older generation, like this idiot that everyone can mock.”	
	FC7 “…so in reality that encounter with brutal environment we were able to avoid, again there was the village, so why should we put the child outside by force who doesn’t want to go to the public, which creates discomfort and insecurity feeling, in that same way it annoys the society.”	
	MC9 “Precisely that they would show how unpleasant it is for them, that these kind of children needs to be put to special institutions. It was twenty years ago, fifteen. That I don’t need to walk around with him that he has to be isolated, in special institutions, these kind… They are more hurtful, that I am a bad mother and I am not capable of raising up, now I am capable to not pay attention to that. I know myself and that does not work with me, but when they start to say that he needs to be put away, I react to that more painfully...From more than one person, that he does not speak, that we don‘t train him and don‘t speak with him, that he is simply is spoiled, by me with my incentives, that he is running around and me with candy after him. He simply is spoiled child, that he doesn‘t have any disorder. I heard it from my relatives and in the street... That someone like that should be spanked or put to corner, he needs to be punished and that is normal reaction, that simply he is spoiled child.”	
	FC9 “We avoid public places. I mean we have a lot of activities. But they are all connected with autism. But the people there they know what autism is like, they understand. We really have very little unstructured cases when we go out to the city or somewhere. There were many reactions before, from misbehaving children to… [laughs] Lithuanians are intolerant	

Category	Examples/Exerts	Units of Meaning
Stigma and rejection	in general. We get in those situations quite rarely. Others do more often, because there are kids with additional disorders, such as mental retardation or Down's syndrome."	
	FC10 "Then people notice. In general people do not know what autism is, or know very little about it. You cannot say anything about this child because he looks like all other kids. Unlike other disabilities, autism is like that. That from the outside, for many, nothing…Person will not notice anything at all...In the past it was like a problem, at least for me, but now it doesn't matter. In the past I was very worried, when he has some kind of anger attack, when he would scream in such a place, where there are a lot of people. When everyone around is watching. Before, it used to worry me, now after some time passed, it doesn't worry me at all. You may watch...aw, I don't know, how the socialization of these people will proceed in Lithuania. How it will develop. We will see. At this moment it is not good with this issue. With this it is yet not right... These people in society are yet...maybe it is already no, meaning...At least, already, it is not pretending that these people don't exist in society, but still doesn't do anything, so that there would be less of these children or these people, who need to be maintained by the government. Because it is...again, maybe I say, maybe later it will be a different topic, but while I have this thought on my way. Experience of these developed countries show that you need to invest already in the child, into this kind of child, at the very beginning, in the childhood, rather support him, as the disable person for the rest of his life. So...am...These are very few of these kind of countries, and until they realized it at the level of state, nothing will change."	
Education	FC2 "Like in our case…I tell you, we don't have these physical problems, but you go to kindergarten, good day, such and such child, show the papers, these are the papers…Aaaa… he is disabled.... No, we don't need this kind of ...We don't know how to work with someone like that. Sometimes the reason is not that they don't know how to work…of course this kind of kid needs... aaa... let's say more workers, effort, specialists. But one other thing pops out...aaa... parents at these educational institutions…of the children... also…like you are…how to put his... like Jewish people with the stars were walking in ghettos, you are marked. They say, no, we don't need disabled ones, we don't want that in our group or class, so that our children would...instantly...aaa…would see or interact with these kind of…well... they are scary, somewhat different…They might hurt our child…like...so…so that is that."	98
	MC6 "Of course we are concerned. Like for example, we recently had this breaking point period. Changing, when we had to leave old educational institution, which we were	

Category	Examples/Exerts	Units of Meaning
Education	attending for already three years, where we were feeling good, safe and calm and we knew everything and child got used to it and we got used to everything and... So now we had this changing period and changed the educational institution, because simply we had to leave according to age. So we were really worried about this adaptation period, but like, I still cannot say like that, we don't have these big problems everything seems to be fine at the moment."	
	FC10 "I could not say in detail. Maybe wife could answer this question more, but as I know, that they, before, we handed application to this school, asked us conclusion about development of the child from the educational psychological services, and on the basis of that and conversation with us, what are the features of the child, what he is capable and what he is not. They, like for each child, came up with this kind of program, so the worries were taken away."	
	FC3 "We know these specialists, we now these educators... And... Not, at all quite... it is faster than perhaps if we were alone in some public kindergarten, and if we needed to look for separate specialists...Jeez... that would be a nightmare. Thank God, that we now have this direct help, fast and clear one...like in the beginning of course, the biggest misery was most likely at his first kindergarten. Because there was probably like, I bring him, he goes to his corner and nobody pays attention all day long, because when I came back I found him in the same corner, so maybe…It was biggest misery and education for him always worried me."	
	MC3 "The biggest worry started since he turned two, when he was two and a half he started to attend this kindergarten, regular public one. There, it started, it was impossible to understand him, and since he turned three years old, he became difficult. It was really hard in the public kindergarten when he was three and more years old. Then we were thinking where else we could bring him, because it was really bad at this public kindergarten. Child had difficult time, but he was comfortable kid, he was never angry or in anybody's way... He... We would bring him to the kindergarten, he would sit by the toys, he would play alone, would eat and sleep, then again would play alone and then we would bring him home. We sometimes, we really blame ourselves for that… How did it happen that we put this child in the public kindergarten for a year, let's say that we kind of dropped him there and left, when actually we could have done something more useful that year? Well but it happened as it happened, and education is out priority now."	

Category	Examples/Exerts	Units of Meaning
Education	MC4 “The school is very small and the head master works in two schools. A kindergarten and a school. She said this school is heaven, like a rehabilitation. It would be great if these two could become one...But in the beginning we went to regular kindergarten, but after the development centre, they said we needed a specialist. And the school head master suggested to find a new place, no one would pay for him… there were all kinds of… I said you can do whatever and then I… I called ‘J’ and I told the diagnosis and they said he was not fit and I had to find a specialized place for him, the worry about his education followed us, it is still even now.”	
	FC4 “And the… after some time the headmaster was like… this is a different child and maybe he needs a different school. They didn’t tell us to take him, but… That a special would be better, where there are the same kids… Then we switched to the special school, and person we knew worked as a psychologist there, but the education of our child, it worries us and it is a challenge.”	
	MC7 “Well... During period of school year, we wake up at approximately 7:20am, it depends. And then son is going to this specialized, multifunctional development centre. And... There he has these activities. And there are activities. I mean this class, which he got into, is educational. In the volumes of Lithuania, they are not the ones who are written off and nursed, but the ones who could be taught something. I am very happy, that we succeeded to find this school and class for him and the future seems bright now.”	
	FC7 “So this and also this specialized governmental school he goes to ‘School Z’ is a huge help too. And these people who work there and what they deal with, they are worth of so much respect and gratitude, it helps us to be certain about the help he gets there.”	
	MC8 “And also they have big groups, and the normal children might hurt her. She walks slower, does not speak, and she won’t have much to do here. So they told us to take her to a special kindergarten where they have specialists, where we would get the care we need. And after that we signed her up for the special kindergarten, and we are happy, thus we can relax now...”	
	FC8 “We did not yet go to the kindergarten when we had this diagnosis. We had her signed in the same kindergarten as her sister. But when we learnt about her diagnosis, we asked, and they said they have no specialists there and we had to solve this, with little help. But we manage to secure a good school, which secures a better future for her.”	
	MC9 “His teacher says according to his knowledge. Boys in his class…no one can even count to ten hardly, but he can practically already play chess and checkers and for them he	

Category	Examples/Exerts	Units of Meaning
Education	is very advanced and for him, they look silly. They do not understand him and for him there is nothing to play with...thus he just does not see much typical behaviour that he really needs. I wish they blended them in instead of making a class of 'retards' – this makes me worried about his future as he spend so much time in there and learning little typical behaviour."	
	FC9 "What comes to school, workers and teacher are wonderful and children. And the assistant just makes the children feel calm and safe and well. Sometimes during the breaks, they open the classroom door and children are afraid to leave because of the noise outside, but they are taught there. That makes me happy as in school he learns."	
	FC10 "Before we had this aspiration, so that he would go to school with all the kids, so that he would learn by the special program, with assistant. As it happens, it is also happening in Lithuania. But we realized that this won't work now, because he is unable to speak. If he would speak just a little, maybe it would work...Because in regular school, teacher might not understand, easily dismiss this child. It is twenty of them sitting in the class, thus I have to keep on going with them, I have this problem, I need to move on. This topic is for discussion, but at the moment it is as it is. We are letting him to this school and we see, that there are things which I would like to change myself. But in general it is not bad. And we see that little by little, there is something, there is progress. <...> Maybe, Maybe someday we can be back in regular school"	
	FC1 "General education, he always went to the general kindergarten. He always went there. And are looking for a school for two years now, something different…We are asking around, looking. And he went to the preschool 'M'…They have more experience with kids like that. And we are looking parallel for something, choosing, looking at what's best for him and that relates to his future what he will be able to do."	
	MC5 "It's only beneficial. Because... First of all, he is learning from his classmates, how to behave socially acceptable. And it is... How to say... Well, I'll wonder a bit now. I have seen my child's reaction, when he saw a child with a cerebral paralysis. He did not speak, only howled. My boy was scared, he even started shivering...As I said before, we have to work in order to let this child out to the world. And while working through those years I just intuitively or maybe consciously realized that... I don't remember... That we have to go to the mainstream class, among so called 'normal' children, to the same mash. So this was the decision. Doesn't matter was it separately or not… I said, I'm afraid to say… He somehow naturally…Maybe through work, maybe this was an intuition…You just can't	

Category	Examples/Exerts	Units of Meaning
	make him go there… This special education…I don't know…he needs to observe the norms, that will help him in the future."	
Child's future	FC2 "So I see this problem in this, that it is hard for these children when they grow up, precisely because it is hard to live forward and hang on…And for now, let's say that, parents are still alive. Still some twenty, thirty years going to pass, but still... So to add to my wishes... So... I is not enough to only work with your children, but as well to work with society, in which we going to leave or children. To change the attitude a bit. So I do that myself. I am trying."	134
	MC3 "I guess all parents are concerned with their children's future, it doesn't matter if they are autistic or not. This is like general feature of parents, that they are made in a way, to be concerned and to worry. I don't have this property to dream about far future. I don't have it...my character feature is, that I simply don't have this property to dream and to make lawyer, or some builder, or president of the child…I don't... Even, we were joking with husband... when son was still very little, he would slip or hit his head, when learning how to walk. We with husband were joking, saying: so well... He will be swimmer, or athlete. So what? Or he was singing some song, then of course parents are thinking, well then what...? He will be singer. I don't have these... this character features I don't have and I cannot say, that I don't have expectations well... Simply…Simply, future is future... Future is future... And... It will show, how it will be."	
	FC3 "Well yes. Everything stands in its place, worrying about the future, because the future as I think is foggy. Anyways this diagnosis will not go anywhere. This, it is not the illness, first of all. As many confuse them. Well simply, this all independence, future...Internal. This internal fight between yourself...If it is now that I am always worried about what the future will be like... during that time these worries were even bigger."	
	FC4 "I am optimistic in my head, that everything will be okay, he will get better, and maybe not because he is like that, and because they write that there are more people like that, and I think…"	
	MC4 "I cannot imagine what will happen when I won't be there anymore. There are older ones as far as I saw (gets even more emotional). I don't know how he will continue to develop. Maybe he will know how he is, he knows the school, and he might get his job later. And I will take care of him as much as my health will allow, I would like to live while my kids are little, I don't think much… The day passed and I thank God. So we live like that [laughs]..."	

Category	Examples/Exerts	Units of Meaning
Child's future	MC6 “And further, there is surely a worry, what will happen next, how it’s going to be with studies, how it’s going to be in general with all the future of his life, what will happen when we [parents] will be gone. So there are a lot of these kind of question marks. Nothing you can do about it...And how did it change expectations, well in a sense that future became very unclear and you cannot know what to expect, and what to wait from it.”	
	MC7 “Certainly, this patience breaks down and you begin to think how you will get through this. Adolescence will start. And it’s scary... And all the rest... But…It is hard to deal with this fear, that, what will happen when we will grow old, or we will be no more. How will he live in general after he will turn 18 years old, here in Lithuania, what he will do. This never leaves you. Every year it’s getting closer, when he grows up, because when he was 3-4 years old, he was simply cute, little kind of creature. And now he is a big man, and that’s scary. It is.”	
	FC7 “What worries me the most, very complicated question, well what worries is his future… All the maturation stuff you know; he is becoming an adult in some 5 years. So does the routine will have to change at some point? How well will the person adapt to it. But the nearest task is to somehow go through the adolescence stuff.”	
	FC8 “Future of my child. This is the most difficult. Because while parents are alive, then everything is okay, and later I don’t know how it will be [father starts crying] I am sorry. [We stopped interview] … It is most likely, really, the hardest for every parent, to think what will happen next, how it will happen. Of course while parents have their health its fine, but later, you don’t know what kind of future it will be.”	
	MC8 “We understand that one day we will be gone, and people with this syndrome live a long life, and what will happen next. It is not like everything is clear like it would be with a normal child, and this is not a usual situation, all of this is different. Sometimes you cannot even see what changes you need to make or what to do it make it better or more comfortable...Well the unknown… Who will look after her, where she will live? Maybe our children will not want to look after her and have this burden, maybe we will have to put her in a home, and this is the most difficult thing. While we are alive you can take care of her, but later… [Gets emotional, starts crying]. Maybe somehow it will get solved.”	
	FC10 “Let’s say that general restlessness is about the child’s future. To know, what will happen? But his... that thought will not leave. It is always somewhere there. Not even in subconscious...Most worrying thing is that if he never be independent. Like all the kids who grow up. You know what... Parents are not eternal and when the parents will pass away,	

Category	Examples/Exerts	Units of Meaning
Child's future	then... All the time in the head. If he will never become independent person, who will be with him. Well…there are these care institutions, he won't be on the street. But do you know what kind of these institutions we have here. Always this worry and depression takes over, when you think what would be, if your child, or any child, especially your child would need to live there…So... So yes... This is the main...when talking about child's future. For me I say, I would want that the most, that he would later be able to be independent. He can, he has <...> to become this specialist, or someone else not. He could work in a bakery, bake bread. But the he would become independent. That is the main problem."	
	MC10 "I myself try not to think about it, just do what I can do, to ease my child's life, his state, physical and psychological. Thinking what will happen, how, when, takes a lot of energy, I noticed, it's not worth it."	
	FC9 "I don't know, I didn't really think about this too much, because we are in the stage when we have so many problems that need immediate attention, and in general, there is no order or a system in Lithuania for this, so we have to create it ourselves [laughs]. We don't look at the far future."	
	MC9 "I am optimistic. At least for now it is easier to see it optimistically, because four sons and I see that like everyone will live independently, will have their own families, something else. But I also think that way about my older ones. Now I look at my grownups, that both of them now have returned to me, mother, and I start to realise that maybe not all of my future visions maybe like... Maybe I would like that all four of them would live with me until my old age. I do not comprehend yet."	
Siblings of ASD	FC2 "She does not distinguish her brother, I tell you she is very big helper for us, she takes a lot of our shoulders, when her brother gets sick. Well... mother to work, father to work. Sister is student…we... student can miss the lectures when there is a need for that...You see, I tell you again, for you to understood, what kind of sister is that. So…she is our right hand, or perhaps both hands."	46
	FC1 "Well… They started interacting only recently. They have their own interaction, mostly they are fighting. They cannot share something, one wants this… and that's how they fight. And after some time, now, they are getting along, started sharing… And son is becoming more patient. And then…one for another… We get along fine, but it took us awhile it was not like that in the beginning."	
	FC4 "It's not like that. My son spends more time at home, at the computer, and the daughter… she uses her phone and watches TV, stupid cartoons on CARTOON	

Category	Examples/Exerts	Units of Meaning
Siblings of ASD	NETWORK or something. Two of her hobbies. On weekends she sometimes has friends over, they go roller-skating. The son is afraid, like… When we went outside last year… My daughter has a bike and the son doesn't, he doesn't know how to ride it, but if he sees his sister doing this, then he also needs it. He knows he is stronger than her and doesn't let go of the bike. So we tell them not to argue, we compromise with our daughter to give him the bike for a little…We agree... If I am alone at the house, the wife is out, and I am alone, I really can. If I need to go to the store or something. I tell her she needs to look after him and there are no problems with that. She has a phone and she can call me if something happens. No problems."	
	MC5 "She… But she accepts him the way he is. Without any conditions. They play together, argue, they fight, and fight for our attention. Let's say that the family connection is casual. For now, the scariest thing for her is to speak about it loudly. For her...she hurts... Even though she is angry with him, that sometimes he teases girls or somebody else... I would say, everything is fine, but God forbid, if somebody mocks him, she strikes."	
	FC5 "They have a good relationship, they normally fight, irritate each other, just like regular kids, at least I think like that…My wife and I have given her these feelings and responsibilities, so that she could look after him, help us. We imposed this on her, and we are trying to remove this. She started reproaching us, she sometimes says she needs something of her own, she is becoming a teenager. It is not easy for her… You buy her with attention or other things, try to compensate."	
	MC6 "So I would want that his interaction with his sister would be more peaceful. I feel that sister wants that too. She would like to play with him and run around and involve him to her games, but not always it possible, because he, simply is lacking of certain skills that raises conflicts among them."	
	FC7 "Since the two came later, they kind of took as a given fact, of course at some point we had to explain what happened and why he cannot talk, that's it. When they live together kids are growing and reconciling with the fact too. Everything is calm at this point, compared to before."	
	MC7 "Well the little one there, sometimes he touches her and tries to squeeze her stronger. Again, he has this stimulus, that he has this strong grasp, our oldest one. So she gets angry right away, doesn't wait…and reacts physically back... But…Again...Again... that is just like with any other families...When there are these situations when oldest one falls behind. Only the little one is the one who worries and shouts: 'Come here, faster,	

Category	Examples/Exerts	Units of Meaning
Siblings of ASD	come I will give you my hand.' Really, I cannot really complain for now. Good brother and sister and good relationships."	
	MC9 "Let's see. One is an adult, twenty-four years old, and he looked into this topic quite a lot, he learnt how to behave with these kids. He gets along quite well. The two younger ones, it depends, though they love each other, but just like with all the kids there is a spectrum from the nicest friendships to fights and argument. The older one from the two is a very big leader, he has even given a complex to the younger one...Everything for him… Everything is easier for him, he is the smart one, and also an athlete. The younger one has more troubles, not everything goes as well, and he treats the authority of his older brother with respect. Until the older one annoys him. Then there are flying chairs and toys or something, they start biting and fighting…before it worried me, but now I see it as a norm."	
	MC10 "When other children ask him… I heard it couple of times, well he says: 'Well he is like that.' Somehow he doesn't give these, maybe, special kind of...mhm...basis for further questions. Well... well he is like that. For now it's like that…I don't think he is ashamed…"	
	FC10 "He doesn't play, he can even bite, he can fight and it is hard for him. He can't do the same because it's his little brother how could I hurt him, I can't. But I tell him to look at the situation and if you feel as if he is mistreating you, hurting you try to defend yourself, hold his hands, finally, you could flight, what else you can do. I tell him to protect himself. So he tries sometimes. Maybe sometimes he uses the situations. We have noticed that the younger child was bitten in his cheek and we asked: 'what is this?' and the older son explained that the younger son bit him three times and he had to defend himself and bit him once. But this is nothing, it's normal that brothers fight with each other, if it wouldn't be this way it would be strange."	
	MC8 "I have never asked him, but he walks with the little one and he meets friends, so I don't think he hides or something, he tells them…but again because she is still small, and there is a big age gap, there are no problems because the interests are totally different."	
	FC8 "Well how to say, of course the older one understand everything, so he takes her and plays with her, and holds her, so everything is alright, so they get along well."	
Perception of ASD	MC3 "And what does he like? He likes a lot of stuff. His games are quite interesting; it could look quite weird to others. But on the other hand he likes to play as others five-year-old kids: cars, Legos, games with ball, contact... Everything is like... like always. I don't	33

Category	Examples/Exerts	Units of Meaning
Perception of ASD	know about other parents... For me... simply I don't know, what more interesting to tell about him. Something more exclusive... He is just a kid as a kid. Different, but a kid."	
	MC8 "Every mother and father want their child to be healthy. Why is it like it is, I don't know? Sometimes I think that even miscarriage is better than raising this kind of difficult child. When sometime it's these intensified miscarriages. And we stop it...Until you do not have children, like them. This is why, when I had problem of getting pregnant. And it was this threatening, I got hold on every straw just to get this little 'grasshopper'. And now when you have this little grasshopper you start to think, what I would have done?"	
	FC2 "I think, that we are in the range enough, we do not evoke some kind of interference for the people around... Child like a child... Like all kids. Even with ASD he is still a child."	
	FC3 "Simply calm down, think, do not stress so bad. Children are beautiful, happy, that is most important to me. Grinning, running, not hungry, not thirsty. Has the favourite toy, something else - child like a child and everything else, is possible to try to do."	
	MC5 "Because my only purpose for today is that this child would be happy. We are doing everything we can. He would come and cuddle, cover mommy with kisses, that's what my child is like. He is my burden, my joy."	
	MC7 "In his mode of life, he really has achieved a lot, so that it would be somehow possible to live with him well, comfortable and quite peaceful, having everything else in mind."	
	FC7 "Essentially this is not a problem whatsoever, and nobody looks at it as if it was a problem. This is life, and stuff like that happens, and you have to accept everyone, and love people for what they are. He is my my child no matter what…"	
	FC8 "She is like ordinary child, only that she doesn't speak and need different kind of attention, but she is still a child…"	
	FC10 "Later I was saying like this, well what…You start with this, what is in the worst scenario. You start to look on the positive side, how it is sometimes good. What we now have to do, so that we would have success. Not like others. To do, to act. Well... mhm...That we haven't achieved anything you cannot say. We want more, we work more. You do what depends on you."	
	MC10 "I really had to work a lot on myself in order to accept everything the way it is and even rejoice in some of the moments. Well, life is really multi-coloured and we can really be happy even in situations like this."	

Category	Examples/Exerts	Units of Meaning
Relationships with the typical child	MC8 “In family we have three. Thus we have assistance, who certainly help. And now I do not feel that much of difficulty...He helps me a lot. He helps me “ferociously”. There are no problems with him. Like other children. Even neighbours wonder. They say, God, what good son you have, who understands and already helps, I don’t know we are that kind of family. We really stand for each other...Yes, like how much equally? Surely for our youngest one, that special child we pay a lot more attention, but in general we love everyone equally. Because really, no one is pushed aside.”	31
	MC10 “Sometimes I ask for help if I feel that I am not in the right emotional state, completely wrong state, then sometimes I say that I need to leave and ask my husband to help, sometimes older brother offers help: ‘mom I will talk to him’, he sometimes says: ‘I understand him better’. That really does happen...He is our main assistant.”	
	FC10 “From him, we do, yes. It happened that he even, he even learnt it from us, sometimes: ‘Why are you angry. Easy, easy, - he even separates us, and says you go to your room, I will stay with him’. He is very mature and a true help for us.”	
	MC7 “Plus, as I said, they get some rest from him. They get our full attention, with the little ones. Full, like adapted to them. We go everywhere. So they don‘t feel this grievance, that because of the oldest one we cannot do anything, go anywhere and everything is just about him, this different from what it was.”	
	MC4 “I need to have a walk with my daughter, where she wants, I give her attention, she likes spending time with her mom and to go shopping or whatever. We are attached to our home, I get tired of the four walls…so I try to give her more attention, and do personal time, as otherwise she gets jealous.”	
	MC5 “Of course, I feel very sorry for the older daughter, whom we just... She would just hold him, that he would stop scratching…It is hard to distribute attention evenly.”	
Relationship and diagnosis	FC3 “I would say, that it got stronger. Anyways, there is this bigger connection. Anyways, common goal. This additional one goal, despite those common home, kids, future plans, one extra added up, son’s needs, so just like that.” MC3 “No, it made us stronger, got us closer together. Because now we have this common goal. If let’s say, family’s goal is children, right? Some kind of creation of life, household, maybe some kind of personal goals, career, right? So to all of these goals of ours, one additional goal added to that... That is, to help son. To help him grow. So yes.”	78
	FC1 “…our relationship did not get stronger or did not get worse, it stayed in the middle...It helped that my wife is humbler, she somehow softens everything… I am hot-headed, so I	

Category	Examples/Exerts	Units of Meaning
Relationship and diagnosis	can work as a horse, go and do everything, but then I can explode. And she strokes my head, motivates me and we keep moving forward."	
	MC4 "Dad really loves kids and I do too and we… But his character is that he never complies, and I won't. We argue all the time, and I say my truth, and sometimes he is not right, but he knows that, he changes the subject and goes astray, because he cannot be wrong."	
	FC4 "On weekends. In the mornings if I do not work and she is at home we clean up - rooms or something. But the lack of money, I think, she always compares us to other, what they have and we don't. And I tell her to look well at those, who have less than we do. And she is like…she just makes me upset."	
	MC5 "Well, it hasn't destroyed the relationship for sure... This diagnosis... I think that when looking from the future after ten years, the perspective... Today I think that it has strengthened our relationship. It glued it. It is the thing which you have to overcome together."	
	MC6 "Sometimes you feel, that you got tired, that, that it is hard, but anyways we are together all the time, we are thinking together about what's going to happen next. Well I as well don't know here anything, but we hope that everything will be alright...We take each other by the hand and keep on going, so, so everything kind of has stayed the same."	
	FC7 "I think as it was it is still strong from the beginning and at specific moment it united us even more and "glued" as stronger and I think it is like until now. I think this common goal and vision helps a lot in our relationship."	
	MC8 "We support each other. And actually this kid did bind us more. Especially this disorder of [used girls name] connected us more...strengthened. Like we are more like. Of course it happens that we are sadder, but our relationship like it was or even is stronger..."	
	FC8 "I think it is exactly these difficulties that keep us strong. A lot helps, not only this, and we live okay and everything happens of course. I think everything is fine, and the fact that we have this child just changed our future plans and lifestyle, but it is not the end of the world and does not mean we have to change anything drastically."	
	MC9 "...because, they are raised by us together in practically twenty years, and those stressful situations, and how much we went through together, that diagnosis and everything and I think that if it did not collapse until now it is pretty strong...The only thing that we have, its conflicts and arguments about upbringing. These are the only reasons."	

Category	Examples/Exerts	Units of Meaning
Relationship and diagnosis	FC9 “I think both. I can’t tell that it was specifically autism that changed our… It made the relationship stronger in one area. Some division happened in some areas. I think it made us a little more apart...It did a little bit, but not directly. It is difficult to understand that I cannot communicate with my son as well as she can. And automatically I get upset the she tries to have the same expectations [laughs] for herself and me. I think she has a God’s gift with communicating with children, she has no specific education, she just feels how she needs to talk to them, what she can do, and I don’t have this.”	
	MC10 “Overall I would say that we got to know each other much better going through this challenge, because this is a challenge, I think that the relationship got better. In general, life virtues and life changed... I think that it changed, changed for the better maybe, just because we had to go through so much together, the relationship became more open, stronger, of course there are hard moments, very hard, than I start to doubt if we can persevere all of this.”	
	FC10 “Most likely it makes our relationship stronger. It didn’t make our life, somehow, easier, but... Me together perhaps, our bond with wife, it made it stronger...Parents perhaps don’t withstand the tension and divorce. It often happens, with families with these kids... I personally, never had these kind of thoughts that we should break up. I would say that the opposite, it makes us stronger and it did. This stronger immunity for these kind of problems.”	
	MC3 “At that moment. It is not like that we sit down together in the evening and star to lecture each other, that I told you this today, that you did it wrong and so on... No, we figure it out among ourselves exactly that moment, how and what. Oh he will tell me now. I already did that... We learned how. We figure it out in healthy manner. Sometimes we criticize each other well. Surely...but that just helps with our relationship. When children go to sleep, then there is time for parents. But this some kind of free time, to go somewhere and be together, it is less of that, but it exists.”	
Coping strategies for marital relationship	FC3 “This last year and a half, when we know this diagnosis, is like. These kind of going out together to the cinema, or to go somewhere. You see, it is difficult, because there is one thing, my parents do not look after him, not really…This lack of time. Because when, if son is at the day centre, it would be possible during that time. But during that time, I am working.”	22
	MC6 “I mean, sometimes it happens that we do not agree on something, but we have agreed on this strategy between ourselves, that if you feel that you are wrong, then you	

Category	Examples/Exerts	Units of Meaning
Coping strategies for marital relationship	descend and in that sense that who has said it first... Maybe sometimes you don't wish to do so, but you accept, that it will be like father said, or like mother said. So well, well we are trying to stick to this united kind of, united principle."	
	FC7 "How did we manage to stay a strong couple? Probably because we fit each other and we like each other. That daily routine does not have any power that two people met and live together, we agree on a lot things and we make sure we spent time together."	
	MC7 "Sometimes it happens that it looks for me, that what I do is certainly right, and for him not. Then we may have a discussion about that, but that this would weaken our relationship, no. Sometimes you don't want to admit that something is wrong. But that is a normal discussion...It always strengthens that you can spend more time together. And it weakens when you are surrounded by kids for weeks, or you already are collapsing exhausted to sleep and don't have time to look in the eyes, talk something else than children and dinner. That's a fact...Well I tell you, probably I will repeat myself. But these chats most likely, telling out your emotions and everything strengthens, that he listens to you, hears you and tries to understand you. Doesn't leave it like, - 'Oh, what are you talking right here is wrong'."	
	MC9 "We try to talk, to analyse, understand… Until we make it and we find a compromise."	
	MC10 "And really my husband helps very much and it was good that sometimes we weren't able to reach an agreement, this means that there were things that we had to think through both of us and then try to change the situation. So there, I tell you there are moments that pass, if we talk openly about it, this is how it is. The fear is not there."	
	FC10 "Do we agree between ourselves? I don't know if there are families, where both sides would agree. Where parents would totally agree about…Or their views towards child upbringing would be totally same. I, to be honest, don't believe that there are parents like that. That's why we...we talk, somehow agree. But anyways there are no major differences. "	
	FC2 "So again…We don't see each other for twelve hours. Subtract the time we sleep. We are left four hours per day, so... Which we also need to give to mode of life, to do something... We have very little time…and that what makes it difficult, we do not spend time just relaxing together…"	
	FC8 "You have to spend some time without children. Sometimes we take the kids to our parents for the weekend, we spend some time in the same city, relax somewhere without the kids."	

Category	Examples/Exerts	Units of Meaning
Coping strategies for marital relationship	FC4 “Not often, we try not to when the kids are around, but there is constant nagging, I get exhausted. You work six days a week and you see there is no understanding, she is always like ‘me me me, I also used to work’. So what? One thing we get older; we don’t have that much energy. When I was younger I also could work more, maybe even seven days, but not anymore…”	
	MC5 “And we have such thing like holiday, for only two of us. Every year we are going on a vacation, and we tell to our children, for example, for the older daughter, that it is parent’s vacation... The same like we used to be interested in something, we are still interested now. The routine has not eaten us. Not... our relationship...The most important thing is love, agreeing with the other, communication with your spouse, because you cannot leave everything to one person, and you must support at least morally, to agree and trust, because there are so many things you will have to do together. I don’t know what else to wish, that all of them would look in the same direction.”	
	FC1 “Friends well when you meet them or interact with them, you can feel the support. They don’t judge you because you are different. Of course, the child is like that, similar to others, and I don’t know how to call it – not judging. So you interact like you have before, nothing changed.”	
Friendships and friend support	MC3 “We don’t hide, we share, we meet. Our friends are wonderful and our child is greeting them very well. We are truly having this warm and close relationship with our friends...Perhaps they saw it from our behaviour, that the least we need is a pity. I guess, well... People want... people want to really have a compassion, or to comfort and the rest... But... When you tell them, in a certain tone, that everything is fine and we will manage it all... then... these, friends, they will always know what to really say. I think. And apparently we have very good friends…”	42
	FC3 “Very strong somehow, they have accepted it. This one colleague, who lives nearby. One time I left him for an hour with son, because I needed to bring my wife back, we come back, he has him on his shoulders, son is…son is red from laughter, and friend is also tired. They were fooling around, running, kicking ball, and, and…Shortly, everything is fine.”	
	MC4 “I read and told all my friends, and they would call me if they heard anything. Did you see, they talked about autism in ‘Good morning’ [TV show]. I told them yes, I did, and then again my friends supported me, and were all happy when he said his first, his two more words…No, even got stronger. Nothing changed.”	

Category	Examples/Exerts	Units of Meaning
Friendships and friend support	MC5 “Now... I don’t even think about that, is it support or not... Well, it’s normal... There was never a repulse…In my life it has not changed. I would say, there are even more now. How to say... Maybe...About those friends... It’s not more or less of them now, comparing with past. I think it’s maybe only me who is communicating less now...Well yes, from neighbours. They look after children. Last year there was a situation when we had...Me and a husband had...We didn’t have where to leave children and we had to go to the wedding. And neighbours took them and let them stay overnight. No problems. Looking at these children... I would say, this is the most needed support.”	
	MC6 “Practically almost all of closest friends know about it. All of them know. Everyone is reacting normally, what can I say, nobody says like, what is this? Nothing similar like that. We are going on vacation all together, and it is clear to everyone, how we, what we can do and what we cannot do, and somehow everyone accept it normally. I mean there are no, some kind of exclusion."	
	MC7 “In the beginning I didn’t share it at work. Later I did... Everyone was very sorry. <...> I said it because at that moment we were constantly in the hospitals, so that I wouldn’t be there. Everything is fine, no problem. I didn’t receive from no one that: ‘Nightmare, I won’t be friends with you anymore.’ Really. Every person was showing their compassion as they could...it was like that. I, myself, not the one who would share a lot or amplify with bunch of friends. I am more to myself I live through. Friends were…they would come, they would try to react normally, without emphasizing that.”	
	FC7 “well yes, but it was normal reaction, normal compassion and care for the child and that is it. It was not some sort of dissuasive.”	
	MC8 “So because of that I really… If I didn’t have it, maybe it would be harder for myself to survive all of this, but when you have these friends, who supports us…everything does not seem so bad.”	
	FC8 “the friends we have are okay, the neighbours I don’t know, the ones we had a relationship, it stayed the same. If you meet someone outside when you leave for a walk with the kids, you talk a little, everything seems fine, and I haven’t noticed anything different...As much as we asked to help, we receive some help. We asked to look after her for a half an hour if really need to go somewhere, and we ask neighbour, and she comes to us or we take the child there.”	
	MC10 “communication with friends also, I felt supported by my friends, I would say morally everyone really really supported and never rejected in my friend circle, just like we	

Category	Examples/Exerts	Units of Meaning
Friendships and friend support	communicated before, we communicated after. And our child they accept the way he is, they are grown up people."	
	FC10 "Anyways, mostly we are in the companies of people or at places where everyone is already knowing us and everyone know what kind of child, he is. In the circle of our friends, with this, thank God, everything is great. Nobody even had a thought not to invite us, because of our special situation, special kid. Everything is really good. So... Friends accepted it normally, it wasn't like someone would turn their backs on us. I also did not hear people say: 'well I won't invite them, because they are only trouble'. There is nothing like that. Everything is fine. There is sometimes children celebrations, so we all go together."	
	MC9 "From... I have practically left with no friends of mine. Only same children raising mothers. They have become real, real friends I could say, because for my friends it was hard to comprehend that I cannot do things."	
	FC9 "Since we cannot really leave the kids and the circle of friends got smaller, we live by a structure. It is difficult for others to understand this, you would have to arrange visits or meetings a lot earlier and so on. We really limit ourselves in such situations. Our kids don't really like big companies and we decided to avoid them. If there is a bigger company we try to stay there shortly or to avoid them in total."	
	FC2 "Well again, similarly. I can describe them the same, I tell you…well…There are not too many of them, how to say…This circle of friends so that we could choose from ten or twenty, to whom we should go today, as guests. But there are few friends, who know our situation. Again, they help they support, they give their time with nothing in return, and, I tell you, and sometimes contributes financially, when there is a need. We cannot complain now."	
Relatives and support	FC2 "And support, again…Which closest ones? Closest ones, so like sister, I have said, she really didn't refuse to give her time. So it is already a big support."	88
	MC4 "my sister would find everything she doesn't know in the internet, she sends to me, all sheets… And she printed, and about the kindergarten, because she worked in education, and she tried and learnt everything… A lot of information for me she would send. And she even knows those in education… She looked for everything and told me, and it was easier for me to accept. My brother was also surprised when we told him, that it is a normal child, walking… He thought that autism was like Down syndrome. And this is a nice child, what are you imagining. But I am like that I always tell everyone what good happened."	

Category	Examples/Exerts	Units of Meaning
Relatives and support	MC5 “Well, there is not a lot of support. Sometimes she would ask something, and talk about some kind of pity. I don’t know... I can’t describe the relationship. ‘Oh God, how is he doing? Probably difficult, right? Ok, I’ll say ‘sorry’ to you.’ Then I just want to ask, ‘So why do you even call me...’My husband’s sister the same… Also...How to say... I don’t feel rejected, but also I don’t feel big support and compassion as well. She is more like neutral. Maybe, I would say, she is the type of person, who does not know how to reveal feelings.”	
	FC5 “Parents of my wife accepted this very well, because she has a very understanding mother, which immediately showed support, she did not exclude the child, she asked all kinds of supportive questions. The other kids in our circle of relatives accepted him with no problems.”	
	MC7 “Again this emotional intelligence, maybe it’s a thing of generations, or else. It is not as developed as you would want. But they helped as they could, and all the time politely. To physically be with him they didn’t want, didn’t show any interest, and didn’t wish to. Especially when he is bigger now, they say: ‘we don’t know how, we don’t know’, and that‘s it.”	
	FC7 “Anyways, wife’s parents were great help and financial support, from my side it was the same with all those cares and everything that all those things brought ABA and all that family support and we can really be happy about it. I think, the support and the shock was at the same time, I was not like that at one moment they would say – excuse me now I am in shock so you will have to wait, no they provided encouragement and help any ways possible, there were trials like dolphin therapy suggested or even other things that were more or less effective.”	
	MC9 “My mother looks after kids. At seven o ‘clock we go to quiz night together. Two of us, simply, simply, simply looked like oversight. Looked like constant justification, oversight, everything is alright, some sort of closing eyes, and kind of everything he does he does it wonderfully. Grandmothers and grandfather seemed not to notice anything wrong. Also just as he would become irritated they would pay attention to something else, they would go around the conflict, around the stress, around everything. Everything was left for me. You learn with him, you read with him, you do with him, it’s for you. We have to spoil him. Grandparents were like, he is most precious we have to spoil him.”	
	FC9 “*interviewer*: ‘Let’s go to the last part – support. How did your relatives react do the diagnosis? Your parents, your wife’s parents, if you have any sisters or brothers? *FC9:* Probably the best word would be disappointment - the child himself was disappointed	

Category	Examples/Exerts	Units of Meaning
Relatives and support	that we got this unlucky. It does impair the social life, all these rules and structure, and you cannot give as much time as in a 'normal' relationship…"	
	MC10 "At first I saw that parents also really really worry and I was maybe even a little ashamed to tell relatives, that something is wrong and to tell my friends or show. I saw that they are not taking it easily and then I saw that with time they also read information and asked us questions and accepted it the way it was. Once again communication, we talked about this. Maybe this helped the most that we kept communicating, I tried to inform everyone about the situation and how everything is and relatives also read, accepted, asked questions. I think somehow they managed to accept this, I don't know if they have fully accepted it or not, but enough for us to go on holidays together, be together and enjoy being together."	
	FC10 "I would say it like that. When we are together somewhere for vacation, we were, in August, with my whole family together. With my parents, sister and her kids. There, again, was this, but they know less about all of this. They know less, what to do with it. This... Is why they always help somehow different? They say: 'I will do this thing - if you do this- and you go to be with him'. Or takes him outside. All kinds of situations. Usually they ask us, what to do, in order to help him."	
	MC8 "We really stand for each other. Parents help a lot too. When there is a need to go somewhere, I leave my children with my parents. So like that...Finally, my mother doesn't work. She goes grocery shopping. All the time. But when she goes to shop, she calls me and asks if there is something she should bring from the store? She buys it, brings it to my husband to his workplace, husband pays off and brings it home. So she is there to help."	
	FC8 "So maybe in a very manly way, nobody really went very deeply to this, they all love child, try to spoil her and give her attention, I would say everything is normal. It was stressful for everyone, because she is the only one like that, it was stressful, but nobody really asked many question or something, nobody blamed us, nothing like that. At least I don't know."	
	FC1 "Right, so my mother is my biggest help and practically when it comes to child's education and taking him everywhere and looking after him… This is a huge advantage. Maybe we spoil him, give him everything. But really. Really there was understanding and support everywhere. Everywhere in the family, they were friendly. It was a big support and understanding."	

Appendix D. An Example of Extracts from Focus Groups Discussion – Medical Professional's

GP versus Specialists

1. Knowledge about autism

G1: Autism is a very broad concept, with many symptoms and I don't think I can clearly tell you, but they have problems in their everyday tasks, have slower development. These are the main things.

G2: Autism is a broad spectrum developmental disorder that manifests very individually, what can be to one, might not fit someone else at all.

1.1 *Autism is a spectrum*

G3: It can be mild, medium and severe in degrees. My boy has the mild degree and he gets the disability.

G4: because there is more than a hundred characteristics of autism and that means each person with autism is individual, with its own features, so it is difficult to talk specifically…

1.2 *Autism – Behavioural issue*

G6: He is interested in numbers, in the phone, he can turn on the phone by himself but there is not communication at all, no commands, he needs to be held constantly so he wouldn't run away. He really is autistic, while the Asperger syndrome is like, there are smart kids, and they just have problems with communication and socialisation.

G2: stereotypical movements, behaviour… The behaviour can be very different in each case, but it is repetitive.

G3: Autism manifests in socialising and behavioural deficiencies.

G4: The same... Behavioural problems,

G5: When he arrived at two it was difficult to understand, he was uncontrollable, you had to hold him down really tightly, he was throwing everything around and doesn't interest in anything.

G6: no commands, he needs to be held constantly so he wouldn't run away. Just behavioural problems

G1: Lack of independence because he has additionally severe retardation, so it is really difficult.

A (E): impair the formation of individuality and independence, and the occupational sensory integration impairment...

1.3 *Autism – communication challenges*

G1: there are three kids I know in my district, and they are hyperactive, have language deficiencies,

G2: So I tell what I know from literature, from my studies, there are so many symptoms and I think the main ones are lack of social skills, the lack of communication

G4: as colleagues mentioned - communication, sometimes they don't write autism the same everywhere…

G5: he has no verbal or nonverbal response, he doesn't react to anything, he reacts only to his own emotion, and he doesn't really hear what you are telling him, he still does whatever he thinks he needs to.

G7: my child does not communicate, and had no interests.

G3: She has no language; she goes to a special school, to the pool that she really likes, mostly nothing else.

G6: now he is not speaking, well he can speak if something interests him, for example you take out and he says a phone. He can say difficult words, but he doesn't speak for communication.

G5: I would see something but I could not trace back how much he spoke and I don't see him that often, but the moms really noticed very precisely, that he changed, started talking less, then stopped talking at all and now he speaks worse than before, and then G4 (disagrees): They don't speak until a year… G1: He practically couldn't speak until one year... G5: He didn't see, he needed some more attention until he was one year old… G4: Everything [autistic characteristics] comes out after one year… G7: Yes, exactly at this age… G5: He can think at six months… G6: but this is more like…rare cases because that is not language that you pay attention to but to actually the body language of the child [refers to not looking to the eyes]

D(P): Autism, maybe I will not be very medical, I will use my own words. I think it is a disorder that manifests with communication impairments, behavioural difficulties,

L(P): I agree with D(P), this is a disorder that manifests with behavioural problems and

A(P) And of course a specific behaviour, thinking features.

R(K): I will agree with my colleagues and something from the physical, the movement side is that the behavioural or communication difficulties cause difficulties in movement, they have troubles learning specific tasks, because they cannot concentrate, and automatically they have difficulties with doing a task or planning a movement, what concerns mostly coordination is some exercises.

A(E): I can describe things from the occupation therapy view, what I see the most, are the behavioural problems that impair the formation of individuality and independence, and the occupational sensory integration impairment, and an autistic person has difficulties in everyday tasks, in school, in leisure time, he also has motor problems: forming movement means all kinds of problems, during holidays or playing...

A(L): It has the main features that appear very individually, and this is a different way to view the world. These impairments can be somehow a little bit compensated when using certain strategies.

D(P) I think it is a disorder that manifests with communication impairments, mostly it is a combination or interaction difficulties, accepting other people, lack of empathy emotionally.

L(P): communication, also stereotypical play, but mostly communication is the most difficult, both verbal and nonverbal.

D(S): Also, the lack of social skills, you need to work more on social, communication, interaction

A (P): I agree with my colleagues, maybe just add… They have difficulties to express themselves verbally and to understand other's language, to identify emotions, to recognise them in gazes, a difficulty to show emotions themselves, so that they would be understood.

V: A complex developmental disorder, which has language and communication impairments,

V: but when you take the differences into account you need to flexible, to look at the child as an individual.

2. Challenges at work

G7: Yes, but you see the child's face, eyes, if he understands… I will tell you in a non-medical term, you see if he is normal, he begins then to suddenly talk and if you see…

G4: Until three years... G7: And if his behaviour and everything else and you see that... G6: How he plays, understands... things, his surroundings G7: Yes

G3: How he hears... G4: When you look into the eyes, the tell everything. G3: if it only language it means nothing... you need to observe his behaviour

G5: You know, when there are kids who come into my office and run to the sink to wash hands, I know there is something wrong…

G2: Washing hands, and it turns out to be true. They all go to the sink and I noticed that kids with autism, little kids they go, others don't, they go to wash their hands immediately.

Interviewer: okay, what are the most difficult aspects when interacting with a child with autism, from your perspective and experience?

G6: In my case, I cannot interact at all with them…

G7: You cannot find the common ground sometimes…

G1: There is no contact, and with the ones who have Asperger's syndrome, they have a very specific communication. They are deep in their thoughts, and while they don't finish, if

you interrupt, he will begin where you stopped him, and it is very difficult to talk. He is interested what is specific and really interest, and he doesn't hear the rest.

G7: You have to use short sentences, not to talk broadly, and there is no contact with the most difficult ones.

G4: Yes, no contact, no communication

G7: You have to use short sentences, not to talk broadly, and there is no contact with the most difficult ones.

G7: how the appointment will go, and you talk very specific things and don't understand all this… G6: It is almost like commands, not to give them a choice… G7: Yes... G6: NO, these "Do you want it like that…" G7: Yes, yes, briefly and clearly. They probably like order. Maybe the parents are just raising them like that…

G3: well, he is communicative, but moves a lot, takes things, look at my closet, runs around, but responds when you call him. He speaks poorly, goes to speech therapists, there are no problems in the communication…

G5: And when we talk about him he is interested only in what concerns him, and you have to speak about what he wants. He doesn't talk much, only uses some words, but he is six now. He has more problems... like he still uses diapers

G2: He is friendly with me, I can to talk him if there are no vaccines, for him. He can press my hand, he has his ritual, when he comes he needs to shake my hand, sit on my lap, but he is friendly.

G1: also, these children have fear to come to surgery, and it is a challenge for them

G7: If it is very difficult, sometimes there are parents without the kids, and if we saw him/her any time before, we know much and then the parents tell us, so we just write down and that's all, you don't have to drag the child, if he/she is scared, and you just need to measure, once a year. We sometimes have to do this, but when you just need a dispatch you don't have to traumatise the child. No way.

G6: Yeah, and you have to accept that it will be unusual visit. I just don't react when my child comes, it is little I can do. These are problems for parents, they have to control.

2.1. ASD child diagnosis

G3: yeah until one stops, or breaks something (laughs)

G4: And my girl which is four or five now, she is very musical, with musical instruments, she walks in to the surgery and is always playing… She sings and dances calmly… So parents know what to give her to distract her

G5: No, none at all, you talk with the father or the mother. And the child is playing, but he is alone. The others come and you can see they are prepared and everything is explained, how the appointment will go, and you talk very specific things and don't understand all this…

G1: Not everyone who works with kids… In my practice mostly are brave, but for example, some are encouraged and explained what the doctor does, like we talked at home, we played, we looked at everything, what the doctor does, so they know, and when mine comes, he says: the doctor will listen, will talk, will look. So, in general he repeats me everything what we do. Or you do something and then he says what you just did.

G3: I have child who is not yet diagnosed. So, his mother keeps doing something by the sink, she says: one, two, three, you need to close the tap. And then the child one, two, three, he knows the command, and this is how the mother tries to work with him...

G6: The parents are apologising and I think sometimes act too strictly with the child, but maybe there is no other way…

G7: There is one that you talk with parents and the child is running around they just do nothing while others come and you can see they are prepared and everything is explained, how the appointment will go, and you talk very specific things and don't understand all this…

G7: Yes, when he is bigger, but when the child is preschool we send them wherever we can. The parents are taking care of the child if it is a normal family… Interviewer: What do you mean a normal family? G7: Takes care, is normal, understands that there is something going on with their child… And if you advise them, tell them and they agree, then yes.

G6: Yes, the parents cooperate, they understand that this is their child… G4: They don't think that the medical specialist...will come and fix everything…

G1: Other kids with autism have great parents, one of them I think will deal with everything and maybe lose the diagnosis.

G5: he is a difficult child but parents are working a lot with him, he is quite friendly.

2.2 Parents reactions in the beginning of ASD diagnosis

G4: Of course, the first step is that they always deny, that no, this is not happening to their child…

G6: I have a girl with Asperger's syndrome and the mother knows that, but she doesn't go to psychiatrists here, she only goes to private practices, she just needs helps because she doesn't want this diagnosis to be written down, she understands but doesn't want the disability,

G5: Yes, most of them does not want the label, they are resisting the disability as it is something that forces parents to come into terms that their child will always be different

G7: yes, doesn't want the diagnosis and mother tries that the child would go to normal school, even if he fails. It is an intelligent and educated family, but they think that after the diagnosis the child will be written off, and without the diagnosis they can make the child normal and maybe even get the driver's licence…be integrated

G1: Or it is very different, two or three years ago. All mothers demanded to be sent and examined for autism, you know, it was hyper-popular. We have these trends that if someone heard about something new, everyone needs to be examined, and the one of the moms that I sent her child to examine, she demanded and I really sent them, now she does not want the diagnosis, asks how to lose it, there are these things…

2.3 What can I help with?

G4: From us they get a referral for the psychiatrist, psychologist. G7: or Psychological pedagogue services

G7: Yes, yes. That is all. It is not our specialty, we just advise, suggest, send, and talk…

G4: also we don't have information on therapies or treatments. G5: yes we don't know what is available in private sector even...no info (GP's agrees): No, no, not really

G4: The parents find everything themselves, there are…the ones that know more G7: Yes.

G3: There are all kinds of schools, therapies, and specialised kindergartens like „XC"... G7: Yes, but this is not the case where you give a tablet and they get better? Right? G6: That is where we end…our services, it is not our department anymore, we help diagnose that is it, and the rest goes to parents G4: Services are totally different… and they are responsible to helping the parents after not us...

G7: Yes, when he is bigger, but when the child is preschool we send them wherever we can. The parents are taking care of the child if it is a normal family

G3: If we needed something the head of the department could tell us where to ask, why not, but otherwise we know where the psychiatrist, the child development centre, the parents come and we give them the dispatch, or the parents know themselves…

G4: No, because of vitamin D, there is a trend right now and everyone wants to get tested for Vitamin D, and at that time autism was the trend. We have trends in medicine as well… (GP'S agree with the statement) EVERYONE: yes yes yes.

G4: Mostly parents themselves… they fin d things G7: They themselves, so what can we do… we do like that…

A(E): Sometimes you bring all these emotions home and this for a few days until the people leave the hospital, and you forget… Sometimes these problems with the parents are solved by asking if they are okay, did they take this information…

D(P): I think this negative parents' reaction is normal, and everyone would be angry who heard this diagnosis. So when I get to this vicious circle, I think that maybe I could be doing something wrong

V: Maybe I would do the sake, I cannot say, I did not have this experience with my families or my own health, maybe I would go to get more opinions. And then you connect all the dots and the person opens his eyes and sees the true situation, and then they get a very different view…

A(L): the parents really need a lot of time naturally to accept this child with all the problems, the way he is. I think that only when parents accept this problem they can move on. To have the first step of education they need to know and accept.

A(P): I always try to begin with noticing something positive, what the child can do. And really almost every child has a bigger or smaller strong side. So I start with the positive thing, and only then I mentioned what seems to be the problems, and the parents don't close down so much, at least from my experience. If you start mentioning the problems from the very beginning, you don't even see the primary position of the parents, and then they withdraw from you and don't hear you anymore. The process becomes a lot more difficult.

A(P) Right now I constantly see that parents have their own understanding, some strange information that autism is the worst thing that can happen to their child. All other disorders become less scary, and they hope that there would be anything else. You really try to find proof that maybe we were wrong. The approach for giving information, for making the parents accept the diagnosis is very individual for all the parents, and you need to provide this information a little differently for the parents. At least I have not yet found a best and single way to tell them.

V: I work for more than twenty years but it still is extremely different to be the one who tells the bad news, because all developmental disorders are like a curse in Lithuania. Either it is autism or cerebral palsy or any other condition, there is not organized help or support for the parents of children like that. And really telling the diagnosis is extremely difficult. The diagnosis itself is very difficult to take, and after that parents as what they need to do. And there is nothing you can say or offer, on the other side, the public speaking about these developmental disorders, including autism, should help. Of course the press likes to give everything with a taste of scandal, with a negative element. On the other note, the indifference of government to these children and their families makes the diagnosis a lot more difficult to the person who has to tell it and to the one who hears it.

A(E): Maybe from my side, I don't tell the diagnosis to the parents. But they find out information from other specialists, and they always try to check if it is right (AL and R(K) agrees). You work so many years, is it really like that? Of course not a hundred percent like that, the ones who encounter this for the first time are usually in denial, thinking that maybe someone else will show some doubt, that this might not be true... This is what I see.

AL: I will second A(E) here. Parents come to me after they talk to the psychologist, so usually they have already heard the primary diagnosis. But they really want to know the prognosis as soon as possible, they want to know what will happen, if the child will start talking, will it do something, can it go to a regular school, and usually it is too early to say anything. So from the beginning I try to tell them to begin and learn to listen, to hear, to react, and then you will be able to see his abilities. So it is very hard because they need the answers immediately, which are impossible to give, in the early stage of the diagnosis it is very difficult to withstand those constant questions: "So he learnt how to show this… Will he have to learn everything like that, will he talk now if he started doing this?" A lot of questioning, and it is normal, because they are scared about the child's future.

A(P): I could just second AL that parents really ask about this very often, and what you do give is the information that they need to see how the child will do later on, how he will accept the information, and that usually in the very beginning you cannot give any prognosis (ALL AGREE). But probably the question that ninety percent of parents have is "What will be next?", "What can we do?" and of course – school. Parents usually begin to think about this early on, they begin to look. The ones I meet mostly want smaller classes, it doesn't matter how much the child with achieve they need a small class, and maybe if they live in the city they are looking for something in the outskirts, to integrate better.

R(K): From my perspective I will second AL, the parents are really glad that their children are moving, that walking and moving is their stronger side, but sometimes, as AL mentioned, they check the information they got from other specialists.

V: Of course the child is never alone, it always has parents, and the parent's view, their understanding, and acceptance is a huge part.

A(P) They need to do it, otherwise our help is very conditional, and for the most part of children we meet, when talking about autism, there are still some behaviours from the parents that impede the progress of the children. The whole family needs to change their perspective and change behaviours, sometimes even the lifestyle.

R: Mhm, got it. You mentioned there are situations with parents. Let's go back a little. Do you get complicated parents? That are difficult? And what do you do then, how do you work with them? D(P): of course we have! EVERYONE LAUGHS

V: We send them to the psychologist... (Everyone chuckles) D(S): There is also some apathy, indifference. Parents don't want to work with their kids. They simply want to follow

tasks. A(L): the view is that specialists have to do everything. D(S): Yes, really. I came here to get this... V: Cure me... D(S): Yes, and actually that is very hurtful... R(K) Yes for example, you stand there, work, and the parent stands in the corner and doesn't even throw the ball or catch, because you have to do it, the parents don't want to interact, I need to do everything. V: there is still that old Soviet mentally I come to this medical institution so cure me

A(E): I think that any negative reaction from the parents causes problems for the specialist. You cannot get used to those negative reactions and react in the same way our sessions end and the anger, the conflict is not resolved. So you wait for the next meeting and think how it will go. Sometimes it happens that the parents just needed to vent and you got in the way D(P): I think this negative parents' reaction is normal, and everyone would be angry who heard this diagnosis. L(P) but what about when they come second time? That negativity of the parents when you tell them if they come for a second time with a child with a speech impairment, for autism… You ask the child and the mother replies: "he doesn't speak", and I ask: So wait, you are here again so you probably went to the speech therapist and they taught you alternative communication, do you use it at home?. They reply: "No, they don't use it in the kindergarten and we don't either". "But wait, you live the child, and how does he tell you what he wants?" "He doesn't tell what he wants anyway". The parents don't get that part, the treatment, developmental disorder needs work so they just get upset and create a conflict instead of investing in helping the children

A(L): Of course there is, and you mostly remember the best or the worst examples. Of course there are parents you work with us and the child improvement is stunning when they come here. And there are always the ones who try to distance themselves, to leave everything to the hospital, the kindergarten, if the kindergarten is not doing this, then the parents are not doing that as well…

D(S): And they don't listen to me, the only phrase such parents use who don't want to work with the kids...

A(P): And as A(L): mentioned, there are many cases when you are surprised that after the three months (all agrees) the child made this much progress, and you realize the parents really did their job, or there are moms that you stay in touch, write them how are they doing. Sometimes they send you something, once I got a video recording how a child, who was diagnosed early with autism, goes to a dance club and dances in a competition. It is very nice, because when he came, he had minimal social skills, he did not accept other kids, nobody really, and this is where they got to… Of course, there were a lot of work put into this from the parents.

3. Society views on ASD

G6: My child cannot go to school not because he is unable to learn, but because other kids are disturbing him…

G7: she only goes to private practices, she just needs helps because she doesn't want this diagnosis to be written down, she understands but doesn't want the disability, doesn't want the diagnosis and she tries that the child went to normal school, even if she fails. It is an intelligent and educated family, but they think that after the diagnosis the child will be written off, and without the diagnosis they can make the child normal and maybe even get the driver's licence…

G1: But these things hurt, they read something somewhere, but I think that the majority of society does not… Is not even interested in autism unless they have a child with a problem… Then they start looking for information. G7: Or in the family. Otherwise, why should they be interested?

G2: I think they don't know autism, they think it's because of the vaccines… G3: Most of the people don't know… The ones who do say this is the cause of vaccines.

Interviewer: Vaccines, what do you mean...? G7: They don't vaccinate the kids because they think it can cause autism… Interviewer: the children parents? G7: Yes... G4: In the society in general, not only the parents...

G1: Some time ago it was told that the composition of MMR might have some mercury and that is how autism is caused, so who gets vaccinated, those get autism. Some still think about this because of the stupid article from twenty years ago…

G1: The article of course, but… G7: It is renewed once in a while… people come with these ideas...

G7: yes, in general yes, and the society is like sheep… G6: especially after TV shows we get many questions… R: What shows? G6: Well against the vaccines, when there are some discussions, some are for and others are against, then there are many questions and they don't want to be vaccinated… and you have to challenge that... Interviewer: is that in general population or... G6: yes, general society has these questions G1: So you work with them accordingly, you know what they mean, what they want, what to tell them, where to send them and so on… but the general society has these questions… or they tell themselves…they are experts and know best (makes everyone laugh)

G3: mhm, and parents who have children they look for a reason/cause and ask about vaccines, I can deny the information but they still do not accept G2: Nobody believes it, if they have this something in their heads, you cannot change it…

G1: So the ones who have firm opinion they do, but you can talk with them, a lot, and normally, you might not change their opinion, but really if you talk normally, with arguments, and you both tell your opinion, you suggest something to read something, you talk more and then you have the result, but there are stubborn people who would never will vaccinate, and you will not change their opinion no matter what they just cannot accept that their child is born like that, they need to attribute that to something outside to reduce the burden of uncertainty But these are just single people…

G5: There are times there is some regression after the vaccines, but I cannot explain anything here, they after the vaccines the child began speaking less than before, changed…

G7: What vaccine? MMR? G5: MMR. But it is not me who thought of this, it is the mom, then I would see something but I could not trace back how much he spoke and I don't see him that often, but the moms really noticed very precisely, that he changed, started talking less, then stopped talking at all and now he speaks worse than before, and then until a year I thought it was normal development, because everything seemed normal.

G3: I had this case, I was substituting a doctor and the mother brought a girl of six years to be vaccinated, she says I vaccinated her when she was three and she stopped talking, but she talked well before that, I am sorry, but we were so scared, and then little by little she started, and she didn't know what to do… I told her to wait for her doctor and talk, because I did not want to be responsible… G4: Sometimes there is some belief that you cannot change. It is better not to hurt the parents…they are already hurting a lot, I just let them believe it if it helps them move on....

G6: So, my patient with autism is seven, he arrived in the city when he was two. He came from Moscow; the child was not vaccinated because the mother was scared of vaccines because of autism… It is a great proof that vaccines have nothing to do with it…

D(S): I can say a thing I noticed not from the family, but from other people. There are rooms where more than one or two people live in, and these emotions that are expressed by the autistic person are called bad, this other person tells that the child is bad, and these kinds of remarks should not be said... He then acts exactly in the same way, because he knows he is bad and he doesn't… It looks like this is an ill-mannered child, that the mother is not working with him but just playing with the computer and doesn't spend time with the child.

D(P): And I think that the reaction from the strangers not only in this institution, but in the streets, in stores as well as I see it from the parents, is so negative. It is not motivating, but there are parents who stop trying, because what can you do, and this society's view has a really negative emotional aspect. I saw parents with a great emotional striving forward, support for one another, and for the child and one another.

A(L): Mostly they know the name. But they don't understand that what they know is only a tiny part of what autism really is, mostly they understand this wrong. For example, the kindergarten teacher informs that there will be an autistic child in the group. The first reaction it that the child will bite everyone, beat, without the teacher finishing the explanation. Maybe the child speak, is behaving well. But the primary reaction is of dark autism, the ugly autism. A big part is because of the same society or people who encounter autism. We have residents coming, right? I had to supervise two of them to the child development centre, and when I came back, they were the future children or adult psychiatrist, they say they don't know what autism is anymore when they saw these kids. They had a very different view, so the view of the doctors should be different as well as the knowledge. The same is with society. But now we are spreading the information more. Step by step.

V: I have a boy and my knowledge about autism grew together with him. I think he is fourteen now, and when he needed to go to school I wrote them a note, wrote down the

diagnosis and the mother was very resistant to this. I told her the teacher has to know, the child will be going to school, he needs help there, maybe she will sit him in the front desk and so on. And they found a school in the city, went to the first grade, and they talked to the teacher as well, and the teacher informed the parents… The pressure was too great for the child and the mom took him after a month or two. Then they went to another school with no notes, didn't tell anyone they are diagnosed with autism. She came to me and told the whole story, how they are learning successfully in the second grade already, and nobody knows, we work a lot, I help him do the homework, just like any other child. He goes to school but nobody knows about the diagnosis, and the teacher's attitude, behaviour and she was not the only one, he reflects the whole society's attitude… the ones who must know about children like that…

A(P): I think it is pretty negative. I see it from my practice. A teacher told the parents that there will be an autistic child in the class, and gave them the impression that they can change this. And the child did not even have the chance to come, the parents gathered signatures so that the child couldn't attend the preschool. (DS agrees).

R(K): I will agree to the colleagues, the attitude is really negative, everyone sees the negative side, like A(L) mentioned, the children are beating others…

D(S): The conditions are not made for the kids like that, they have thirty or twenty six kids in a group...There is one child who needs more attention, where are the rest twenty fie when you go out for a walk? There really are no conditions. No assistants and a few children, two or more... You cannot say this is only the attitude, there are no conditions...

D(P): It is not motivating, but there are parents who stop trying, because what can you do, and this society's view has a really negative emotional aspect

Interviewer: Negative shallow views about autism--> lead to form actions, biases towards autism in society and institutions-->leads parents of experiencing struggle and stress in having such a child

D(P): They contact the associations and the questions arise from the first diagnosis and they now there are almost no perspectives in Lithuania for a proper education, educational institution, proper teaching in schools. These this are really stressful for the parents, and automatically for the child as well, because they can feel it.

V: Last year a big part of our children started going to schools. And there were several articles in the press that LBS (name of the person) is opening schools in Kaunas, and I thought what a great chance. I can meet with her, talk, explain that we have a centre and we prepare the children, and then they can take them and work well, because they have a different view. They answered my call and asked to write an email, but they didn't respond to it. So it shows what our society is like, it doesn't matter how much you are in the press, it is about the whole view of our society.

V: I work for more than twenty years but it still is extremely different to be the one who tells the bad news, because all developmental disorders are like a curse in Lithuania. Either it is autism or cerebral palsy or any other condition, there is not organised help or support for the parents of children like that. And really telling the diagnosis is extremely difficult. The public speaking about these developmental disorders, including autism, should help. Of course the press likes to give everything with a taste of scandal, with a negative element. On the other note, the indifference of government to these children and their families makes the diagnosis a lot more difficult to the person who has to tell it and to the one who hears it.

V: Mhm, I think that I keep putting everything to one system, and the lack of structured help... But here I think it is very important that from the soviet times we are trying to cure everything. Autism is a disorder and we have this...

V: yes, and the whole system shows this is a disease, all rehabilitation programs are based on hospitalization, they create the view that here, we will got to a hospital, specialists will treat us, and me, as a parent, have nothing to do with this. I can use my phone during the time, because the specialists need to treat the child, and the negativity of the parents when you tell them if they come for a second time with a child with a speech impediment, for autism… You ask the child something and the mother replies: "he doesn't speak", and I ask: So wait, you are here again so you probably went to the speech therapist and they taught you alternative communication, do you use it at home? They reply: "No, they don't use it in the kindergarten and we don't either". "But wait, you live the child, and how does he tell you what he wants?" "He doesn't tell what he wants anyway". The parents don't get that part, the treatment, developmental disorder and life, they create a conflict. The parents think it is not their business, they can come and be hospitalizes, and when you try to say something different, they get defensive, that we do not prove the help their child needs. I tell them they

needs to read books, interact with him, to go and watch how the grass gets greener. “But this is not treatment; he needs to go the hospital”. And this is the wrong view which is very strong in Lithuania. Time needs to pass for this to change.

A(L): I want to continue A(P) thought and tell a very recent story from last week. We have children in the autism centre who need to go to school this year. The parents of a boy were choosing between a smaller class outside the city and a school in the city, because it is famous for tolerance, interpersonal understanding and a free admission for the child. They had to go there and spend three days in three lessons to meet the teacher. After the first lesson they got a call, the boy is speaking and well controlled, he just needed a small remark and he controlled his behaviour, he had no aggression or unacceptable behaviour, only some stereotypical movements, fluttering, and started to speak. But when you tell him to stop he is able to control and keep quite. But he was not accepted in the latter school and that the view of the school and the teacher are really important, how much the parents want the children to go to school, but they are not accepted and they have a lot of problems…

4. Training and Teaching

Interviewer: How did you learn, was there a definition what autism is? (Everyone): No, no, no. There were no results then...

G1: Psychiatric disorders where not there, even autism

G7: No, there were these, but as all psychiatric diseases, they never underlined autism, everything was lumped together

G1: There was no diagnosis as such, there were main psychiatric disorders with main symptoms, like socialisation…

G7: yes, like that... agrees with G1 G4: So autism only now, recently, I think, for two years…

G1: No, maybe ten years... G4: No, that it is diagnosed… Well…maybe it is a recent diagnosis before it was infantile schizophrenia I think...

G1: Yes, no maybe it is taught now, but 40 years ago it was not a case...

4.1 Training received

G2: (the youngest GP) There was, but during the residency in the child psychiatric division there was nothing, but in the studies, maybe in the fourth year, there were really classes in the child development centre. They didn’t let us to the rooms, they didn’t show us anything, and it was just theoretical. There was not observation of their behaviour, just theory.

G3: And nobody really cares, it is very difficult to go to conferences, they don’t let us out from work, and the conferences are always during working days, and of course, you do it as much as you can do, as much as you want to, and as much as training, but nothing else…

Interviewer: Yes, I understand. And then you mentioned you need to organise something, I am talking about the support you get from work, do you feel supported, information from colleagues, from the institution… G7: If you need to…you seek it G4: We decide everything ourselves…

G1: No, since we have this diagnosis, we write it. CF (another doctor) told us seven years ago, we went to training, we listen to the classes and as I said, this is a hardly covered topic, because there is more than a hundred characteristics of autism and that means each person with autism is individual, with its own features, so it is difficult to talk specifically…

G2: Of course, the kids are there with their parents and they don’t want to, but it was not like we saw many cases when graduating…

Interviewer: Mhm, what about conferences, do you attend them? Trainings? G7: Very little with psychiatry.

G6: There are no programs... Nobody cares...

G4: well no now they give us a procedure, instructions, and norms of development we have, and we know where to send further...

G6: There is the development, the normal development, if it begins from a baby if you look at the development like that, and for autism…

G1: Autism, so we have no specific methods, what to do, and we do everything according to ourselves.

G1: In our clinic, there is ECDC... G6 & G7: Early... Early child development corrections... G2: Yes... To get there you need to wait for two or three months, and

the child growing, you understand, he/she is changing, and they need help right there and then… Massages and everything…

A(L): During my education I had a month or a month and a half course about autism, but something very unclear with a very old professor and in my view autism was something that nobody would ever look at, respond to you, nobody will understand, just a very dark view in general. Then after school I taught a boy through a special program and he was my first encounter with autism. I got a good beating, because he was big and started to be taught only very late, and I could not understand his behaviour, he was so interesting, the reaction, how he sees everything, why he does what he does, a practical encounter was stronger than the university gives you. The surface was touched of what to do with kids like that and how to teach them.

L(P): Since me and A(P) graduated from the same school I had a very similar experience. There was one class where they explained about autism in very general terms, to understand the prevalence, probably causes or that was all.

D(P): I probably graduated the first here, I have never heard anything about autism, we learnt a lot of adult psychiatry and there was not even one word about children. I encountered them here for the first time, to learn about them, read how to help them, simply learnt everything myself while working here.

V: I didn't hear about this during my university classes, I worked in the neurologist clinics and had consults with children, I have never heard about the diagnosis. Here we started having children, but I think you don't need my longer experience here. We work with Master degree students, occupational therapists, physical therapists and psychologists and really we can put one or two lessons about this topic. Nobody really prepares special child occupational therapist, child physical therapists or child speech therapists or child psychologists. The people who learn in the Master's degree get the general knowledge and then they come here… And if they learn specific tests or if there is an opportunity to go abroad and learn ADOS or something…

D(S): This diagnosis was not there at all… only through qualification course… I participate and learn.

4.2 Instruments available

A(L): The main thing is using those instruments and learning how to work with hose kids. When I came I came to work here I really had very little experience, but the daily encounters with the kids, learning, trying to understand, going somewhere to learn, to conferences, all these things help. Everything adds up from the tests that mostly psychologists use, we as speech therapists don't have specific instruments to evaluated autistic children. We rather use clinical observations, because in general we, speech therapists, don't have any adequate evaluation instruments in Lithuania. Everything goes to the everyday experience and the opportunities you get from the workplace.

A(P): I was lucky, because the institution had the main tests, „CARS" , „CHAT", and „ ADOS", and I could learn from the colleagues with more experience, and then practice. Do I feel strong? I think no, because I don't have that much experiences, secondly, you can always do something better and you continue to get better if you have this view. You cannot think you know everything. The biggest part of cases are very different, very individual…

A(E): I agree with A(P), that the best teachers were other colleagues, their experience, the information, our common discussions, you listen what they said, how they said it when you were too shy to ask. But of course, you need some basis that it really is as it is, of course it is individual, but you interpret everything with the knowledge you have, you use your experience, you can read some more, but you are never a hundred percent sure that it is exactly as you say. Sometimes your experience and the chosen methods don't work.

A(P): I will interfere, to be as sure as one can be we make the discussion like this week. We had a child and met with AL and A(E), the three of us, to talk about what we can see with the child, how it looks to us.

D(P): Without the teamwork nothing would happen, and we have this teamwork principle, we share information to get the best result.

A(L): Even more so that we see the kids a very limited time, during the activity, and you see very different things each time with a different specialist. Maybe you saw this or that, and you have doubts for the diagnosis, we ask another specialist, maybe they saw something

you didn't. One person cannot decide things like that, more so that there are no testing that could say a hundred percent.

A(P): I think we had only one or two lectures about autism. Not more. General ones that did allow us to get the full picture. We went to VB Street in the centre once, where we saw kids with this disorder and spent thirty minutes in a group of three people talking with a child with mild autism. I had only this experience in my studies. Really, nothing…

A(E): I even had less. (Everyone laughs)

4.3. Professional support

V: We have the diagnostic test, now we are not the only ones, but at the time we were the only ones in Lithuania. And if we have them, it is not a standard for Lithuania, we just bought them, we found the money, we found the money to translate them and use them. Now, when we have experience, we can use the effectively. One of the psychologists went through a learning course how to use the test and shared her experience. I want to say that what we do, we try do it professionally, because this is our goal, to provide quality services, but it is not a standard.

V: If we talk about the evaluation possibilities, just yesterday I once again saw that… I was asked to have a lecture about autism for the paediatric association members who are going to work in clinics as paediatric doctors. A girl talked after me. She belonged to APA therapy and she works somewhere privately. I saw that this method is considered effective and proper, but when a person of unclear profession begins to interpret autism, the possible therapeutic methods, and the indications and even the diagnosis, it is very sad. ABA has nothing in common. It means that the person is assuming the merits of the methods, he doesn't understand that he needs to work only when the child is fully evaluated and has the diagnosis. Only then he needs to begin to teach the child.

A(E): For the first four years we had no experience at all about child development or disorders, nobody talked about this, and only at the end of the fourth year during practicum I saw some kids, but they had other diagnoses. Then in the Master's degree I had a cycle about child development, and I have started my work here. I have heard about autism then, but I couldn't say what it was, how it looked, maybe because they are very different or…

R(K): I can second A(E), that I have never heard the term autism (everyone laughs). In my fourth year of Bachelor's degree we had child development but we never talked about autism, how to work with it, what to do when you encounter one, nothing. I saw it when I started working here.

A(L): During my education I had a month or a month and a half course about autism, but something very unclear with a very old professor and in my view autism was something that nobody would ever look at, respond to you, nobody will understand, just a very dark view in general. Then after school I taught a boy through a special program and he was my first encounter with autism. I got a good beating, because he was big and started to be taught only very late, and I could not understand his behaviour, he was so interesting, the reaction, how he sees everything, why he does what he does, a practical encounter was stronger than the university gives you. The surface was touched of what to do with kids like that and how to teach them.

A(E): But of course, you need some basis that it really is as it is, of course it is individual, but you interpret everything with the knowledge you have, you use your experience, you can read some more, but you are never a hundred percent sure that it is exactly as you say. Sometimes your experience and the chosen methods don't work.

V: I have a boy and my knowledge about autism grew together with him. I think he is fourteen now, and when he needed to go to school I wrote them a note, wrote down the diagnosis and the mother was very resistant to this. I told her the teacher has to know, the child will be going to school, he needs help there, maybe she will sit him in the front desk and so on.

V: A big part is because of the same society or people who encounter autism. We have residents coming, right? I had to supervise two of them to the child development centre, and when I came back, they were the future children or adult psychiatrist, they say they don't know what autism is anymore when they saw these kids. They had a very different view, so the view of the doctors should be different as well as the knowledge

A(L): A big part is because of the same society or people who encounter autism. We have residents coming, right? I had to supervise two of them to the child development centre,

and when I came back, they were the future children or adult psychiatrist, they say they don't know what autism is anymore when they saw these kids. They had a very different view, so the view of the doctors should be different as well as the knowledge.

4.4 Complexity of Diagnosing

G3: Autism is observed in a long period of time...

G4: Observed… Only now we have diagnosis of autism, basically a psychological disorder F-83 is diagnosed.

G1: Yes...To get there you need to wait for two or three months, and the child growing, you understand, he/she is changing, and they need help right there and then… Massages and everything…

G6: The same is about the child development centre... and they have to wait in the queue and I cannot do much for the family as to wait for the results with them

G7: Yes the queue is minimum - Half a year...

G1: And working with speech therapists, waiting for a long time, they make in imbalance, and you get the answers, I look at the name and surname, and I see that the child was here a year before, in the child development centre, and I get the answer only now, and you do realise that I needed this a year before, not now… There are many problems in this area…

G4: And it is not me who needs the answer, but the child…

G7: Why? Then there is the service… So, for the dispatch… For choosing preschool and school institution… they cannot do much without the diagnosis - and I cannot send them to any services without diagnosis

G4: Observed… Only now we have diagnosis of autism, basically a psychological disorder F-83 is diagnosed.

G4: Yes, F-84, but really F-83...

G5: because I agree with everything that was said…

G6: But there are these varied, and I am a general practitioner so these kids stay, and there is this varied with autism signs, and is written like F varied developmental…

G7: Also, patients come to us first before we send them to psychiatrist and they get specialists opinion we don't need to know the details we are not specialists

G6: But I think there are more psychiatrists, this is their work and getting deeper knowledge, while we don't really have time for that.

G1: For example, if the child development is not consistent with the norms, you consult with neurologist, if it is reflexive or muscle problems, or you see there is some lagging, it means psychomotor development, then you think, if the neurologist has already seen him, you send them to the psychiatrist. It is problematic that there are only a few of these specialists, for example, and…

G4: Yes, yes. That is all. It is not our specialty, we just advise, suggest, send, and talk…

G1: Autism, so we have no specific methods, what to do, and we do everything according to ourselves. G6: And the parents tell us...information and we work things through, but decision final one lies with us

G3: The child needs it, for example, the parents and I decide what to do next (*others agree*). Everything is put on the district not psychiatrist takes the case not neurologist, we (GP's) have to control and monitor everything

G7: When we get the answer from the child development centre, the speech therapist, the psychologist, social worker, what to do, and you read what needs to be done, but you have to work with the child…

G4: We spend most of the time in our office, and the society is reflected in the media, we don't see the personal perspectives at all… And there are also other psychological disorders…

G4: They still write this, even if they really look autistic, but the diagnosis… It is only a year or two that I diagnosed autism.

D(P): Without the teamwork nothing would happen, and we have this teamwork principle, we share information to get the best result.

L(P): The privilege is that we can use the knowledge of our colleagues, experience, and to assess the child's abilities and difficulties as much as we can, according to the institution's and country's abilities.

A(P): I will interfere, to be as sure as one can be we make the discussion like this week. We had a child and met with AL and A(E), the three of us, to talk about what we can see with the child, how it looks to us.

A(L): Everything adds up from the tests that mostly psychologists use, we as speech therapists don't have specific instruments to evaluated autistic children. We rather use clinical observations, because in general we, speech therapists, don't have any adequate evaluation instruments in Lithuania. Everything goes to the everyday experience and the opportunities you get from the workplace.

D(P): In a complex way, and then to work with him, help him, help his family, and during the time the children grow, their needs change as well as their family's needs.

L(P) I think this should be a standard, that a child with autism, it might be like that in other countries, but it is not yet like that in Lithuania, that there is a standard for the child like that, its needs, to evaluate at least each year.

R(K): Right, they need… I cannot imagine not having a psychologist or a speech therapist, and if I want really good service for the child, I need an occupational therapist evaluation, a physical therapist evaluation, and help, consults from the social worker that works with the parents, and without this it is impossible.

V: As a single doctor I couldn't imagine working somewhere in a kiosk "Child neurologist" and handling autism diagnosis and all the problems. I don't think this is even possible.

A(L): Even more so that we see the kids a very limited time, during the activity, and you see very different things each time with a different specialist. Maybe you saw this or that, and you have doubts for the diagnosis, we ask another specialist, maybe they saw something you didn't. One person cannot decide things like that, more so that there are no testing that could say a hundred percent.

A(P): A good thing is that we have different environments in our offices. The child needs to sit by the table, while he can move around freely in another office, and you can see different things, to have a full picture, as AL said.

V: Well, this is a privilege in our work, because we meet a child with the diagnosis of an autism in our office, but really the work doesn't happen there.

AL: There are norms how you need to work with children... The structure is needed and used mostly in the same way but a little different for each child.

D(P): Here probably me or the doctor (V) could begin (appeals to the other specialist because I work in a clinic and very often they have first visit there and there they see first a doctor, and then me (the psychologist).

Appendix E. Sibling's Interview Extracts from the Responsibility Theme

Responsibility

1.1 Always Being Responsible

<Internals\\SIBLING:1> - § 3 references coded [1.64% Coverage]
Reference 1 - 0.59% Coverage SIBLING: I don't know, because for example this happened recently. He fell and my mom told me to throw away what I had started to eat – it was ice cream. To throw away my ice cream and bring his bike.
Reference 2 - 0.95% Coverage SIBLING: My brother didn't hurt himself, just a little bruising, but he was crying because he fell over… and that was why he came back, my mother put some bandages on, he became happy and I was still upset. Firstly, it is because I was sorry for him and secondly, that I always have to take care of what he breaks or does.
Reference 3 - 0.10% Coverage RESEARCHER: Got it, you are often blamed…
SIBLING: Yes, very often. And my mom says he doesn't lie. I told her then, that like that time my mother said, on April 1st he said your hair is on fire… He lied more, and the started lying even more. Now he doesn't anymore.

<Internals\\SIBLING:15> - § 5 references coded [3.69% Coverage]
Reference 1 - 0.54% Coverage SIBLING: Because they sometimes listen to me. For example, they throw their toys around, and I tell them to tidy up, and they do. The situations when they listen.
Reference 2 - 1.35% Coverage RESEARCHER: Do you agree with your mom that they are different and need help?
SIBLING: No.
RESEARCHER: No. Why not?
SIBLING: Because they look like normal kids. Sometimes they help, sometimes not. I was similar. I didn't like to clean up.
Reference 3 - 0.22% Coverage RESEARCHER: Do you think you are an example for them?
SIBLING: Yes.
Reference 4 - 0.76% Coverage SIBLING: I get mad, begin to shout at them. If I lose it completely. But I handle myself. My mom says I cannot do this, and I stop. Sometimes she punishes me. I get mad at her and tell her this isn't fair. But that's what it is…
Reference 5 - 0.82% Coverage SIBLING: Sometimes I lose my temper. And that is why she doesn't like it. She says they cannot do it any other way. Punishes then (exhales). Or if I don't help her. She asks for help, and I say I have to do something else. But she says I have to.

<Internals\\SIBLING:11> - § 5 references coded [1.34% Coverage]
Reference 1 - 0.25% Coverage SIBLING: They pull out all their toys and then you have to clean them up, the small details, they don't want to…
Reference 2 - 0.38% Coverage RESEARCHER: Do you think your parents require more from you because you are older?
SIBLING: We do a lot, work with them, do therapies – change our lives for them, our routine is not the same…
Reference 3 - 0.25% Coverage SIBLING: Alright. I used to want to go out more with my friends, but you know you can't, so you get used to it.
Reference 4 - 0.23% Coverage SIBLING: You know that friends might change, while your family stays the same, that's the difference.
Reference 5 - 0.23% Coverage SIBLING: You cannot spend much time for yourself when they are like that. I don't know how to explain.

<Internals\\SIBLING: 12> - § 5 references coded [140% Coverage]
Reference 1 - 0.11% Coverage RESEARCHER: You don't think it is difficult?
SIBLING: Mhm, it is challenging, you have to be patient, and…yeah it is hard when parents make you the responsible one.

Reference 2 - 0.70% Coverage RESEARCHER: Sometimes you have to look after your brother? When?
SIBLING: When my parents go to work for the whole day. My mother‘s cousin comes early and takes to school.
Reference 3 - 0.10% Coverage SIBLING: Until she comes we have to get ready
RESEARCHER: So you help your brother with that?
SIBLING: Mhm.
Reference 4 - 0.21% Coverage RESEARCHER: How do you feel that you need to look after your brother?
SIBLING: Good, I try to enjoy it.
Reference 5 - 0.28% Coverage RESEARCHER: No, there are no disappointments or jealousy that you need to look after him and others can…
SIBLING: Maybe sometimes, but one must choose the battles

<Internals\\SIBLING:13> - § 3 references coded [1.05% Coverage]
Reference 1 - 0.29% Coverage SIBLING: You just have to see. His screaming, these screams are different. It can mean anything. You have to understand everything, otherwise it is going to be bad.
Reference 2 - 0.37% Coverage SIBLING: Protect, protect your brother. You need to protect everyone, really. I don‘t know anymore, protect, respect.
RESEARCHER: protect from who?
SIBLING: In general, FROM EVERYTHING
Reference 3 - 0.39% Coverage SIBLING: Bad things, people, negativity… Just not to let him… Not to let him anywhere he wants. You know better what is better or worse. If somewhere is worse, you automatically don’t let him there. That is all.

<Internals\\SIBLING: 3> - § 5 references coded [2.30% Coverage]
Reference 1 - 0.23% Coverage SIBLING: When I was at school it was just routine, every-day life, and he was an adolescent and it was difficult to explain this relationship. There were no conflicts, but now the relationship is closer.
Reference 2 - 0.66% Coverage SIBLING: I notice that when we go to the store he says hello to the cashier and if she doesn’t say it back, he is angry at me. If I see that the cashier does not understand, I find it uncomfortable and I see that my brother told her hello and she didn’t respond, the brother is angry at me while the cashier is looking at us weirdly. They I feel embarrassed, but then you realise nothing happened. I don’t know any situations that made me extremely embarrassed. He says all the hellos, thank you and goodbyes, and if people don’t respond, he thinks they are angry at him.
Reference 3 - 0.64% Coverage SIBLING: So, I tell him not to worry, maybe the person didn’t hear you. I try to go around this matter, without using any specific methods. Sometimes it works, sometimes it doesn’t and he keeps repeating and then the person responds. These situations are usually when we go to the store or somewhere, and depends on his mood. Sometimes he says hello to every stranger and then it gets complicated, but I try to subdue him somehow, tell him to maybe stop, you don’t know these people. But there are no situations that could cause terrible embarrassment.
Reference 4 - 0.18% Coverage SIBLING: We try as much as I can to understand each other, and that is the main connection. I don’t know how many years I would need to make him understand me more.
Reference 5 - 0.59% Coverage SIBLING: I just want him to have an activity, because he won’t be creating, he won’t be planning his own life. He cannot do it. There has to be a person there for him, and I hope he will be able to create this. He will get the horticulture diploma, and the can look after gardens and environment, because he likes to cut wood. He will contribute, the society can get something out of this, and he can clean something, trees or something. He might have his routine, can make some money, and then we can do something…together

<Internals\\SIBLING:4> - § 2 references coded [0.88% Coverage]
Reference 1 - 0.18% Coverage SIBLING: Well… we talk and mostly I try to teach him to say the words right, try him to be more independent
Reference 2 - 0.70% Coverage SIBLING: Family life with Brother NAME is very interesting and unforgettable.
RESEARCHER: What makes it interesting?

SIBLING: Many things, we have to catch him, take care of him.

<Internals\\SIBLING: 5> - § 6 references coded [2.45% Coverage]
Reference 1 - 1.04% Coverage RESEARCHER: What is the most difficult thing?
SIBLING: It is very difficult to watch over him, the way he is.
RESEARCHER: What is difficult in that?
SIBLING: Because of his actions, that is the most difficult.
RESEARCHER: What actions, Why is it difficult?
Reference 2 - 0.15% Coverage SIBLING: He begins to act out, screams, makes noises, and turns in circles…
Reference 3 - 0.22% Coverage SIBLING: Normally, I accept him the way he is, like a normal person, he just likes to act out.
Reference 4 - 0.31% Coverage SIBLING: I am in my room usually if there is something hard for him, or if he falls outside I take him home immediately to get fixed
Reference 5 - 0.56% Coverage SIBLING: It used to be, often. I want to talk with my friend on messenger or something, because we didn't meet. Sometimes I just don't want to be with him, but I do if I have to, because I don't want something bad to happen to him.
Reference 6 - 0.18% Coverage SIBLING: I always take him when I go out with my friends, I have to take him.

<Internals\\SIBLING:6> - § 5 references coded [1.69% Coverage]
Reference 1 - 0.49% Coverage SIBLING: Sometimes when he runs somewhere and you are speaking with someone and can't stay, you constantly have to look after him. Maybe it is not embarrassment, but something uncomfortable.
Reference 2 - 0.10% Coverage RESEARCHER: That you have to take care of him?
SIBLING: Yes, always.
Reference 3 - 0.38% Coverage SIBLING: Sometimes it happens that he has a very strong position. I want to do something with him, and he says no, or wants to do in his certain way.
Reference 4 - 0.48% Coverage SIBLING: Not really. When I am with my brother I don't meet my friends. So when I am with my brother, I spend time with him. It happens that if we go somewhere and I meet them, then yes…
Reference 5 - 0.24% Coverage RESEARCHER: Do you feel that having a brother like that restrict you somehow or makes it difficult?
SIBLING: There is more attention or work, but I don't feel that I couldn't do anything just because of that.

<Internals\\SIBLING:7> - § 7 references coded [3.35% Coverage]
Reference 1 - 0.16% Coverage SIBLING: I was quite smart at the early age so… My parents spoke with me like I was a grown-up.
Reference 2 - 0.08% Coverage SIBLING: So they shared with me everything mostly.
Reference 3 - 0.56% Coverage SIBLING: I don't know, sometimes it made me upset, when somebody would come and say that my sister was doing stupid things or something like that. Otherwise it was okay. The school was big so we were not constantly together. My mom was in the same school with her, so the communicated. I didn't face any big problems.
Reference 4 - 0.65% Coverage SIBLING: Canoeing, now she can do it, she couldn't before. I started swimming a lot earlier than she did, so when I and my dad went swimming, my mom and she stayed. If my parents are going somewhere I cannot go without her, I must stay with her. They just recently began letting her stay at home alone and it is great, however, I still feel a little unsure about this.
Reference 5 - 0.59% Coverage SIBLING: That something could happen to her. She could think of making a cocktail out of pepper, stock, ice-cream, milk or some bananas and everything is a huge mess. I am worried she might think of cooking something, boiling water, would try to reach something ant throw it onto herself. She might invite someone and that is worse.
Reference 6 - 0.35% Coverage SIBLING: They do ask, but these requirements are logical, they don't cause me any problems. I have responsibilities in the family and feel a lot of responsibility for myself and [SIBLING's NAME]. Everything is fine.
Reference 7 - 0.95% Coverage Of course, there are times when you say, hey, sister, let's not say this or you have to greet this person in another way or that don't talk, we talk only with mom and dad, and sister. You have to explain this and stop her. Sometimes she might

get a little crazy if someone accepts her really well. She goes for the physical contact, not like hitting, but touches you, touches the hair, takes off glasses, looks, asks detailed personal questions. You tell her to stop, to stop touching and asking, because it is inappropriate.

<Internals\\SIBLING:8> - § 2 references coded [3.88% Coverage]
Reference 1 - 3.26% Coverage RESEARCHER: You do everything together; you go to the store together?
SIBLING: No, sometimes I go alone with my friends.
RESEARCHER: Okay, why?
SIBLING: just because.
RESEARCHER: you want to spend time without your brother sometimes?
SIBLING: He doesn't go outside. He asks to go every day, but not to the one I go… There is a store by our home, but he wants to go to the toy store. He likes cars.
Reference 2 - 0.63% Coverage RESEARCHER: He likes to play, got it. Do you have to look after him often? No? You have enough free time?
SIBLING: A lot, it is my responsibility, I cannot do much without making sure he is okay.

<Internals\\SIBLING: 9> - § 8 references coded [5.04% Coverage]
Reference 1 - 0.80% Coverage SIBLING: Well… Maybe it should embarrass me when my mom comes to my school to talk to my teacher, she usually brings my brother. And then she wants me to look after him while she talks. My classmates walk up to me and see he is different. But it doesn't embarrass me.
Reference 2 - 0.39% Coverage SIBLING: When my parents leave somewhere, I have to look after my brother. A simple ten-year-old could be left at home for a few hours.
Reference 3 - 0.79% Coverage SIBLING: They keep trying to find my brother. Sometimes in the supermarket he walks very fast somewhere, you look, and he is gone. Then they go to look for him. When they find him and I say I want to go to some store, they usually say no, you have to watch Justas.
Reference 4 - 0.64% Coverage SIBLING: You constantly have took after him so he wouldn't do something. Sometimes people are scared of him, you want to protect him from what he doesn't know, so that the people wouldn't start saying he is somehow…
Reference 5 - 1.01% Coverage RESEARCHER: Just leaving the situation? You mentioned about other people, when they ask you, like your friends. Did your brother ever was a reason you couldn't go out with your friends?
SIBLING: Yes, not once. You want to go but you have some responsibilities.
Reference 6 - 0.79% Coverage RESEARCHER: How did you feel?
SIBLING: It is sad, because the whole summer went like that, and I had to look after my brother and help my parents.
Reference 7 - 0.39% Coverage SIBLING: I told them. Sometimes they agreed, sometimes they reminded that I have a brother like that and I have to take care of him.
Reference 8 - 0.23% Coverage SIBLING: I understood. Friends come and go, while my brother will always be there.

1.2 Babysitting and other Chores

<Internals\\SIBLING:1> - § 2 references coded [0.52% Coverage]
Reference 1 - 0.17% Coverage RESEARCHER: Got it. Do you often have to look after your brother?
SIBLING: Yes.
Reference 2 - 0.35% Coverage RESEARCHER: Sometimes it doesn't depend on you, right? You still have to drop whatever you are doing and help your brother?
SIBLING: Yeah, always – the hierarchy is clear, my brothers needs and then my needs…of course my parents would not admit to it.

<Internals\\SIBLING:2> - § 3references coded [2.17% Coverage]
Reference 1 - 0.94% Coverage RESEARCHER: You mentioned you need to look after them a lot. What where the things that changed in your family when you had your brothers? What activities had to be stopped, or something changed from the routine? Maybe you had to give up something because your brothers are different?

SIBLING: You don't have to look after them a lot. Mom goes somewhere and asks. But it doesn't take forever, I have time.
Reference 2 - 0.82% Coverage SIBLING: Sometimes I lose my temper. And that is why she doesn't like it. She says they cannot do it any other way. Punishes then (exhales). Or if I don't help her. She asks for help, and I say I have to do something else. But she says I have to.
Reference 3 - 0.41% Coverage SIBLING: look after them, vacuum the house, clean the floor, and wash up. Clean up. There used to be less of the chores compared to what I do now as I grew up.

<Internals\\SIBLING:12> - § 3 references coded [0.89% Coverage]
Reference 1 - 0.48% Coverage SIBLING: He didn't run away far the other times, he was walking somewhere in the store.
RESEARCHER: So you have to look after him mostly?
SIBLING: Mhm.
Reference 2 - 0.23% Coverage RESEARCHER: Did you ever have to look after your brother?
SIBLING: I do, a lot.
Reference 3 - 0.18% Coverage SIBLING: I don't have to look after him for long, because he finds what to do.

<Internals\\SIBLING:13> - § 5 references coded [2.12% Coverage]
Reference 1 - 0.27% Coverage SIBLING: Sometimes I stay here like the nanny. But they know that when they stay with me it is going to be different than staying with my parents.
Reference 2 - 0.15% Coverage SIBLING: Yes, when he stays with me. He is calm, and much calmer than with my parents.
Reference 3 - 0.67% Coverage SIBLING: Unless I let him. It was like that when they used to leave us together in the beginning… They asked me to stay with him occasionally, and there used to be some problems, I couldn't deal with alone. Then we began interacting and communicating more, more personally, and I began talking to him, tell him what goes where… And that was it.
Reference 4 - 0.11% Coverage SIBLING: I was little and had to take care of even smaller ones.
Reference 5 - 0.92% Coverage SIBLING: Yeah, of course. But I mean we interact the whole day. For example, if parents are not here, he comes to me, asks for soup, and asks to turn something on, the computer or something. But he comes to ask me. Of course I also go and check if he is hungry or not. And that is how our interaction ends. Just superficial. Now he interacts with me as and everyone else as much as ne needs. I don't think he needs more, that he would be happier. He knows what he needs and how much he needs.

<Internals\\SIBLING:4> - § 1 reference coded [0.27% Coverage]
Reference 1 - 0.27% Coverage SIBLING: Well, when we are alone (whispers "not very silently"…) my brother and I have a lot of fun on the bed.

<Internals\\SIBLING:5> - § 3 references coded [1.04% Coverage]
Reference 1 - 0.30% Coverage SIBLING: If we are alone at home, so I watch TV with him, go outside with him, watch what he is doing at the neighbours and so on.
Reference 2 - 0.56% Coverage SIBLING: It used to be, often. I want to talk with my friend on messenger or something, because we didn't meet. Sometimes I just don't want to be with him, but I do if I have to, because I don't want something bad to happen to him.
Reference 3 - 0.18% Coverage SIBLING: I always take him when I go out with my friends, I have to take him, otherwise I cannot go…

<Internals\\SIBLING:6> - § 4 references coded [2.49% Coverage]
Reference 1 - 0.97% Coverage SIBLING: It is hard to remember, but mostly just like any other child. It wasn't, I don't know… He was taken to the kindergarten, to school, somebody had to take him from there. Maybe I was there, so not only my parents took him, I also took him to school. Somebody had to stay with him, so these where the things that changed, but it would be the same with any child.

Reference 2 - 0.66% Coverage SIBLING: they do, but as I said, this would be the same with any other child. You still need to look after him, if parents are at work or something. Now you can leave him alone in his room. We don't let him outside alone, but I think in time he needs to…
Reference 3 - 0.32% Coverage RESEARCHER: Does it happen that you want to meet your friends and you have to decline because you have to watch over your brother?
Reference 4 - 0.54% Coverage SIBLING: It happens that nobody else can help, but that is something you need to do. It would be the same with any other brother, the difference is that you might give him more freedom if everything was fine.

<Internals\\SIBLING:7> - § 1 reference coded [0.65% Coverage]
Reference 1 - 0.65% Coverage SIBLING: Canoeing, now she can do it, she couldn't before. I started swimming a lot earlier than she did, so when I and my dad went swimming, my mom and she stayed. If my parents are going somewhere I cannot go without her, I must stay with her. They just recently began letting her stay at home alone and it is great, however, I still feel a little unsure about this.

<Internals\\SIBLING:8> - § 1 reference coded [0.63% Coverage]
Reference 1 - 0.63% Coverage RESEARCHER: He likes to play, got it. Do you have to look after him often? No? You have enough free time?
SIBLING: A lot, I basically babysit him

<Internals\\SIBLING: 9> - § 3 references coded [2.25% Coverage]
Reference 1 - 0.84% Coverage SIBLING: Oh yes, this is the biggest problem why we fight. Sometimes he listens to me, sometimes I want to be alone, and he just barges in my room and I could not imagine what he needs there. Or when I am with my peers, he barges in. Sometimes I get upset and try to make him leave?
Reference 2 - 0.39% Coverage SIBLING: When my parents leave somewhere, I have to look after my brother. A simple ten-year-old could be left at home for a few hours.
Reference 3 - 1.01% Coverage RESEARCHER: Just leaving the situation? You mentioned about other people, when they ask you, like your friends. Did your brother ever was a reason you couldn't go out with your friends?
SIBLING: Yes, not once. You want to go but you have some responsibilities.

1.3 Receiving the blame for conflicts with ASD SIBLING

<Internals\\SIBLING:1> - § 1 reference coded [0.30% Coverage]
Reference 1 - 0.30% Coverage SIBLING: Once he broke the toys and blamed it on me, and I was told to throw them away. He broke my toys.it was sad that I lost my toys and mom did not say anything to my brother…

<Internals\\SIBLING: 10> - § 1 reference coded [1.75% Coverage]
Reference 1 - 1.75% Coverage SIBLING: I get mad, begin to shout at them. If I lose it completely. But I handle myself. My mom says I cannot do this, and I stop. Sometimes she punishes me. I get mad at her and tell her this isn't fair. But that's what it is…
RESEARCHER: What punishments do you get?
SIBLING: I cannot use the computer or cannot go out. But not for long. A day or a week.

<Internals\\SIBLING:11> - § 1 reference coded [1.17% Coverage]
Reference 1 - 1.17% Coverage RESEARCHER: Does it happen that your moms gets mad at you because they did something? And she tells that you did not watch them, didn't help or didn't do something?
SIBLING: It happened some time ago. But when both are hyperactive it is very difficult and she understands that. Sometimes it is hard for my mom as well.

<Internals\\SIBLING:12> - § 2 references coded [1.62% Coverage]
Reference 1 - 1.19% Coverage SIBLING: When mom comes back she gets mad that he didn't do his homework. Because then it gets late.
RESEARCHER: She gets mad at you? Or him?
SIBLING: Brother.

RESEARCHER: Mad at brother, not you, that he didn't do his homework. How does he react?
SIBLING: He cries and says he doesn't know how, that he can't. Sometimes she is angry with me that I did not push him or attended to him and allowed him to do nothing.
Reference 2 - 0.44% Coverage SIBLING: When he doesn't help or something (pause), or when we eat all together and my brother makes noises, and they make me nervous, my dad tells me to go to another room to eat.

<Internals\\SIBLING:2> - § 1 references coded [1.86% Coverage]
Reference 1 - 1.86% Coverage RESEARCHER: everything is right? Got it. So if you needed to summarize and tell someone what does it mean to have a brother with autism?
SIBLING: mmm I don't know.
RESEARCHER: What would you tell someone else from your own experience? For example, I recently learn that I have this brother and he is autistic. What would you tell me, what do I need to know?
SIBLING: I don't know.

1.4 ASD SIBLING: Future

<Internals\\SIBLING: 1> - § 2 reference coded [0.75% Coverage]
Reference 1 - 0.55% Coverage RESEARCHER: You don't know what I need to know? Okay, got it. How do you think your brother will do when he gets older, his future?
SIBLING: I have no idea (silent).
Reference 2 - 0.20% Coverage RESEARCHER: Do you think he can ever be independent?
SIBLING: Maybe.

<Internals\\SIBLING: 10> - § 1 reference coded [0.84% Coverage]
Reference 1 - 0.84% Coverage SIBLING: they definitely will have a job, because they are good at something. They like to draw and play computer games, with phones. I don't know about families, maybe. They interact with other kids. Just maybe have more problems getting to know them.

<Internals\\SIBLING:11> - § 6 references coded [1.50% Coverage]
Reference 1 - 0.44% Coverage RESEARCHER: Just like that? What future do you see for your brothers?
SIBLING: I think about this a lot, but I don‘t have a vision.

Reference 2 - 0.15% Coverage SIBLING: What will happen when they grow up, when they go to school?
Reference 3 - 0.17% Coverage SIBLING: Will it happen that we will have to take care of them the whole life.
Reference 4 - 0.21% Coverage SIBLING: Will they be able to communicate by themselves, fix their lives? Will they need help?
Reference 5 - 0.11% Coverage SIBLING: So these are the questions I always have.
Reference 6 - 0.42% Coverage RESEARCHER: How do you feel when you think thank you might have to take care of them your whole life?
SIBLING: And I will. I don‘t know, somehow...

<Internals\\SIBLING:12> - § 3 references coded [0.47% Coverage]
Reference 1 - 0.15% Coverage RESEARCHER: DO you think about your brother‘s future?
SIBLING: Yes, sometimes…
Reference 2 - 0.14% Coverage RESEARCHER: You think your brother‘s future looks bright?
SIBLING: I hope it will be bright, but it will depend on by parents and him.
Reference 3 - 0.17% Coverage RESEARCHER: You don‘t think you will have to take care of him?
SIBLING: no

<Internals\\SIBLING:13> - § 3 references coded [2.16% Coverage]
Reference 1 - 1.22% Coverage SIBLING: I don't even know what to say. The future… like none. I don't know. I don't see the future in Lithuania. I read and looked into autism. Initiative in Lithuania is almost none considering other countries. In America or Russia, it is very

different. They work with them very seriously. I think it is much better abroad. I tell them to go live there and try. Of course, I am not saying they are not doing anything, they work with him, but still. It is better abroad. Just different results. I don't know what is going to be next. I don't know what till be tomorrow. He won't get lost. Everything will be fine. We will help as much as we can.
Reference 2 - 0.17% Coverage RESEARCHER: What do you mean? You will help?
SIBLING: yes, if they need, me, I will help.
Reference 3 - 0.78% Coverage SIBLING: What I don't see? I just looked into the fact that he could have it as easy as possible. We are not eternal. To teach him as much as possible, for himself, to have this need. And I don't know about his future. I didn't look that far… And I don't know. I can't imagine it for him, I can't even imagine it for myself. I hope everything will be fine. I hope to help, but I don't know what his future is like.

<Internals\\SIBLING:3> - § 4 references coded [1.06% Coverage]
Reference 1 - 0.27% Coverage SIBLING: Of course, we talk about the future, but they are very careful, they don't show any hope for me, and that I need to decide or something. They hold everything in their hands, in creating brother's future I have no part right now.
Reference 2 - 0.47% Coverage SIBLING: You would like to have some continuation and this relationship. I cannot imagine his future; he needs to be integrated. I think the biggest challenge now is his future, how to integrate him into the society, to make him feel well, so that he wouldn't feel like he is always in a specialized environment. He sees that, he notices that he is among difficult people and it is more difficult for him
Reference 3 - 0.04% Coverage SIBLING: so this is the biggest puzzle for me.
Reference 4 - 0.28% Coverage SIBLING: I am happy that the awareness is increasing, and especially in our environment. It is easier for the families, and I believe that further in time the autistic people will have it easier in Lithuania, because it is different in other countries.

<Internals\\SIBLING: 4> - § 1 reference coded [0.32% Coverage]
Reference 1 - 0.32% Coverage SIBLING: Maybe he can learn to speak and learn to be…mm… a normal guy.
RESEARCHER: You hope so?
SIBLING: Mhm.

<Internals\\SIBLING:5> - § 6 references coded [1.31% Coverage]
Reference 1 - 0.16% Coverage RESEARCHER: What do you think brother's future is like? How do you see it?
Reference 2 - 0.20% Coverage SIBLING: Like a normal person, to grow up as a normal person, have a job that like liked.
Reference 3 - 0.13% Coverage RESEARCHER: Do you think he could do that?
SIBLING: yes.
Reference 4 - 0.13% Coverage RESEARCHER: And everything will be alright?
SIBLING: yes, want to believe that
Reference 5 - 0.27% Coverage SIBLING: Yes, I have, when I was smaller and I learnt, I thought how he would speak, what he would do, draw or act…
RESEARCHER: What do you mean?
SIBLING: He could maybe be alone for then minutes, he know how to do something, he asks for some bread if he wants, he know how to clean up, take care, eat, clean his room.

<Internals\\SIBLING:6> - § 2 references coded [2.57% Coverage]
Reference 1 - 1.38% Coverage
RESEARCHER: When you think of your brother's future, how do you imagine it?
SIBLING: I can hardly imagine it
SIBLING: We have a cousin who is autistic, he is more than twenty years old now. He finds some jobs as a housekeeper. He is a great person. So I imagine something similar. With jobs like that. He is getting better each year, language is getting better and better. So maybe he will learn to speak fully, maybe then it will be easier to do everything with him and get along.
Reference 2 - 1.19% Coverage RESEARCHER: Do you think you will have to look after him even when he grows up?

SIBLING: We try to teach him as much independence as we can. As I said, our cousin is quite independent. He has his own room, takes care of himself, has his own activities…But I don't know about the future. My cousin looks alright. When I meet other people, they seem to understand and everything is fine

<Internals\\SIBLING:7> - § 2 references coded [1.30% Coverage]
Reference 1 - 0.26% Coverage SIBLING: I don't know… well (laughs). Positive, I mean, it's not that I see her and get some negative emotions, I love her a lot, everything is fine.
Reference 2 - 1.04% Coverage
SIBLING: They have hopes for both, but they are rational. They understand how much I can achieve, how much can my sister, and now we are talking what she can do next, how much she needs to learn in school. Maybe she doesn't need all twelve grades, maybe ten and a professional school is enough. They understand that when I graduate I will go to the higher education school, maybe I won't, but there are a lot more chances I can achieve more than her. But we plan her future, what she could do, we search for her stronger sides, what she likes and is good at. We try to plan rationally.

<Internals\\SIBLING: 8> - § 2 references coded [1.63% Coverage]
Reference 1 - 0.46% Coverage RESEARCHER: How do you think he will do in future? Will he have a job?
SIBLING: I don't know. Well I worry about it, I don't know…it is painful to think, as future does not look promising
Reference 2 - 0.70% Coverage RESEARCHER: You don't know, you don't think about your brother's future, when you grow up?
SIBLING: I don't think about anything…it is too hard to think
RESEARCHER: You don't think about this, because it is hard. Can you shortly describe your relationship with your brother?

<Internals\\SIBLING: 9> - § 2 references coded [0.80% Coverage]
Reference 1 - 0.29% Coverage RESEARCHER: How do you see your brother‘s future?
SIBLING: I don‘t know, can‘t say.
Reference 2 - 0.51% Coverage RESEARCHER: Are you scared of it?
SIBLING: I never thought of it.
RESEARCHER: You didn‘t think about it?
SIBLING: no not really, because I don't know how tomorrow going to look like, so why bother myself about it?

1.5 Advocacy

<Internals\\SIBLING:10> - § 1 reference coded [0.62% Coverage]
Reference 1 - 0.62% Coverage RESEARCHER: You have enough time, you can spend it with your friends, and everything is fine? What about your friends, do you tell them you have different brothers?
SIBLING: Yes, I talk with them, because they ask and they notice that they are different. In the beginning they act weird around them but then get used to and everything is fine.

<Internals\\SIBLING:11> - § 2 references coded [1.48% Coverage]
Reference 1 - 0.25% Coverage SIBLING: I would say they are autists and they have some specific behaviours, and that why they act like that.
Reference 2 - 1.23% Coverage RESEARCHER: People might not know what autism is. They would ask you what that is, what would you say? If the person didn't know what that is.
SIBLING: I don‘t know myself.
RESEARCHER: Aha.
SIBLING: I don't think there is a specific definition I guess.
RESEARCHER: Mhm.
SIBLING: I don‘t think I could explain it. I would say to look it up online.

<Internals\\SIBLING: 3> - § 5 references coded [1.87% Coverage]
Reference 1 - 0.30% Coverage SIBLING: Or when there were some adolescent girls walking by the lake, laughing. It is terribly irritating, but of course I understand that people don't know and I don't react to it. I realize that I won't be able to walk up to them and explain, but it is very upsetting

Reference 2 - 0.44% Coverage SIBLING: Because I am extremely nervous at the time and I don't know. A good question. I see someone sitting with other, I cannot go ant teach them or explain, let them laugh. It usually is in episodes, we pass on the street or something, it is not like we sit in one room. Sometimes they are in distance, just walking by, and in the moment I feel hurt, but I walk by and don't stop.
Reference 3 - 0.30% Coverage SIBLING: I don't know how my brother would react, because I know he would notice. It would be interesting, I have never done that, but my feelings were very uncomfortable and I understand this is not my, but the peoples' problem, and I don't go saying something.
Reference 4 - 0.51% Coverage SIBLING: There are people that use these insults as Down's, while the people don't have the Down's syndrome. I have heard people saying that somebody is acting like an autist. I get shivers and think did they even know what that meant, why did they say that. It is a label, an insult. The word autist became like and insult as Down's was. It bothers me and I think to myself, whether I should give a speech to people like that. It is a dilemma.
Reference 5 - 0.32% Coverage SIBLING: My family does a little of education and tell people about this. More people get involved. My parents' friends are studying psychology and people who knows about this and tells the society is increasing. I am really happy about this, the situation is getting better. Mostly…

<Internals\\SIBLING: 4> - § 2 references coded [1.97% Coverage]
Reference 1 - 1.09% Coverage RESEARCHER: Do you have friends over?
SIBLING: yes.
RESEARCHER: How do they interact with your brother?
SIBLING: Sometimes they fear my brother.
RESEARCHER: What do you say then or do?
SIBLING: I explain to them that he is different.
Reference 2 - 0.89% Coverage SIBLING: Because we are a family, and they ask. I just tell them what kind of sound that was, but I don't tell them where from. Either it is my brother, or that it comes from my brother's room.
SIBLING: or that my brother starts jumping. I just tell them I didn't know.

<Internals\\SIBLING: 5> - § 4 references coded [0.98% Coverage]
Reference 1 - 0.35% Coverage RESEARCHER: It hurts that they laugh. Have you ever tried explaining him?
SIBLING: Yes, and it worked, positively.

Reference 2 - 0.25% Coverage RESEARCHER: Have you ever felt embarrassed to tell your friends that your brother is different?
SIBLING: no.
Reference 3 - 0.12% Coverage SIBLING: I don't usually tell, because they never ask.
Reference 4 - 0.26% Coverage SIBLING: My mom tells them, I don't. If I am with my mom, she tells other people so that they would understand.

<Internals\\SIBLING:6> - § 3 references coded [1.59% Coverage]
Reference 1 - 0.10% Coverage RESEARCHER: Do you explain to strangers that he…
SIBLING: No, usually everything turns out great. If he walks up to someone it's because he has a matter. Either he needs a straw for his drink or something else, or he lost something, or he thinks this person looks familiar and he says hello. Usually I just tell him this is not it, or I ask why he talked to this person.
Reference 2 - 0.37% Coverage SIBLING: The system in part, at least the older children, doesn't see well. While people are usually nice to people like that, they understand.
Reference 3 - 0.28% Coverage SIBLING: No, or if it happens they usually apologize or at least understand that there is something different.

<Internals\\SIBLING:7> - § 7 references coded [3.80% Coverage]
Reference 1 - 0.38% Coverage SIBLING: I don't know. There were times when she was pushed away and told to go away. I felt bad because she was still my sister. It was difficult, bet when I grew up a little it became easier to explain to others.
Reference 2 - 0.70% Coverage SIBLING: No, they are too young. You could talk more about her classmates. I think my friend met with them sometimes, but I think when she came

to talk to them, she asked how it will be without SIBLING' NAME, because she wasn't there. She just explained then and the kind of understood. Sometimes they push her away, but they are a good class in general. They comfort her and help her with the school work.
Reference 3 - 0.56% Coverage SIBLING: I don't know, sometimes it made me upset, when somebody would come and say that my sister was doing stupid things or something like that. Otherwise it was okay. The school was big so we were not constantly together. My mom was in the same school with her, so the communicated. I didn't face any big problems.
Reference 4 - 0.76% Coverage SIBLING: Yes, still. I try not to pay attention and I blame it on the person who doesn't understand. There are times when she does and says some stupid things. She talks about whatever she sees. She might say something that should stay in the family, something others shouldn't know. Not like secrets, but some uncomfortable things. She doesn't understand where she should stay silent, so she talks about things she shouldn't…
Reference 5 - 0.14% Coverage SIBLING: If I need to, I apologize or change the topic. Just handle the situation.
Reference 6 - 0.48% Coverage SIBLING: It is quite difficult to me, because I always have to explain everyone why she is doing what she's doing, to justify her. It depends on whether they understand and how they react. If their reaction is not well, I try so that she would have a contact with them.
Reference 7 - 0.79% Coverage SIBLING: Looks or some words… Closer friends interact with her more, knows her more and learn how to react with her. But there are the ones that I don't communicate as much. At first they enjoy that she asks so many questions people she meets for the first time. She seems nice, but some are irritated and they are not afraid to show it. They ask me she asked so many questions and so on… I try to react in a situation and to handle it somehow.

<Internals\\SIBLING: 8> - § 4 references coded [3.51% Coverage]
Reference 1 - 0.94% Coverage RESEARCHER: Celebrations, right. Got it. Can you tell me what is autism to you? If friends ask you what is with
SIBLING: That he is autistic.
Reference 2 - 0.63% Coverage RESEARCHER: No? Do you think people in Lithuania know what autism is?
SIBLING: some do, and some don't.
Reference 3 - 1.22% Coverage RESEARCHER: Some knows, some doesn't. Have you ever met people that didn't know what autism is?
SIBLING: I don't speak with grown-ups, but there are many kids, like a million.
Reference 4 - 0.73% Coverage SIBLING: Is there something in school that tells about different kids? No?

<Internals\\SIBLING:9> - § 1 reference coded [0.80% Coverage]
Reference 1 - 0.80% Coverage RESEARCHER: If your friend asked you: "Your brother is different", you say: He is an autist. And he asked what autism was. How would you describe it to your friends?
SIBLING: I had to do this more than once, and I told them that he is different, does not understand things and just let them ask questions if they had.

Appendix F. Answers to the Option "Other" of Questions 27, 28, 29 from Knowledge, Attitude and Practice Questionnaire

Number of the participant	Statement: 27. In Lithuania, how is a person who has autism usually regarded/treated?
525	People do not know how to behave around them
866	We are not tolerant, yet
947	They are institutionalized
981	People feel fear, as they do not know how to behave
1068	Are neutral
1150	They want but not sure how to communicate with such person and are afraid to start
1202	I think they are perceived as a weird people. I think only a small part and mostly specialists perceived them as people who have disorder.
1203	do not declare themselves how
1224	Have little information about this disorder
1253	I have not met one, because probably they are separated from other people, healthy people, like other disabled people.
1258	I am not sure
1259	Avoid such people
1265	I am not sure
1276	I cannot answer for others
1285	I think they help
1286	I don't encounter
1295	I am not sure
1313	I cannot answer for all Lithuanians but only for myself
1319	It depends on people's attitudes and stigmatization. If the person, who has ASD is integrated himself to society, then often people will perceive him as "strange" and would not pay much attention.
1325	There is such feeling of ignorance and faith that he will "grow out of it"
1351	I think Lithuanian's don't know and therefore cannot communicate with such people
1374	There is a saying everyone beats an idiot, even at church
1284	I have no clue
1425	People avoid people with ASD, therefore individuals with ASD have low self-esteem and do not think he is worthy of school or to have a job.
1439	It is hard to decide about friendliness, but I think people who do not have person with ASD in their surroundings, mostly are afraid and not sure how to behave around or accept such people.

Number of the participant	Statement: 27. In Lithuania, how is a person who has autism usually regarded/treated?
1483	In Lithuania, there is lack of knowledge and publicity. When encounter personally they hardly accepted. Having in mind that there are various people and child is accepted differently depending on the person. I try to communicate with those that can positively accept a different type of child. But unavoidably we meet people who reject.
1485	I am not sure how to behave around such person
1508	Majority of people have very little knowledge about autism, therefore does not understand, avoid or reject people with ASD
1518	I think they isolate such people
1559	Majority of people does not understand that there is a person in their environment with ASD
1578	Even the specialists have distorted view of what it is and etc. and society mostly does not know anything about autism. Mostly think that we have uneducated and disobedient child.
1582	Majority of people mock them
1593	It all depends on the environment. More educated people accept them normally, just maybe does not know how to communicate with them. The children and less educated adults can be less friendly.
1601	Majority does not understand what kind of diseases is that and how it effects the person, thus they might perceive it as a severe disorder, when having it is difficult to function in the society. I think majority feels sympathy, would help but does not know how.
1633	I have not met an adult only a child
1647	I am not sure
1652	I am not sure.

Number of the participant	Statement: 28. How do you feel towards people with autism disorder?
41	People communicate like with others
743	I feel sympathy, but I cannot help with anything
867	I work with them
1016	People with special needs
1068	People like people you just have to adapt to them
1080	I feel sympathy
1083	I want to help
1085	Maybe a disease you can catch
1098	It is difficult to communicate with them
1102	They are human beings that does not have a developmental disorder but just asks more attention and care
1177	I am a bit scared, because I am not sure, how to react properly around them

Number of the participant	Statement: 28. How do you feel towards people with autism disorder?
1186	I am amazed by their intellect, and their problems seem weird but also interesting all together
1192	Would like to help them as much as possible but would be afraid to commit them for a life
1198	The same human beings just seeing things differently, we need to accept everyone, we all have defects
1201	These humans are smart and have special talents we just need to learn to be surrounded by such people and come to the contact with them
1202	I think we need to learn how to be around them and accept them
1224	I would like to help but I lack information
1232	They are humans like all of us
1233	Would like to help them integrate into society
1238	I feel sympathy
1245	It can be difficult to communicate as they don't understand social norms
1269	Would try to understand them and talk with them
1280	They are full members of society like anyone else
1286	I would feel sympathy as I am not sure how to behave around them
1293	I wish to help
1307	I feel sympathy but I am not specialist that I could help them
1314	They are humans like us just has a special and weird needs
1316	I feel love, wish to help and understand
1319	I would be great that people like them could be integrated and realize themselves, I don't think they need sympathy or special attention.
1323	I feel sympathy for them and their family
1325	The families and community members that have people with ASD in their environment should be help to each other and counsellors and educators and therapists
1331	The people with ASD are great
1333	I try to understand them
1347	I am missing the communication with such people, have not met one. I don't think bad about them, but understand that it would not be easy
1356	They would be more accepted if society would know more about autism
1358	I don't encounter them
1372	I don't feel sympathy but a wish to help
1414	I seem them as a healthy person
1428	I don’t want them in my life
1437	They are humans like all of us
1452	I think that they are normal like everyone else
1467	I think how properly to behave, communicate with them smoothly

Number of the participant	Statement: 28. How do you feel towards people with autism disorder?
1483	Everyone one are individuals, unique. I am amazed by characteristics that people with ASD have, some of their abilities are fascinating. It is a pity that different experiences, behaviour is not accepted in our society and people concentrated on things that are wrong. I dream that strengthens of such people would be educated maybe they would create something that others - "normal" can or could not
1492	I accept them like everyone else
1540	Often, I get lost and not sure how to behave and communicate with them
1571	I think they are "different" then society is usually used to call the "normal ones"
1578	All of them are special
1582	I view them as a member of the society that has special needs, which I do not discriminate and if needed I help them
1589	They need help to integrate to society
1601	I want to understand, to know more, to know how to behave with them and if needed provide help for that person.
1602	I respect and value them like every other human, but I lack skills and knowledge in how to communicate with them
1607	They are humans like everyone one of us - the "healthy ones"
1608	I would like to spend more time with them. They are humans too
1614	I am not sure, how to communicate and behave around them
1622	I view them as a full-on human, who in different situations of life might need help
1628	I communicate with such human as like with any other one

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
18	I would try to help
29	I would try to help
34	I would be concerned
37	I would try to help
38	I would try to help
39	I would try to help
40	I would try to help
50	I would be responsible
86	I would have to accept it
88	I would react normally
90	I would have to accept it
95	I would have to accept it
136	I would feel lost
139	I would feel sympathy
150	I would have to accept it
177	I would be more interested about disorder

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
190	I would have to accept it
196	I would have to accept it
200	It would be very difficult
224	I would try to help
225	I would have to accept it
235	I would feel lost
305	I would feel sympathy
318	I would feel sympathy
320	I would try to help
393	I would be concerned
419	I would feel sympathy
422	I would react normally
447	I would feel pain and love
481	I would try to help
487	I would try to help
514	I would want to help
517	I would be concerned
524	I would try to learn more
588	I would react normally
610	I would react normally
620	I would react normally
630	I would react normally
637	I would react normally
638	I would try to cure it
647	I would react normally
648	I would try to cure it
665	I would seek help
672	I would try to help
694	I would react normally
719	I would try to help
733	I would react normally
778	I would try to adapt
828	I would try to help
831	I would want to help
835	I would try to help
837	I would try to help
857	I would react normally
859	I would react normally
861	I would react normally
863	I would be concerned

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
867	I would try to learn more
879	I would try to help
933	I would try to help
934	I would try to help
942	I would want to help
945	I would try to cure it
948	I would try to help
950	I would try to cure it
961	I would be concerned
1012	I would react normally
1014	I would react normally
1016	I would try to learn more
1020	I would be concerned
1032	I would try accept
1043	I would want to help
1065	I would try accept
1086	I would react normally
1099	I would try accept
1102	I am not sure. Maybe in the beginning I would feel sad, but later would try to behave normally and love that person.
1105	I would support that person no matter what
1106	I would seek more information about this disease
1107	I would try to help
1117	I would seek more information
1119	I am not sure
1133	Normally would view him as a person who has problems and I would learn to live with him
1134	I would support in everything
1149	I would not panic
1153	I would feel sympathy and wish to help
1160	I would try to help as much as possible
1167	I am not sure
1168	I would try to look positively towards that person and help him
1172	I would seek more information and how to live with such person
1173	I would seek more information
1183	No difference
1192	I would accept it as my destiny and not reject that person, because firstly it is a closed one.

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
1198	I would accept
1199	I am not sure
1201	I am not sure now how I would feel in that situation
1202	I am not sure how I feel as I don't have it. Autism is a disorder and be happy about it is a disorder. It is a challenge for family and closed ones.
1203	I would be concerned
1208	I would try to help
1212	when you have autistic child, there are various feelings
1214	normally
1217	I would try to help
1224	I would seek more information
1227	normally
1232	When you accept it, everything seems simple
1233	I would be interested about this disorder and seek information how to live with it
1234	I would comply with situation and seek help
1245	I would seek information about autism
1246	I would accept him as he is
1254	I would be sad and instantly look for help
1255	I would communicate as with the healthy person
1257	I would feel normally it is not a big disgrace
1258	I would be confused as I am not sure how to behave with that person
1264	I would feel sympathy and wish to help
1266	I would like to help
1271	No difference
1280	That is normal
1285	I would try to help and learn more about autism, read more would definitely not leave that person.
1290	I am not sure
1291	Would try to help
1293	Would think what to do next?
1295	It would be sad I would try to help
1308	I would accept as he is
1311	I would try to learn more about it
1313	It would be sad I would try to help
1316	What is the differences? If it is a loved one

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
1317	I would seek specialist help
1318	Autism characteristics can be noticed in many, thus it is not worth highlighting it
1319	Like everyone else, would doubt, it is hard to tell what I would feel in situation that has not happened, easy to say anything but I know that would not be the case.
1327	Confusion, hopelessness, guilt, sadness, anger and all the other feelings that are temporary
1328	I would think how to make life easier while having this
1329	I would seek more information
1331	Simple. Would love him as I loved before
1333	Totally normal it is part of person's character
1339	I would be surprised but straight away would take actions to assist with that person development and integration
1341	I have experienced it already, firstly was lost, even though I knew it before the doctors told me the diagnosis
1343	I would try to help as much as possible
1346	I would try to learn more about it
1347	I would try to live with it
1349	I would think about how to help
1353	I would be sad
1357	I would still try to love him
1361	I would accept
1366	I would like to help
1367	I would accept it naturally
1370	I would take actions for his well-being
1372	I would not feel anything special
1375	I would accept as my reality
1378	I would be concerned about his future
1388	I am not sure
1395	I would accept it naturally and try to help
1398	I am not sure
1404	I would feel a wish to help him/her
1412	I would be confused
1413	I am not sure
1414	It would be difficult but would accept it
1419	I am not sure
1424	I would be not sure how to behave
1433	It is hard to tell
1435	I would seek more information, how to help such person and behave in certain situations

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
1437	I would communicate as I did before finding out
1442	I would be surprised but would accept and try to help
1443	I would accept as the challenge
1445	I would behave naturally, would try to help in multiple ways
1446	I would react calmly
1452	I would feel lost
1457	I Would try to help
1463	Would try to find more information as there is little information about autism in our society
1467	Would try to understand and help him/her
1472	Would seek help and learn more about this disease
1475	I am not sure what feelings I would feel
1480	I would be concerned
1483	Would be a clear explanation why he is standing out from the society. :)
1486	I would feel sad but not desperate
1489	I am not sure
1492	I would try to provide life basic foundations, would teach how to integrate yourself in this negative and hostile society
1497	I would want to understand the person and help him
1500	I would try to think how to help such person
1508	I would try to get more information
1515	I would try to help
1516	I would panic
1517	Would try to help and take care of the person
1524	In Lithuania, you cannot feel any other way.
1531	Would learn to live with that
1545	I don't think I would feel somehow specially, just would try to support and be together.
1549	Would go and try to understand what autism is and how to behave in that situation and care for a person like that.
1551	I would not feel anything
1554	I am not sure
1556	I would help

Number of the participant	Statement: 29. If you found that you or someone you love had autism how would you react?
1558	Would be worried, because in Lithuania there is lack of help for autistic people and their families and society does not accept them at all.
1566	Would be surprised…
1571	Would accept that as it is. Would like to understand how to communicate that both sides would feel well.
1574	I would be concerned
1575	No difference
1578	Would not think, I know that things would be different. Autistic people understand, feels and sees the world differently.
1579	I would accept
1582	I would be sad but would not reject him
1586	Would feel discouraged, concerned but would like to help
1589	Would have in order to prevent from getting things worse later
1590	Would try to help
1593	Would feel like it is a stone on my heart...but it would depend on severity, how close is the person, how much independence he/she has to live on its own and how much help he/she would need from me. In any case the news about any disorder would make me discouraged, at least in the beginning.
1601	I would be sad
1604	I am not sure
1606	I would react calmly
1611	Would continue living as we lived before
1613	It is too personal...
1614	Would seek more information about the disorder
1619	Would try to do the best I can to help
1627	Would seek more information about the disorder
1628	I would have to pay more attention and care
1630	I cannot imagine
1635	Not sure
1637	Would want to know more about the disorder, so that I would know how to behave and etc.
1643	Just continue to communicating as before