Parent Training Programmes for Families of Young Children with Autism Spectrum Disorder in China: Systematic Review and Real-World Mixed-Methods Evaluation

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To millions of invisible families of children with disabilities in China

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I, Zuyi Fang, hereby declare that this thesis is my own work, except where otherwise stated.

Signed: 

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ABSTRACT

Background

Autism Spectrum Disorder (ASD) is associated with elevated levels of child behavioural problems that limit child daily activities and impose challenges to parenting. Parent training programmes have been shown to be effective in improving the behavioural adjustment of children with ASD, but there has been limited evidence to date of the effectiveness of such programmes in China. This DPhil thesis involved: a) the conduct of a large systematic review of parent training programmes for families of children with a broad range of developmental disabilities in mainland China and b) a real-world evaluation of the effectiveness of a short-term intensive parent training programme, called Beijing Stars and Rain Education Institute for Autism (SREIA), delivered to Chinese caregivers of young children with ASD in the context of routine service provision.

Methods and Analysis

The systematic review involved a search of Chinese and English databases, as well as the grey literature. Where possible, multi-level meta-analyses were conducted to synthesise the data evaluating the effectiveness of such programmes in reducing child emotional and behavioural problems, improving parent-child relationships, and diminishing child abuse. Subgroup analyses and meta-regression were carried out to investigate treatment effects for different diagnoses, including ASD, as well as to explore potential moderators with a focus on the intervention and delivery components. Risk of bias was assessed for each study and outcome domain.

The SREIA programme was evaluated using a quasi-experimental design involving a mixed-methods approach. Participants were drawn from the SREIA programme waiting list. Data were collected at baseline and immediately post-intervention. The primary outcome was child behavioural problems measured by the Child Behaviour Checklist Externalising Scale. Secondary outcomes included child ASD symptoms, caregiver mental health, caregiver knowledge, parenting styles, and family function. Between-group comparisons were conducted using a difference-in-differences technique with propensity score weighting.

A process evaluation was undertaken in parallel to assess participant involvement, programme acceptability, and programme delivery. Qualitative in-depth interviews were conducted with caregivers who were identified based on participant attendance and engagement rates, and focus group discussions were held with all programme practitioners, with the purpose of developing a deeper understanding of the quantitative results and exploring the experiences of stakeholders in participating in and delivering the programme. Data collection was structured around three theoretical concepts - participant involvement, programme acceptability, and programme delivery - as well as stakeholder perceived changes and areas for improvement. Qualitative data were analysed using thematic analysis with a combination of data-driven and theory-driven approaches.

Results

The systematic review identified 20 randomised controlled trials and 11 quasi-experimental studies involving 2410 families of children diagnosed with ASD, Attention Deficit/Hyperactivity Disorder, Epilepsy, or Tourette Syndrome. Overall, the programmes

showed effectiveness in reducing child emotional and behavioural problems (g = -1.37, 95% CI [-2.03, -0.71]) and improving the parent-child relationship (g = 0.47, 95% CI [0.21, 0.73]). Only one study assessed the impact on child abuse, finding that the programme reduced physical and verbal harsh disciplines (RR = 0.51, 95% CI [0.28, 0.92]). A subset of ASD-focused programmes was found to have a large effect on child emotional and behavioural adjustment (g = -1.47, 95% CI [-2.42, -0.52]; 9 studies, 627 participants). Moderator analyses suggested that improving parental knowledge, self-regulation strategies, and empathy increased programme success, whereas the use of reinforcement appeared to temporarily increase child behavioural problems. In terms of programme delivery methods, the systematic review found that programmes with a longer duration; a combination of group and individual sessions; rapport building; ongoing communication extended beyond sessions; and delivery in hospitals or service agencies, were more effective. However, the risk of bias was generally high across studies and outcome domains. Another feature of the included programmes was their brevity, although parent training programmes for ASD can often be delivered with higher intensity in contexts such as China, where the need for such programmes is greater. Moreover, there was an absence of evaluations of programmes delivered as part of routine services. The findings of the review highlighted the need for an evaluation of a more intensive parent training programme within a Chinese context of routine service delivery.

The final sample size for the real-world SREIA evaluation was 111, with 63 caregiver-child dyads in the treatment group and 48 dyads in the waitlist control group. The statistical analyses showed that the programme successfully reduced child externalising behaviours (b =

-2·71, 95% CI [-5·23, -0·18]; Cohen's *d* = -2.80), compared to the waitlist control group. It was also effective in increasing parental knowledge of Autism and child development (*b* = 2.08, 95% CI [2.07, 2.17] ; *d* = 2.91), reducing parental mental health symptoms (*b* = -5.96, 95% CI [-11.74, -0.17] ; *d* = -2.89), and diminishing over-reactive parenting (*b* = -0.63, 95% CI [-0.98, -0.27]; *d* = -5.02). An investigation of version differences found that the version with a smaller group size was more effective in reducing externalising problems (*b* = -3.77, 95% CI [-6.26, -1.28]; *d* = -4.26), improving parental mental health (*b* = -12.52, 95% CI [-19.87, -5.18]; *d* = -4.79), and increasing parental knowledge (*b* = 3.03, 95%CI [1.82, 4.24]; *d* = 7.05), while the other version with a larger group size had a greater treatment effect in reducing parental over-reactivity (*b* = -0.72, 95% CI [-1.15, 0.28]; *d* = -4.68). However, the version analysis was underpowered and thus should be interpreted with caution. The programme had high levels of participant attendance, engagement, and satisfaction. Exploratory analyses suggested that initial parent mental health concerns were inversely related to participant engagement, and that higher satisfaction and engagement could potentially increase treatment effects.

The qualitative study identified two caregivers from each of the seven caregiver groups based on their levels of attendance and engagement as rated by programme practitioners on a daily basis, resulting in 14 caregivers participating in the in-depth interviews. Two focus group discussions were conducted with four programme practitioners in each group. Results of the qualitative data highlighted the benefits of practice and feedback during and between sessions, flexible mentoring, peer support, and ASD information that is delivered in the initial sessions, as well as the need for more individualised coaching, ASD-related resource sharing, formal

mental health support, structured activities for children, brief training for other family members, and organisational resources for practitioners.

Conclusion

Overall, this DPhil thesis provides support to the implementation of programmes that combine parent training and support to caregivers of children with ASD, especially in areas where there is a paucity of ASD-related resources and substantial unmet family need. This thesis also identifies the need for better organisational infrastructure to improve practitioner capacity, offer them mental health support, and reduce their workload. Moreover, it demonstrates the feasibility and advantages of conducting rigorous mixed-methods evaluations in real-world conditions, with the purpose of building the evidence base in low-resource settings. This thesis calls for closer partnerships between implementers, researchers, and programme end users; and for more research to investigate the implementation and effectiveness of parent training programmes delivered in low- and middle-income countries.

Ethics and Registration

Ethics for the systematic review was granted by the Departmental Research Ethics Committee at the University of Oxford in the UK (SPI_DREC_17_049). Ethics for the evaluation study was granted by the Social Science and Humanities Inter-Divisional Research Ethics Committee at the University of Oxford (R67619/RE001) and the Research Ethics Committee at the School of Social Development and Public Policy of the Beijing Normal University (SSDPP-HSC2020001). The SREIA evaluation protocol was registered in ClinicalTrials.gov (NCT04257331).

Keywords

Parent Training, Autism Spectrum Disorder, Behavioural Problems, Multi-Level Meta-Analysis, Quasi-Experimental Design, Difference-in-Differences, Propensity Score Weights, Thematic Analysis, Mixed-Methods Design

LIST OF ACRONYMS

ABA: Applied Behaviour Analysis

ADHD: Attention Deficit Hyperactivity Disorder

AOPS: the Arnold-O'Leary Parenting Scale

ASD: Autism Spectrum Disorder

APGAR: the Adaptability, Partnership, Growth, Affection, and Resolve questionnaire

ASMD: absolute standardised mean differences

ATEC: the Autism Treatment Evaluation Checklist

CBCL: Child Behaviour Checklist

CEBP: child emotional and behavioral problems

CI: confidence interval

DASS-21: the Depression Anxiety Stress Scale-21 items

DD: Developmental Disabilities

DiD: difference-in-differences

DTT: Discrete Trial Training

EIBI: Early Intensive Behavioural Interventions

FGD: focus group discussion

HIC: high-income country

ICC: intra-cluster correlation coefficient

IPW: Inverse Probability of Treatment Weighting

KM: Kernel Matching

LMIC: low- and middle-income country

NGO: non-governmental organisation

OW: Overlap Weighting

PARYC: the Parenting Young Children Scale

PET: Parent Education and Training

PLH: Parenting for Lifelong Health

PS: propensity score

PSM: propensity score matching

PSW: propensity score weighting

RCT: randomised controlled trial

REML: Restricted Maximum Likelihood

RoB: risk of bias

SDQ: the Strength and Difficulties Questionnaire

SMD: standardised mean difference

SREIA: Beijing Stars and Rain Education Institute for Autism

SSTP: Stepping Stones Triple P

TAU: treatment-as-usual

VABS-II: the Vineland Adaptative Behaviour Scales

WHO: World Health Organisation

CHAPTER 1. INTRODUCTION

1.1. Background

1.1.1. Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterised by impairments in reciprocal communication and social interaction, restricted interests, and repetitive and/or restrictive behaviours (American Psychiatric Association, 2013). Individuals with ASD have difficulties in understanding social cues, having conversations, and sharing interests. They also demonstrate inhibited stereotyped movements, strict adherence to routines, strong attachment to narrow interests, and unusual responses to sensory inputs. The symptoms typically appear during the early years and persist into adulthood. ASD occurs along a continuum, such that individuals show wide variation in terms of their functioning and difficulties as opposed to exhibiting distinct symptoms (Kerns et al., 2015). Around 70% of children with ASD are comorbid with one or more further psychiatric diagnoses (Simonoff et al., 2008b).

While the global incidence and/or prevalence of childhood ASD is not yet well established, over the last half century, epidemiological studies have consistently suggested that there is a trend toward increasing numbers of children being given ASD diagnoses. For example, in the past two decades, the global prevalence of children diagnosed with ASD has risen from less than 1 per 1000 to 1 per 160 children (WHO, 2017). Research also suggests that rates of ASD are likely to be higher in low- and middle-income countries (LMICs) than in high-income countries (HICs) due to the accumulation of adversities beginning before conception and

continuing throughout prenatal and early life (Black et al., 2017; S. P. Walker et al., 2011).

1.1.2. Clinical picture in China

China's very large population means that there is a bigger than usual impact in terms of ASD. As with most LMICs, there is no national data regarding the childhood ASD population in mainland China and estimates of ASD prevalence vary substantially. A systematic review that involved the conduct of a search of both English and Chinese databases, identified 44 studies involving 2.3 million children, showing that the pooled prevalence was around 0.4% (F Wang et al., 2018). Consistent with the systematic review, a recent large regional study involving more than 45 thousand children in three cities, found the prevalence of ASD to be around 0.2-0.4% when the data was drawn from special schools, and 1% when both mainstream and special schools were surveyed, both of which are in line with estimates for Western countries (X. Sun et al., 2019). According to the Seventh National Population Census, China had approximately 310 million children aged between 0 to 17 by 2020 (National Bureau of Statistics of China, 2021), suggesting that there could be in the region of 3.1 million children potentially meeting diagnostic criteria for ASD.

1.1.3. Consequences of ASD

It is widely recognised that children with ASD are two to three times more likely to experience co-occurring emotional and behavioural disturbance than their typically developing cohorts, or cohorts with other developmental disabilities such as Intellectual Disability and Cerebral Palsy (Iizuka et al., 2010; C. R. Johnson et al., 2007; O. Murphy et al., 2009; Totsika

et al., 2011). Kaat and Lecavalier (2013) reviewed 55 studies of disruptive behaviour disorders in children with ASD and found that in general, around 25% of children with ASD were comorbid with Oppositional Defiant Disorder or Conduct Disorder. The co-occurrence with other disability problems of this nature can compound ASD conditions, resulting in further limitations in children's daily activities, interfering with skill acquisition, and imposing more challenges to parenting (Georgiades et al., 2011; J. L. Matson et al., 2009; Palusci et al., 2015; Tellegen & Sanders, 2014).

ASD has, as such, historically been associated with a higher risk of psychological problems and greater exposure to chronic diseases in caregivers (Griffith et al., 2010; Richard Patrick Hastings, 2002; Richard Patrick Hastings et al., 2005; Richard Patrick Hastings, 2008; Lecavalier et al., 2006; J. L. Matson et al., 2009; Montes & Halterman, 2007; Totsika et al., 2011). It is also linked to social marginalisation and stigma (Mak & Kwok, 2010; McCabe, 2008; Meirsschaut et al., 2010; Woodgate et al., 2008). The daily parenting difficulties and the lack of social support can also lead to dysfunctional family relationships, creating additional stress and further limiting the potential for child development (Belsky, 1993; Tonge et al., 2006).

Child emotional and behavioural problems and parental stress are important predictors of harsh discipline, which can sometimes be sufficiently severe to constitute child abuse (Patterson, 1982; Tolan et al., 2006). Child abuse is one of the most serious factors undermining healthy child development and its negative impacts have been documented across a range of domains including cognition, language, socio-emotional development, and mental and physical health (World Health Organisation, 2014). Research conducted in HICs shows a higher risk of abuse

among children with disabilities, including ASD (Jones et al., 2012). The limited research available also tends to suggest that LMIC contexts pose even more challenges, including poverty, limited awareness of the condition, a scarcity of good quality services, and social isolation (I. Brown & Schormans, 2014; Guo et al., 2014).

1.2. Interventions

This section introduces parent training programmes in general, followed by a detailed description of parent training programmes designed for the ASD population.

1.2.1. Parent training

Parent training is widely used to support families of children with behavioural problems in the general population. Training models are usually based on social learning theory (Bandura, 1971), operant learning theory (Skinner, 1950), the coercion model of interaction (Patterson, 1982), and attachment theory (Bowlby, 1969). They are aimed at improving child emotional and behavioural adjustment, promoting positive parent-child interactions, reducing parental stress, and increasing positive parenting knowledge and skills (Altafim & Linhares, 2016; Montgomery et al., 2009; Vlahovicova et al., 2017). These programmes often share common strategies such as positive reinforcement, parent-child play, disciplinary techniques (such as time-out and ignoring), and emotion coaching, in addition to incorporating unique intervention components to address particular concerns (Baker-Henningham, 2011; Cluver et al., 2016; Leijten et al., 2019). A variety of delivery techniques are used in parent training programmes, such as didactic teaching, modelling, and role play. Programme duration and intensity vary,

ranging from single sessions to more intensive provision (Frances Gardner et al., 2016; Leijten et al., 2016). Programmes can be delivered individually, on a group basis, or using a mixture of both, by professionals and/or trained non-professionals. Most parent training programmes are manualised and require adherence to the protocol (Skotarczak & Lee, 2015).

There is a significant body of evidence, involving the use of rigorous research designs, that shows the effectiveness of parent training in reducing child behavioural problems, increasing parental knowledge, improving parent-child relationships, reducing harsh parenting, and improving parental mental health for families of typically developing children (Altafim & Linhares, 2016; Jane Barlow et al., 2014; Coren et al., 2010; Furlong et al., 2012; Knerr et al., 2013; Leijten, Gardner, Landau, et al., 2018; Mejia et al., 2012). Studies have also indicated that parent training interventions can be transported across cultures and settings (Baker-Henningham, 2011; Frances Gardner et al., 2015; Leijten et al., 2016).

1.2.2. Parent training for ASD

Most comprehensive treatment packages for children with ASD involve parent training components to various degrees (C. R. Johnson et al., 2007; National Research Council, 2001; Steiner et al., 2012). The complex needs of ASD families have resulted in the development of a range of training programmes for parents/caregivers and wide variation in the terminologies used to describe them including *caregiver training* (Drew et al., 2002; Gengoux et al., 2015; Ingersoll & Dvortcsak, 2006; Jeanne Beaudoin et al., 2014; M. L. Matson et al., 2009; Oosterling et al., 2010), *parent education* (Steiner et al., 2012), *parent learning* (Nefdt et al., 2010), *parenting intervention* (Poslawsky et al., 2015; Koa Whittingham et al., 2009), *parent-*

mediated intervention (Nevill et al., 2018; Oono et al., 2013; Parsons et al., n.d.; Pickles, Le Couteur, Leadbitter, Salomone, Cole-Fletcher, Tobin, Gammer, Lowry, Vamvakas, Byford, Aldred, Slonims, Mcconachie, et al., 2016), *parent-implemented intervention* (McConachie & Diggle, 2007), *parent-assisted intervention* (Laugeson et al., 2009), and *parent-child therapy* (Solomon et al., 2008). The formats differ, comprising self-learning, one-to-one consultation, and group training (Schultz et al., 2011). The intensity also varies from one to 25 hours per week (Oono et al., 2013), as well as the duration, which ranges from one week (Nefdt et al., 2010) to multiple years (Dawson et al., 2010).

In fact, there is a long history of parent training for ASD. Some involve parents as change agents for their children, targeting core ASD symptoms or child maladaptive behaviours, while others provide psychoeducation and care coordination (Bearss et al., 2015a). Parent training programmes for ASD often draw on Applied Behaviour Analysis (ABA), which is grounded in social learning and operant conditioning theory (Bandura, 1971; Cooper et al., 2007; Skinner, 1950). ABA aims to change target behaviours by changing the child's environment. It emphasises the observation of behaviours, identification of functional relationships between behaviours and consequences, careful management of environmental stimuli, and systematic recording of the change process to inform future interventions (Cooper et al., 2007; Odom et al., 2003). Lovaas (1987) evaluated an intensive ABA-based intervention (named as the University of California at Los Angeles Young Autism Project, which originated from the conceptual model introduced by Lovaas, Koegel, Simmons, and Long in 1973) that lasted for 2 years with 40 hours per week for young children with ASD. The study found that the treatment

group (n=19) achieved higher IQ scores at post-intervention, compared to the control groups (n=40) who either received a behavioural intervention with a much lower intensity or treatment-as-usual. The finding resulted in the wide advocacy and implementation of ABA-based Early Intensive Behavioural Interventions (EIBI), as they then became known, for children with ASD.

EIBIs are typically initiated with children between 2 to 4 years of age. They are delivered systematically using a manual in highly structured settings, on a one-on-one basis, and with an intensity of up to 50 hours per week for no less than 2 consecutive years. They aim to improve a wide range of skills (including cognitive, language, social, and adaptive living skills) and involve the use of a functional analytic approach to reduce challenging behaviours (Healy & Lydon, 2013; Reichow, 2012; Reichow et al., 2018; I. M. Smith et al., 2010). At the core of early EIBI is Discrete Trial Training (DTT), which includes discrete components and teaches children one component at each trial. DTT trials involve a three-step contingency: 1) an adult's demonstration of a hint (*Antecedent*, e.g. pointing to a toy), 2) the child's response to the hint (*Behaviour*), and 3) the result of the child's response (*Consequence*, e.g. a reward for the child grabbing the toy) (Delpratol, 2001; Fitzer & Sturmey, 2009; Meyer et al., 1965; Tristram Smith, 2001).

An important aspect of EIBI is the involvement of parents as co-therapists. While children work with licensed providers on an intensive basis, parents also receive training in a range of techniques so that they are able to assist the providers and implement the strategies to extend the effects of the intervention beyond the sessions (Healy & Lydon, 2013; National Research Council, 2001). Lovaas et al. (1973) found that children's skills were more likely to be

maintained when their parents were trained to carry out the techniques at home, compared with children's skills that were not enhanced by parental intervention outside the clinical setting, which tended to fade. As such, training that explicitly focuses on caregivers has become an essential part of ASD treatment packages (Brookman-Frazee et al., 2006; Ingersoll & Dvortcsak, 2006; R L. Koegel et al., 1982; Sheinkopf & Siegel, 1998). This also reflects the fact that despite the numerous hours that children may spend in clinical settings, the role of caregivers in promoting child development is unique, and parents can maintain the delivery of the intervention and thereby maximise child development (Ingersoll & Dvortcsak, 2006; Oono et al., 2013; Steiner et al., 2012; Tonge et al., 2012).

While EIBIs have increased in popularity since the late 1980's, the validity of the initial trial conducted by Lovaas (1987) has been increasingly questioned, in particular with regard to the baseline comparability of treatment arms, the adequacy of the outcome measurement, lack of blinded evaluators, and the failure to include children with severe ASD symptoms (Connor, 1998; Gresham & Macmillan, 1997). More importantly, concerns were raised about the efficacy of the highly structured EIBI models (H. Cohen et al., 2006; Reed et al., 2007; Tristran Smith et al., 2000). Researchers pointed out that such interventions resulted in children's inability to generalise skills across situations, an absence of spontaneity, an overdependence on prompts, and an increase in avoidance behaviours (J. L. Matson et al., 1996; Schreibman, 1997).

The need to advance ASD treatments co-occurred with the progress of early developmental theories, which suggested that there were more similarities than differences between the developmental trajectories of children with and without ASD (Mundy et al., 1987;

Tager-Flusberg et al., 1990), thereby leading to the evolution of training programmes for ASD from a rigidly structured ABA approach to one involving a combination of ABA-based strategies and developmental theories (Schreibman et al., 2015). Early developmental theories highlighted the importance of engaging children as active learners, following children's developmental sequences, connecting new skills to children's existing knowledge, and establishing affective interactions between children and caregivers/therapists to promote social exchange (Bruner, 1978; E. J. Gibson, 1973; Kuhl, 2000; Kuhl et al., 2003; Vygotsky, 1964). As such, training programmes for ASD started to develop a more naturalistic treatment approach, with the purpose of promoting skill generalisation and child spontaneity (E. G. Carr & Kologinsky, 1983; R. L. Koegel & Koegel, 2006). For example, materials, activities and rewards were selected according to children's interests (Dunlap & Koegel, 1980; Robert L. Koegel et al., 1987). Developmental prerequisites (such as joint attention and imitation, which are fundamental to learning and social interaction for all ages) were targeted to set the stage for more advanced skills and development across domains (R. L. Koegel & Koegel, 2006; Rodger & Lewis, 1989). Challenging behaviours were viewed in terms of the child's developmental stage, and behaviour management strategies were individually designed to be appropriate for children's developmental level (McGee & Daly, 1998). The most widely implemented and evaluated models of such naturalistic behavioural interventions include Pivotal Response Training (PRT) (R. L. Koegel & Koegel, 2006), Incidental Teaching (McGee & Daly, 2007), and the Early Start Denver Model (ESDM) (Rogers & Dawson, 2010). Some of them also target socio-communicational difficulties that contribute to child behavioural difficulties. The fact of

'being natural' makes these models highly suitable for parent training (Schreibman et al., 2015; Schreibman & Koegel, 2005). However, a major drawback of those programmes is their high intensity, as they can often require caregiver daily involvement for consecutive years (Bearss et al., 2015a), such as the Early Start Denver Model (ESDM), in which caregivers devote 16 hours per week for two years (Dawson et al., 2010).

In addition to the above programmes, a number of briefer programs for parents of children with ASD have been developed, aimed at empowering ASD families by providing psychoeducation and helping parents navigate services (Bearss et al., 2015a). These programmes are usually attended only by parents, rather than parent-child dyads, and as such need to be implemented in conjunction with child-focused interventions to address the child development issues. They are thereby more appropriate in settings where there are adequate ASD-related services, and their use is as such limited due to the lack of wider services, even in high-income areas (Clubb, 2012; Cutress & Muncer, 2014; Kogan et al., 2008; Liptak et al., 2008; Ravn Andersen et al., 2017; K. C. Thomas et al., 2007; V. C. N. Wong & Hui, 2008).

As a result, parent training programmes that combine the advantages of both intensive and brief types of programme have been increasingly advocated as an alternative (Healy & Lydon, 2013; Masse et al., 2016; Nevill et al., 2018; Suppo & Floyd, 2012). For example, Dawson-Squibb, Davids, & de Vries (2019) advocated the implementation of Parent Education and Training (PET), which involves parents as the direct participants, with or without the child being present. The emphasis of PET is knowledge transfer, including both parent-centred components (such as peer support, mental health, and self-efficacy) and child-focused content

(such as teaching caregivers evidence-based techniques of behaviour management and child skill development) (Karst & van Hecke, 2012). Such programmes can be tailored to varying degrees to the needs of each family. As with the cognitive-behavioural parent training programmes for families of typically developing children, PET programmes can be delivered on a one-on-one basis or in groups, or a combination of the two formats; and take place at home or in community settings, or a mixture of both. Delivery strategies typically include didactic teaching, modelling, in vivo practice, and feedback. Sessions can be conducted in person or online (Lang et al., 2009; McConachie & Diggle, 2007; Nevill et al., 2018; Oono et al., 2013; Postorino et al., 2017; Schultz et al., 2011; Singer et al., 2007; Skotarczak & Lee, 2015; Steiner et al., 2012; Strauss, Mancini, SPC Group, et al., 2013). Additionally, they aim to develop a collaborative relationship between practitioner and caregiver, and use a strength-based approach to empower participating families (Brookman-Frazee & Koegel, 2004).

1.2.3. Systematic reviews of the effectiveness of parent training programmes for ASD

Although it is widely recognised that parent training is critical for the treatment of ASD, there is still a limited number of studies evaluating parent training as a stand-alone programme using controlled trials (Nevill et al., 2018; Postorino et al., 2017). Also, despite an increasing number of parent training programmes for children in non-English speaking countries, prior reviews commonly do not include these studies, mostly due to language and database biases (Shenderovich et al., 2016). This section describes the results of existing systematic reviews of parent programmes for ASD.

Four systematic reviews (Nevill et al., 2018; Oono et al., 2013; Postorino et al., 2017;

Strauss, Mancini, SPC Group, et al., 2013) have quantitatively synthesised the effectiveness of parent training programmes for parents of children with ASD in reducing child behavioural problems, improving child development, and promoting parent-child interactions. Three of them included parent training programmes combining parent-centred and child-centred components, showing that the programmes were effective in diminishing *child behavioural problems* (Postorino et al., 2017); reducing *ASD symptoms* (Nevill et al., 2018; Oono et al., 2013); promoting *parent-child interaction* (Oono et al., 2013); and improving *child language and communication, cognitive, and social skills* (Nevill et al., 2018), for children with ASD aged one to 14 years. The remaining review synthesised evidence from six systematic reviews on Early Intensive Behavioural Interventions, showing that the interventions involving caregivers as treatment providers promoted *child cognitive, language, and adaptive living skills* for children aged two to five (Strauss, Mancini, & Fava, 2013). The programmes identified by the four reviews were all evaluated in high-income countries (including USA, UK, Australia, Canada, and Netherlands) with one exception in Thailand.

Appendix 1 presents a brief overview of all the programmes included in the four systematic reviews, including the programme name, content, dose, delivery, child age, country, trial design, and outcome measures.

1.3. Rationale for the Use of Evidence-Based Parent Training in China

This section describes the rationale for delivering parent training programmes in China. Evidence-based parent training programmes are necessary in mainland China for the following reasons: 1) the financial burden in families of children with ASD, 2) a paucity of local service

provision, 3) a burgeoning need to improve caregiver outcomes, such as self-efficacy, social inclusion, and psychological support, and 4) Chinese traditional beliefs in harsh parenting.

Access to ASD services is often prohibited by the cost of treatments. A survey involving 3581 caregivers of children with ASD from all but one provincial-level administrative division in China, showed that the cost of ASD treatments in mainland China could amount to an average of 8,000 RMB (around 885 GBP) per month, which was affordable in only 13.8% of the interviewed families (China Association of Persons with Psychiatric Disabilities, 2015). Despite the economic burden, half of the families were reported to receive no state financial support. The explanation for this was three-fold. First, local governmental support is insufficient. ASD treatment is not currently included in the national insurance; and the Minimum Living Guarantee System (called as *Dibao*, the social safety net in China) provides subsidies of no more than several hundred local currency per month, with variations in different areas, such as 210 RMB (23 GBP) for urban residents in Guangzhou, 100-300 RMB (11-33 GBP) in Beijing, and 150-300 RMB (17-33 GBP) in Shanghai. The rates for rural residents tend to be even lower than those for urban residents (Beijing Government, 2016; Guangzhou Government, 2018; Shanghai Goverment, 2016). Second, research shows that 50% to 70% of caregivers of children with ASD are unaware of relevant policies, leading to the underuse of resources that are already sparse (China Association of Persons with Psychiatric Disabilities, 2015; P. Liu & Liu, 2018). Third, parents are reluctant to apply for state financial support, due to the complex process of obtaining a Disability Certificate, which is a prerequisite for access to state benefits. Parents are also concerned that labelling their children as being ‘disabled’ can

further contribute to social isolation (Fang Wang & Yang, 2017; L. Wu, 2018). While early interventions have been advocated to optimise child outcomes in ASD (Courchesne et al., 2011; National Research Council, 2001; Sandbank et al., 2020), the prohibitive costs can result in young children missing the 'critical' period of intervention and in aggravating parental psychological distress (Rivard et al., 2014, 2015). This necessitates a cost-friendly alternative, such as parent training (Guo et al., 2014).

ASD service provision in China is characterised by parent self-help and peer support (P. Liu & Liu, 2018). Chinese caregivers of children with ASD pioneered the local ASD service and advocacy programmes. For instance, the first agency—the Beijing Stars and Rain Education Institute for Autism (SREIA)—to offer training for families of children with ASD in mainland China, was established by a mother of a child with ASD in 1993. It was not until ten years later that the number of service agencies started to increase. By 2018, there were 1611 agencies providing ASD treatments, with over 70% being NGOs and 50% established by mothers of children with ASD (China Association of Persons with Psychiatric Disabilities, 2015; China Disabled Persons' Federation, 2018; Sichuan Normal University, 2019). Most agencies offered ABA-based child interventions, with 77% also providing support for caregivers (Clark et al., 2019; Sichuan Normal University, 2019). Despite an increasing number of agencies, the service gap remains substantial due to low service capacity. A study involving 57 service agencies across 18 provincial-level divisions in China showed that almost half were not able to enrol more than 50 families per year and a further third could serve only 51 to 100 families annually. Moreover, only ten percent of them were specialised in ASD, with the

remaining agencies recruiting a range of developmental disabilities (Sichuan Normal University, 2019). The development of ASD service agencies in China is primarily constrained by the shortage of personnel and funding. There is a lack of ASD-related education and qualifications (P. Liu & Liu, 2018). Most agencies, including the SREIA, receive no funding from governments and rely on donations (China Association of Persons with Psychiatric Disabilities, 2015). This general lack of services continues to motivate Chinese caregivers to seek training opportunities, so that they can become the child's educator. Further, like the previous generation of caregivers of children with ASD, by learning the techniques, they hope to become trainers themselves and offer help to more families who experience similar challenges (McCabe, 2007, 2008).

Parent training programmes are also needed to improve parental self-efficacy. The large survey involving 3581 Chinese caregivers of children with ASD found that more than half of those families had one parent who quit their job in order to provide child care, with ninety percent of them being mothers (China Association of Persons with Psychiatric Disabilities, 2015). According to the survey, 43% of the caregivers reported that they lacked knowledge about the ASD condition, and 79% said that they were not trained in any techniques to improve child skills or behavioural adjustment. As such, 85% emphasised a strong need for parent training programmes that are systematic and provide ongoing support (China Association of Persons with Psychiatric Disabilities, 2015). In addition, children with ASD often require prolonged care across the lifespan, leading to parental challenges in terms of long-term social isolation and persistent psychological stress (Davis & Carter, 2008; Richard Patrick Hastings

& Johnson, 2001; Karst & Van Hecke, 2012). This necessitates training programmes that not only improve parenting skills but also empower caregivers to overcome a wider range of difficulties. For instance, 81% of the participants in the large survey highlighted the potential benefit of peer support (China Association of Persons with Psychiatric Disabilities, 2015).

Traditionally, corporal punishment is considered in China to be an effective and legitimate parenting practice that promotes diligence, integrity, and obedience (M. Wang & Liu, 2014). Such disciplinary practices are further viewed as representing a sign of parental affection (Qiao & Xie, 2015). As a result of the fact that many caregivers of children diagnosed with ASD have expectations and understanding of behavioural capacity that are not appropriate to the child's developmental capacity (X. Hu et al., 2015), children with ASD may be subjected to harsh parenting. The high level of parental stress in this population of parents further increases the implementation of dysfunctional disciplinary practices, which in turn intensifies child behavioural problems and increases the likelihood of child maltreatment (Belsky, 1993; Pinderhughes et al., 2000), with no comprehensive detection and reporting system for child maltreatment yet established. This again points to the need for preventative parent training programmes to be put in place.

1.4. Objectives of the DPhil Project

This DPhil thesis consists of a systematic review of parent training programmes delivered in China, followed by a real-world evaluation of the SREIA parent training programme delivered to Chinese families as part of routine services. The systematic review had a broader scope than the evaluation by including a wider range of developmental disabilities and three

primary outcomes (see below). It involved the conduct of a subgroup analysis for ASD-focused programmes.

1.4.1. Systematic review

The systematic review had two objectives; the first was to assess the effectiveness of parent training programmes for families of children diagnosed with developmental disabilities in mainland China in decreasing child emotional and behavioral problems, improving parent-child relationships, and reducing child physical abuse. The second objective was to investigate potential moderators of such interventions, with a focus on identification of the most effective intervention and delivery components.

1.4.2. SREIA evaluation

The primary objective of the SREIA evaluation was to assess the effectiveness of the SREIA parent training programme for Chinese families of children with ASD aged three to six years in reducing child behavioural problems, in comparison to a waitlist control group. Secondary objectives included examining the effectiveness of the SREIA programme in reducing ASD symptoms and improving parental and familial outcomes, including parental knowledge, parenting styles, parental mental health, and family functioning.

A process evaluation was also conducted, with the purpose of 1) describing the implementation aspects of the programmes with regard to participant involvement, programme acceptability, delivery, and sustainability; 2) exploring predictors of participant involvement; and 3) examining potential relations between implementation aspects and treatment effects.

CHAPTER 2. METHODOLOGY AND METHODS

This chapter describes the overall methodology and methods for this thesis. It starts by providing an overview of the mixed-methods approach. It then describes the inclusion/exclusion criteria and three-level mixed-effects meta-analysis models used in the systematic review (Paper 1, Chapter 3) and the analytic designs used for the empirical study (Chapter 4 Paper 2 & Chapter 5 Paper 3). The subsequent sections describe the key methodological steps of the empirical study, including a description of the intervention, sample size calculation, and recruitment of participants; selection of measures; data collection, management, and analysis; and ethical considerations.

2.1. Methodology: A Mixed-Methods Study

Mixed-methods studies have been increasingly advocated as an approach to harnessing the advantages of qualitative and quantitative interventional research and bridging the science-practice gap (Southam-Gerow & Dorsey, 2014). While quantitative research assesses causal relationships and examines theories that have already been constructed using statistical methods, it does not explain the meaning behind the simple numeric results (R. B. Johnson & Onwuegbuzie, 2004). Qualitative research, however, is used to examine interventions from a more in-depth perspective, providing rich information about the context for delivery, the experiences of stakeholders, and the potential mechanisms of change.

Mixed-methods research aims to combine the strengths of quantitative and qualitative research, and offsets their weaknesses. In mixed-methods studies, researchers collect and analyse the two types of data and integrate findings from both to achieve a greater breadth and

depth of understanding (NIH Office of Behavioral and Social Science, 2018). For example, quantitative research is often underpinned by a positivist approach—which focuses on discovering laws of nature and generating causal relationships by operationalising variables (Park et al., 2020)—and qualitative research can be based on constructivist approach—which is underpinned by the premise that there is no single truth and that one's understanding of a phenomenon is always shaped by social and historical factors in one's environment (C. J. G. Lee, 2012). Mixed-methods researchers, however, adopt a pragmatic stance with regard to the issues of epistemology and ontology, putting an emphasis on the link between research findings and action, and focusing developing actionable knowledge (Onwuegbuzie & Leech, 2005).

Creswell and Clark (2018) proposed three core mixed-method designs: a) the convergent design, whereby quantitative and qualitative data are collected concurrently and then combined for analysis. The purpose is to compare the results and develop a more complete understanding of a phenomenon; b) the explanatory sequential design, which consists of two phases of study, with the quantitative data collection and analysis followed by the qualitative investigation to interpret the initial quantitative results and understand the intervention process; and c) the exploratory sequential design, which adopts a consecutive approach similar to the explanatory design, but typically comprises three phases; the first phase involves a qualitative component and informs the design of the quantitative component (such as measures, instruments, and interventions) in the second phase, which are then tested by a quantitative component in the third phase (Creswell & Clark, 2018).

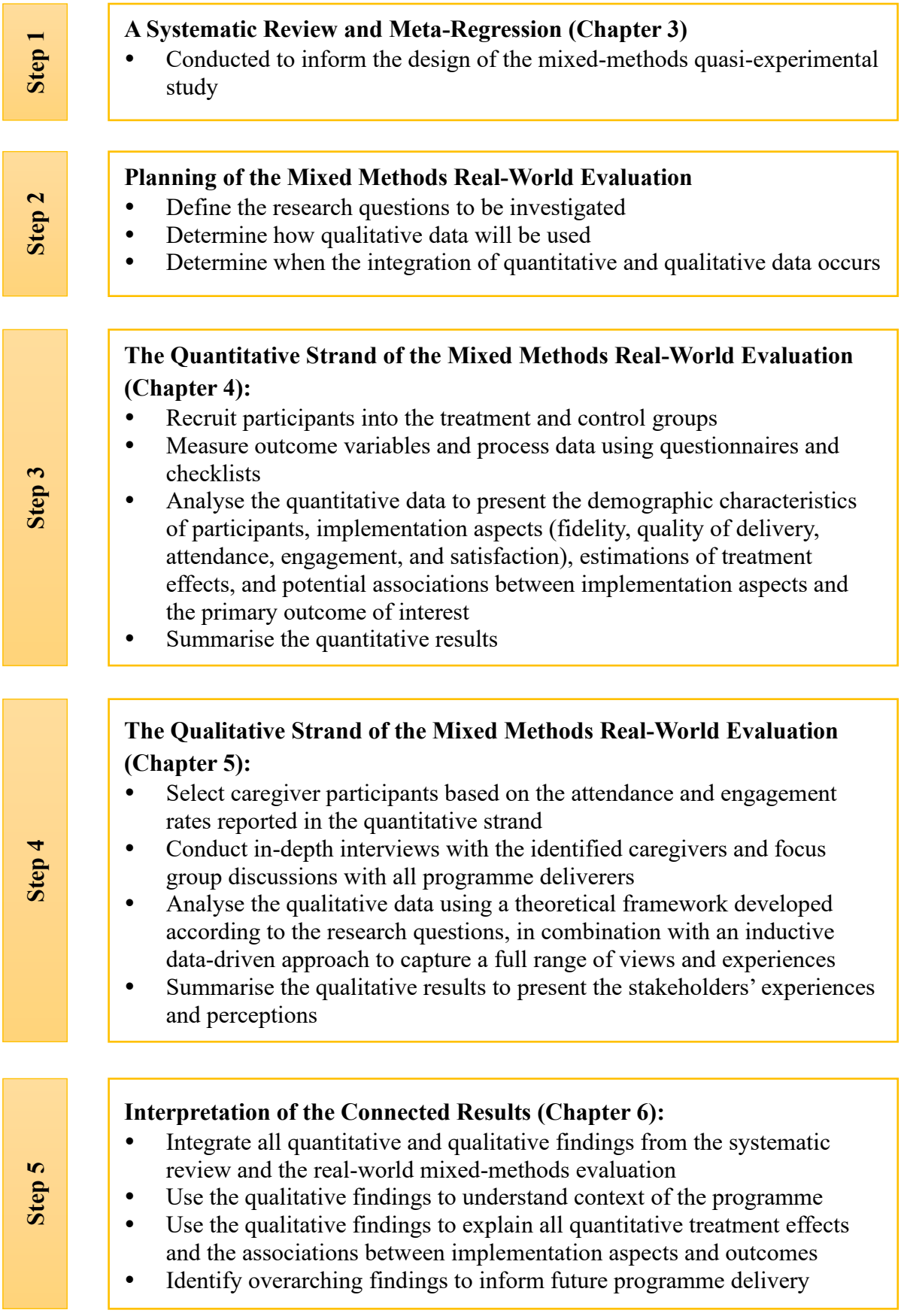
The empirical study in this DPhil thesis employed an explanatory sequential design, which

involved a qualitative component that was embedded into a quasi-experimental study to provide a comprehensive evaluation of a parent training programme delivered in China. The qualitative strand was nested within the quantitative component, and aimed at providing a detailed explanations of the quantitative results, including how caregiver participants and programme deliverers experienced the programme (Creswell et al., 2011).

Figure 1, adapted from Creswell and Clark (2018), presents the procedure for implementing the explanatory sequential design in this thesis. The first step involved the conduct of a broad systematic review and meta-regression to inform the design of a mixed-methods real-world evaluation. The second step involved developing the research questions for the mixed-methods real-world evaluation and determining how qualitative data would be used to complement the quantitative data collected in the mixed-methods real-world evaluation. For example, while the quantitative data primarily focused on the child and parental outcomes related to the intervention, the qualitative data prioritised an understanding of the implementation process. At this stage, a decision was also made to integrate the two strands at two time points. There is evidence showing that the outcomes of parent training programmes for caregivers of children with ASD (T. Carr et al., 2016b) and the general population (Baydar et al., 2003; Nix et al., 2009) are influenced by participant attendance and engagement. As such, the selection of caregiver participants who contributed to the qualitative data collection was based on the participant attendance and engagement rates reported by practitioners during the quantitative evaluation. Another integration then occurred on the completion of both strands when the two sets of results were combined to draw overarching conclusions.

During the third step of the explanatory sequential design, the quantitative evaluation was conducted to collect the numeric data using questionnaires and checklists. Analyses were performed to assess the baseline characteristics of participants, implementation factors (fidelity, quality of delivery, attendance, engagement, and satisfaction), treatment effects, and potential associations between implementation factors and the primary outcome of interest. Results from the statistical analyses were summarised to produce a general understanding of the outcomes and implementation. During the fourth step, the qualitative data collection was conducted. Caregiver participants with the highest and lowest attendance and engagement rates in each group (seven caregiver groups in total) were identified and invited into in-depth interviews. All programme deliverers were recruited into focus group discussions. Data collection focused on stakeholders' views regarding the acceptability of programme components, caregivers' engagement in the sessions, and practitioners' experiences of delivering the programme. Qualitative data were analysed using a combination of inductive and deductive approaches (illustrated more in section 2.6.5). The results were summarised to present details about stakeholders' views and overall experiences. In the final step, all results from the systematic review and the mixed-methods real-world evaluation were integrated to develop a deeper understanding of parent training programmes for ASD. The qualitative results were used to add insight and expand the quantitative results, as well as to contextualise the delivery of the intervention. Overarching findings were identified to inform future programme delivery.

Figure 1 Flowchart of the explanatory sequential mixed-methods design in this DPhil thesis



In addition to the power of integrating two sets of data, another advantage of the explanatory sequential design is that the quantitative and qualitative phases are conducted separately, collecting one type of information at a time (Creswell & Clark, 2018). This is more easily manageable when there is a small number of researchers in the team, such as in a DPhil project. However, a challenge of the sequential phases is the extended timeframe. Access to participants must be maintained after the completion of the intervention for qualitative interviews and data verification (Birt et al., 2016). Participants in this thesis remained accessible to the research team obtaining their contact details and connecting with them via a local messaging and social media platform called WeChat. Another caveat is that, for some mixed-methods research, the qualitative study cannot be pre-specified because the design and research questions may be dependent on results from the quantitative phase (Creswell & Clark, 2018). However, this thesis is able to avoid most of the uncertainties, as the framing of the qualitative study was primarily guided by theories (Brooks et al., 2015).

2.2. Study Methods: Systematic Review

Since the methodological aspects of the systematic review are presented in the Methods section of Paper 1 (Chapter 3 section 3.4), this section presents only the detailed criteria for considering studies for this review and explanation of the use of three-level mixed-effects meta-analysis models.

2.2.1. Inclusion and exclusion criteria

The inclusion and exclusion criteria were established using the PICO framework

(participant, intervention, comparison, and outcome) (Schardt et al., 2007).

2.2.1.1. Type of studies

Randomised controlled trials are studies in which participants are randomly allocated into different groups. Randomised controlled trials are considered the most rigorous design to investigate causality and minimise sources of bias (Blunt, 2015). Quasi-experimental studies do not conduct randomisation but identify a comparable control group. They are promising in assessing causal impacts when random allocation is not possible (Shadish et al., 2002). This review included studies that used randomised controlled trials or quasi- experiments. The review included control conditions of treatment-as-usual (including waitlist treatment and no treatment). Studies that offered alternative treatments to the control groups were excluded.

2.2.1.2. Type of Participants

Studies were only included in the review if they targeted parents or primary caregivers of children diagnosed with developmental disabilities aged from birth to 18 years old living in mainland China. Primary caregivers were taken to include grandparents, relatives, stepparents, and foster parents. Siblings under 18 years old who undertook childcare duties at home and adults who took care of children with developmental disabilities in non-residential settings were not regarded as eligible participants.

Developmental disabilities were defined as a set of severe, chronic conditions that 1) are attributable to mental or physical impairments; 2) are manifested before age 22; 3) continue indefinitely; 4) result in substantive limitations of three or more of the following major life

activity areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency; and 5) require a combination and sequence of special interdisciplinary or generic care treatment or other services that are of lifelong duration and are individually planned (US Department of Health and Human Services, 2000). Thirty-five DD diagnoses were searched, covering the most prevalent ones, such as Autism, ADHD, Epilepsy, Down Syndrome, Intellectual Disability, Cerebral Palsy, Tourette's Syndrome, and Traumatic Brain Injury.

Studies were included if they primarily targeted parents of children with developmental disabilities. Studies that included other types of participants (such as parents of children with other disabilities or parents of children without disabilities) were eligible only if over 50% of the participants met the inclusion criteria of the review, or where separate outcomes measures were available for the participants of interest. Studies were excluded if they were conducted in Hong Kong, Taiwan and Macao, which were classified by the World Bank as high-income areas (World Bank, 2017).

2.2.1.3. Type of interventions

Studies of parenting interventions were eligible for inclusion if they aimed at:

1. reducing child emotional (internalising) and behavioral (externalising) problems
2. or improving parent-child relationships, or creating healthy parent-child attachment
3. or reducing harsh parenting or child physical abuse

by increasing parental knowledge, improving parenting skills, changing parental attitudes, reducing parental stress, or improving parental self-efficacy.

Interventions had to have been delivered to parents or caregivers alone, or together with their children; however, the primary target was parents. Therefore, the time and components delivered to parents had to constitute at least 50% of the intervention, and the outcome had to have been measured separately for parents or there was evidence showing that the outcomes could be attributed specifically to the components targeting parents.

There were no limits in terms of the following criteria: underpinning theoretical framework, intervention duration, intensity, setting, format, year of delivery, or people who delivered the interventions.

2.2.1.4. Type of outcome measures

The three primary outcomes of interest were 1) child maltreatment and harsh parenting as measured by official reports or parent or child report, 2) child emotional (internalising) and behavioral (externalising) problems as measured by parents, service providers, or child report, and 3) parent-child relationships (including attachment, sensitivity, warmth, and interaction) as measured by parent or child report.

A wide range of secondary outcomes were considered, including 1) parental outcomes measured by diagnostic interviews or standardised self-report questionnaires, such as parental mental health, parental quality of life, parenting attitude, parental knowledge, family functioning, and programme satisfaction; and 2) child outcomes measured by standardised instruments, such as child social-communicational skills, cognitive development, adaptative living skills, sensory integration, comorbidity, and school performance.

The outcomes in this review could have been measured at different time points, including

post-intervention, short-term follow-up (within one year after intervention), and long-term follow-up (more than one year after intervention). The primary time point of interest was post-intervention.

2.2.2. Three-level mixed-effect meta-analytic models

This systematic review involved the conduct of several meta-analyses to combine individual effect sizes for the outcomes of interest, where appropriate. Meta-analysis is recognized as having several advantages over individual studies (Card, 2012; Hunter & Schmidt, 2014; E. Walker et al., 2008). First, the larger numbers increase the statistical power of the analysis, thereby improving the validity and precision of estimates. Second, the generalisability of the findings is increased when the included studies are conducted in diverse populations, which can thus better inform policy and practice. Third, with a larger sample size, meta-analysis allows for the assessment of moderators. Fourth, it enables the exploration of reasons for inconsistent findings across studies (such as different sampling strategies or publication bias).

This review included studies conducted in participants of different characteristics using different methods and assumed that the true effect size varied across studies. Hence, random-effect models rather than fixed-effect models were created to pool the treatment effects (Higgins & Green, 2011). Traditional random-effect meta-analytic models comprise two levels, with individual participants being level one and studies being level two. The equation can be built as below:

$$\hat{\theta}_k = \mu + \epsilon_k + \delta_k \qquad \text{(2-Level Model)}$$

where $\hat{\theta}_k$ is the estimate of the true effect size θ_k for study k. The two-level models are aimed at estimating the true population effect size on average (μ), assuming that the variance is caused by a) the sampling error of studies (ϵ_k), which leads to different estimates of effect size, and b) between-study heterogeneity (δ_k), which indicates that the true effect size of an individual study is part of the overall distribution of true effect sizes (Higgins & Green, 2011).

However, traditional two-level models cannot account for effect size dependence. Effect size dependence can be caused by, for instance, a study using multiple tools to measure one construct, or including studies conducted in different cultural contexts with participants and effect sizes within one culture being more similar than those in other distinct cultures. Ignoring the dependency can lead to type I error, rejecting a true null hypothesis (Cheung, 2014).

Some included individual studies in this review reported more than one estimate for an outcome of interest. In order to account for the effect size dependency, three-level mixed-effects models were created as follows:

$$\hat{\theta}_{ij} = \mu + \epsilon_{ij} + \delta_{(level\ 2)ij} + \delta_{(level\ 3)ij} \qquad \text{(3-Level Model)}$$

In the equation, $\hat{\theta}_{ij}$ is the estimate of the true effect size θ_{ij}, with ij denoting effect size i nested with cluster j. As the equation shows, an additional layer was added between the two levels of the traditional random-effect structure, so that multiple estimates of effect size were nested within individual studies (clusters) and that effect sizes within each cluster shared the same covariance (Cheung, 2008). The three-level mixed-effect models assumed that there were three sources of variance: the sampling error (ϵ_{ij}), the between-cluster heterogeneity ($\delta_{(level\ 3)ij}$, indicating that the true effect size of each cluster is part of the overall distribution

of true cluster effect sizes), and the within-cluster heterogeneity ($\delta_{(level\ 2)ij}$, showing that the true effect sizes of individual estimates within each cluster also follow a distribution). The final pooled effect size (μ) was the aggregation of all cluster effect sizes (Cheung, 2014).

2.3. Study Methods: Mixed-Methods Approach in the Empirical Study

This section presents the design of the two main components of the empirical study (Chapter 4 Paper 2 & Chapter 5 Paper 3).

2.3.1. Quantitative design – difference-in-differences and propensity score weighting

The quantitative strand of this mixed-methods evaluation uses a Difference-in-Differences design with Propensity Score Weighting. This section introduces this statistical design. The procedures undertaken to estimate the treatment effects are described in section 2.6.4.

2.3.1.1. Difference-in-differences

One main goal of intervention research is to draw causal inferences, which can be more straightforward when randomisation is conducted to minimise confounders (Tristram Smith et al., 2007). However, randomising participants into treatment groups is not always feasible, especially in the context of routine service delivery (Blunt, 2015). Observational studies are commonly used in these circumstances, such as the Difference-in-Differences (DiD) design.

DiD was pioneered by John Snow in his study assessing the effect of clean water on cholera mortality rates using a simple DiD model (Snow, 1855), and has been strengthened over the years since then to become one of the well-established observational designs to estimate treatment effects (Wing et al., 2018). The concept of DiD can be illustrated using a 2x2 table

(Table 1). It involves a treatment and a comparison group, like randomised trials, and combines a between-group comparison with a within-group comparison. In the DiD design, the pre-post difference in the treatment group ($\bar{y}_{e1} - \bar{y}_{e0}$) is considered as comprising not only the effect of the intervention but also the effect of secular time trends. The pre-post difference in the control group ($\bar{y}_{c1} - \bar{y}_{c0}$), however, allows for an estimation of those secular time trends, which can then be subtracted from the treatment group pre-post difference ($\bar{y}_{e1} - \bar{y}_{e0}$) to reveal the true intervention effect, as long as the time trends are similar across the two groups (Godard-Sebillotte et al., 2019). An alternative interpretation of the DiD model is that the between-group difference at post-intervention ($\bar{y}_{e1} - \bar{y}_{c1}$) is contaminated by important covariates of the outcome that differ between the two groups, but the impacts of those covariates can be removed by estimating the between-group difference at baseline ($\bar{y}_{e0} - \bar{y}_{c0}$) if the covariates remain constant in both groups over the course of the intervention (Fredriksson & Oliveira, 2019).

Table 1 A 2x2 DiD Table

	Treatment Group	**Control Group**	**Between-Group Difference**
Baseline	$\bar{y}_{e0}$	$\bar{y}_{c0}$	$\bar{y}_{e0} - \bar{y}_{c0}$
Post-Intervention	$\bar{y}_{e1}$	$\bar{y}_{c1}$	$\bar{y}_{e1} - \bar{y}_{c1}$
Within-Group Difference	$\bar{y}_{e1} - \bar{y}_{e0}$	$\bar{y}_{c1} - \bar{y}_{c0}$	$\text{DiD} = (\bar{y}_{e1} - \bar{y}_{c1}) - (\bar{y}_{e0} - \bar{y}_{c0})$ $= (\bar{y}_{e1} - \bar{y}_{e0}) - (\bar{y}_{c1} - \bar{y}_{c0})$

Rather than simple subtractions, the DiD is estimated using regression models, which allow for the adjustment of covariates and the testing of statistical significance of treatment effects (Stuart et al., 2014). Two methods are commonly used to build the regression model. In

the first, a long dataset is compiled with each individual having two observations representing the baseline and post-intervention time points, and the model can be created as follows:

$$y_{iet} = \alpha + \beta E_i + \gamma P_t + \delta E_i P_t + \varepsilon X_{iet} + \theta_{iet} \quad \text{(DiD M1)}$$

where y_{iet} is the outcome of interest observed for individual i in treatment group e at time point t. E_i represents the treatment condition (intervention versus control) of individual i. P_t is an indicator of time points (baseline versus post-intervention). X_{iet} denotes the covariate that is controlled in this model and that is exogenous. θ_{iet} is the error term at individual level. The statistical significance of coefficient δ in the interaction term $E_i P_t$ reflects whether the intervention can produce desirable outcomes (adapted from Fredriksson & Oliveira, 2019).

Alternatively, a wide dataset can be prepared with each observation representing a unique individual. Two separate variables are created for each outcome of interest to present the baseline and post-intervention scores. The regression model can be built as follows:

$$D_{ie} = \alpha + \beta E_i + \gamma X_{ie} + \varepsilon_{ie} \quad \text{(DiD M2)}$$

where D_{ie} denotes a new variable created by computing the pre-post difference score for each individual i. This time, statistical significance of coefficient β of the exposure term E_i indicates whether the intervention is effective. The two methods produce the same result, and the decision is often made based on the nature of data and software requirements. This thesis utilised the second approach, creating a wide dataset rather than a long one. Since the data collections occurred at the same time for every individual, this thesis was able to treat each outcome measure as different and non-interchangeable variables, which had their distinct distribution, and to simplify the regression model.

The DiD design relies on several assumptions. First, the secular time trends are similar or in parallel for the treatment and control groups, which is briefly touched upon in the 2x2 illustration table (Table 1). This means that, in absence of the intervention, the treatment group would follow the same trend in the outcome of interest as the control group (Fredriksson & Oliveira, 2019). The levels of outcome in the two groups may be different due to measured or unmeasured factors, but the difference should be constant during the intervention (Wing et al., 2018). This parallel trend assumption can be assessed in a series of sensitivity analyses. A typical assumption check involves conducting multiple pre-treatment data collections and investigating the trends between those pre-treatment time points. If the trends are comparable prior to the intervention, it is then plausible to expect that they would continue, should the intervention be absent (Fredriksson & Oliveira, 2019). Another sensitivity analysis involves running the DiD model using a placebo outcome that is known to be associated with the covariates but not with group assignment, or simply treating a covariate as the dependent variable (Godard-Sebillotte et al., 2019). The absence of a 'treatment effect' on the placebo outcome or the covariate provides support to the assumption that the distribution of covariates in the two groups are stable over time and not affected by the intervention (Wing et al., 2018).

Other assumptions of DiD are that there are no spillover effects that contaminate the control group by exposing them to some of or all intervention content (Godard-Sebillotte et al., 2019), and that the treatment and control groups must experience common shocks (external events, such as the COVID-19 pandemic), which should have a similar impact on both groups (Caliendo & Kopeinig, 2008; Dimick & Ryan, 2014). These two assumptions can often be

investigated through consultation and qualitative research conducted with stakeholders who are familiar with the contexts (Godard-Sebillotte et al., 2019).

However, even with the assumptions being maintained, the DiD design can still result in selection bias in which the treatment and control groups differ in some way resulting in confounding, which is the fundamental challenge of non-randomised studies (Stuart et al., 2014). The following section describes how the use of propensity score methods can address this challenge.

2.3.1.2. Propensity score approach

The term Propensity Score (PS) was first employed around forty years ago (Rosenbaum & Rubin, 1983) and refers to the probability of an individual receiving an intervention (Baser, 2006). Propensity scores are typically estimated with logistic regressions using covariates observed at baseline. They can be used to shift the distribution of baseline characteristics, so as to reduce selection bias and construct comparable groups to mimic a condition as if they are randomly assigned (L. E. Thomas et al., 2020a). The main benefits of PS are that it relies less on extrapolation, increases the validity of the estimation, simplifies multiple covariates into one number, and is conducted without using post-intervention measures, which is considered to be objective and not bias the analysis of treatment effects (Ho et al., 2007; Rubin, 2007).

There are in general two broad categories of PS methods: PS matching (PSM) and PS weighting (PSW). PSM finds for each individual in the treatment group one or more individual(s) from the control group who has or have the most similar PS score(s). The match can be determined in different ways, such as Kernel Matching, k:1 nearest neighbour radio

matching, stratified matching, and radium matching (L. E. Thomas et al., 2020a). Kernel Matching (KM) is the dominant method in the literature, and identifies for each observation in the treatment group a match from the control group whose propensity scores are within a certain distance (Garrido et al., 2014). Untreated participants who are more distant from the treated will contribute less to the outcome estimation, whereas those closer to the treated will contribute more. Each treated participant is then compared with a weighted average outcome of all participants in the untreated group (Baser, 2006). However, this method is sensitive to the selection of bandwidth, which is a problem for all Kernel regression methods (Caliendo & Kopeinig, 2008). Bandwidth determines the boundaries around an individual's propensity score, within which one receives a high weight. Large bandwidths increase model fit and diminish variances but introduce bias (Galdo et al., 2008).

A major limitation of all PSM methods is that they tend to discard observations when there is a lack of cases with similar PS scores, thus leading to a reduction of statistical power (Baser, 2006). This is of particular concern when the initial sample size is already small and the control group has fewer participants than the treatment group, which is the case in the empirical study of this thesis. A few critical decisions must also be made in terms of the selection of matching methods. For instance, what should the number of matches be in radio matching, given that multiple matches can reduce variance but may also introduce bias due to their different distances from the treated individual (Ho et al., 2007)? What radius is sensible, which needs to be predefined in radius matching (Dehejia & Wahba, 2002)? Should the matching be conducted with a control being used several times if the individual has a PS score similar to

multiple individuals in the treatment group, which may increase the analytic sample size but can influence the estimation due to the reduced independence between observations (Baser, 2006)? While some of the decisions can be avoided by using approximation (Rubin & Thomas, 2006) or variable ratio matching (Ming & Rosenbaum, 2001), others are less easy to address.

Unlike PS matching, PS weighting (PSW) does not necessarily exclude observations or involve the above-mentioned decision-making. PSW assigns a weight to each individual based on their PS scores and the outcome is estimated on the weighted sample. There are also multiple ways to compute PS weights (Stuart et al., 2014; L. E. Thomas et al., 2020a), such as Inverse Probability of Treatment Weighting and Overlap Weighting. With propensity score being $e(x)$, Inverse Probability of Treatment Weighting (IPW) weights each individual in the treatment group by $\frac{1}{e(x)}$ and those in the control group by $\frac{1}{1-e(x)}$ to estimate the average treatment effect (Austin & Stuart, 2015). Individuals with higher probabilities of participating in the treatment group will receive less weights, whereas those with lower probabilities will receive higher weights. IPW is among the most widely used PS weighting methods; however, it is known to produce extreme weights especially when the groups differ substantially at baseline, thereby creating large variance and potential bias (B. K. Lee et al., 2011; Stuart et al., 2014). A common solution is trimming, which involves removing participants with extremely high or low probabilities of being in certain group (Crump et al., 2009), which nonetheless reduces sample size and has limited guidance on the choice of cut-off point (Li & Thomas, 2019).

Another PSW method is Overlap Weighting (OW). OW weights each individual by their probability of being assigning to the other treatment group (L. E. Thomas et al., 2020b): those

in the treatment group are weighted by $1 - e(x)$, and those in the control group are weighted by $e(x)$. With this method, participants who have equal chance of being in either group will make the most contribution to the analysis, whereas those with extreme PS scores will receive smaller weights and contribute less in the analytic sample (Li et al., 2018). As the weights are bounded between 0 and 1, OW is less likely to be affected by outliers compared to IPW, thereby avoiding ad hoc trimming (Li & Thomas, 2019). Research shows that OW creates better balance than other weighting methods when logistic regression is used and that it reduces sample variance and improves the precision of treatment effects (Li et al., 2018; Mehta et al., 2020; Yunji Zhou et al., 2020). However, like all other PSM and PSW approaches, OW cannot account for unknown confounders (Li & Thomas, 2019; L. E. Thomas et al., 2020b).

The underlying assumption of PS methods is that there is no unobserved covariates leading to confounding effects on the group assignment and outcomes of interest—the ignorability or unconfoundedness assumption (Caliendo & Kopeinig, 2008; Godard-Sebillotte et al., 2019). However, unmeasured factors are not directly testable. To reduce potential bias, the estimation of PS scores and treatment effects should include covariates identified from the literature. Further, similar to examining the stability of covariate distribution between groups in the DiD design, a sensitivity analysis of PS approaches can be conducted by treating a baseline outcome measure as the dependent variable and estimating the intervention effect. An effect that is not statistically significant indicates no violation of the ignorability assumption (Imbens, 2004).

Another important step in PS methods is to assess the covariate balance between the

weighted/matched treatment and control groups. The model used to estimate PS scores needs to be adjusted until a satisfactory balance is achieved (Rubin, 2001). Covariate balance can be checked with numerical and graphical diagnostics. A typical numerical diagnostic is to compare the absolute standardised mean differences (ASMD), which is the mean group difference of each covariate divided by the standard deviation, before and after matching or weighting (Rosenbaum & Rubin, 1985). A rule of thumb is that the ASMD should be controlled under 0.1 (Rubin, 2001). Some graphical diagnostics involve the distribution of the propensity scores before and after the PS approach (Stuart, 2010), QQ plots comparing the distribution of each covariate in the two groups (Austin, 2009), and ASMD plots for the original and weighted/matched sample (Ho et al., 2007).

2.3.2. Qualitative design – framework analysis

The qualitative strand of this mixed-methods evaluation utilises a framework analysis design and analysed the data using codebook thematic approach to examine patterns across qualitative data. The thematic approach was chosen over other common qualitative approaches, such as qualitative content analysis, grounded theory, and discourse analysis, for the following reasons. First, the qualitative content analysis is often deemed atheoretical (Forman & Damschroder, 2008), whereas this study is shaped by existing implementation theories (section 2.5.4.1). Second, the grounded theory approach aims to develop a theory, rather than describing or interpreting data patterns (Judith Green & Thorogood, 2014). Moreover, grounded theory typically involves multiple iterations of data collection and analysis and is conducted using line-by-line coding and constant comparative analysis (Mays & Pope, 2000). However, these

were not feasible in this DPhil project, given the limited resource and timeframe. Third, discourse analysis view language as a form of social practice and is used to investigate the bi-directional relationships between language and the social context (Willig, 2003). This is beyond the scope of this study—understanding user experience of the SREIA programme.

Thematic analysis is aimed at capturing rich and detailed information about participant views and experiences (Clarke & Braun, 2017). Braun et al. (2019) proposed three broad categories of thematic analysis, including: 1) the coding reliability thematic approach, which is underpinned by a post-positivist epistemological stance—that is aimed at accessing an objective truth, thereby placing less emphasis on the influence of the researcher background and values—and adopts a straightforward, deductive orientation, in which the analytic process starts with a theory and takes a "top-down" approach. The coding reliability approach summarises all data into a predetermined coding frame. It aims to test hypotheses, prioritises the reliability and accuracy of results by using multiple coders, and focuses less on the depth of analysis (Boyatzis, 1998; Kidder & Fine, 1987); 2) reflexive thematic analysis, which is underpinned by a constructivist epistemological stance, emphasising thereby an inductive approach to the data analysis, in which researchers allow all codes and themes to emerge from the data, without any pre-conceived frameworks. This approach involves viewing meaning as contextually constructed and identifies patterns beyond the surface of the data. Codes and themes are allowed to emerge from data and evolve over the course of the analysis. Unlike the coding reliability approach, this approach considers researcher subjectivity as a resource that plays a critical role in generating insights and guiding the interpretation of the meaning of the

data (Brooks et al., 2015; Clarke & Braun, 2017); and 3) a codebook thematic analysis, which sits between the other two approaches. Similar to the coding reliability approach, codebook thematic analysis is also conducted using a pre-determined coding framework with multiple coding domains, but the framework is initially developed with a small subset of the raw data. New codes and themes are, however, allowed to emerge during the analysis of the full dataset and are used to modify the coding framework. This encourages an extensive exploration of data, based on a recognition of the complexity of participant experience. Results are interpreted under the guidance of theories and within a cultural and social context (Braun & Clarke, 2006; Brooks et al., 2015). This thesis uses the codebook thematic analysis approach, combining the inductive and deductive orientations. It leans towards positivist strand, as it is guided by implementation theories and incorporates the development of a coding framework (Brooks et al., 2015) into the traditional thematic analysis procedure described by Braun and Clarke (2006). Steps undertaken to perform the analysis are described in section 2.6.5.

2.4. Intervention, Sample Size, and Participants in the Evaluation Study

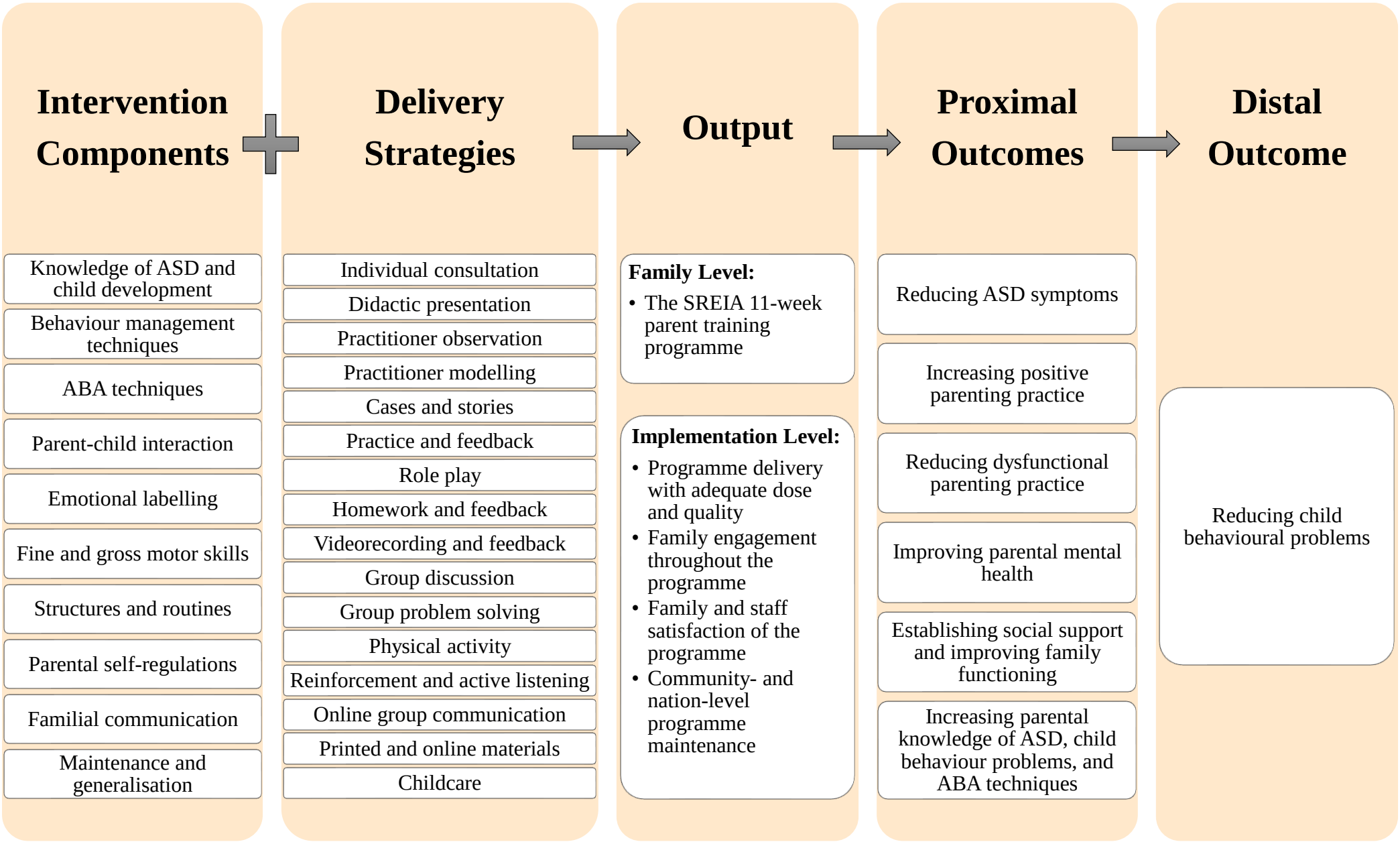
2.4.1. Intervention

The SREIA short-term intensive parent training programme has been delivered by a long-established NGO in Beijing to thousands of families of children with ASD in China since 1993. It is based on applied behaviour analysis (Cooper et al., 2007), social learning theory (Bandura, 1971), operant conditioning (Skinner, 1950), developmental (Schreibman et al., 2015), and cognitive behaviour theory (Beck & Weishaar, 1989). The programme targets parent-child

dyads from families of children with ASD aged between three and six years and is aimed at reducing child behaviour problems and promoting child development by increasing parental knowledge, improving parenting skills, changing parental attitudes, promoting parental mental health, reducing ASD symptoms, and creating social support. Children in this programme do not have to receive a diagnosis of oppositional defiant disorder or conduct disorder.

The SREIA logic model is presented in Figure 2. The logic model was created primarily by the SREIA supervisors with assistance of the researcher. Capacity training was conducted to introduce the concept of a logic model, including the role of a logic model in the evaluation and the illustration of linkages among programme elements. Additional training in the differences between intervention and delivery components; programme and process outcomes; and proximal and distal programme outcomes, was provided. Key programme theories (e.g., applied behaviour analysis, including discrete trial training; social learning theory; operant conditioning; developmental theories, including pivotal response training; and cognitive behaviour theory) and implementation theories (e.g., the Berkel model and the RE-AIM framework) were revisited. After the training, a draft logic model was mapped out by the two SREIA supervisors. It was then finalised in collaboration with the researcher, who filled the gaps in programme elements (e.g., familial communication techniques were taught but social support or family function was not identified as a proximal outcome) and aligned the terminologies with the literature.

Figure 2 SREIA logic model



The programme offers a wide range of techniques and is delivered in an intensive format, involving five days a week, three hours in the morning and two hours in the afternoon, for 11 consecutive weeks. The strengths and needs of each parent-child dyad are assessed prior to the teaching of techniques during the programme. Assessments include administering the Autism Treatment Evaluation Checklist (ATEC) (Rimland & Edelson, 1999) and the VB-MAPP (Barnes et al., 2014), as well as individual consultation and practitioner observations. Based on this information, an individualised treatment plan—covering targeted child behaviours, caregiver areas for improvement, and other priorities identified by caregivers—is developed and followed throughout the programme. Specific content and techniques are taught (Table 2) as part of the programme, using a variety of delivery methods (Table 3). Fourteen two-hour didactic presentations on weekly themes are offered throughout the 11 weeks and attended by all participating caregivers, with childcare provided by volunteers when there is no COVID-19 pandemic or restrictions on mass gatherings. After each presentation, additional training and practice opportunities are offered in smaller groups (each group comprising ten caregiver-child dyads) to enhance the understanding and use of skills. Content delivered in small caregiver groups focus on weekly topics but are also tailored to various degrees for each group to address different needs. Group sessions often start with the practitioner revisiting the content in the previous didactic presentation and modelling the new techniques, followed by caregivers practicing the techniques in vivo and receiving comments from practitioners and other caregivers. Caregivers are assigned homework activities to practice after

sessions. They are encouraged to submit written or video records of their practice at home for practitioners to provide feedback. Communications between caregivers and practitioners remain open and flexible. Opportunities for peer interactions are created by arranging group discussions, group problem-solving activities, and an online social and messaging group. The programme is primarily delivered in person, with the 14 didactic presentations also streamed online to avoid mass gathering during COVID-19.

Table 2 Programme weekly topics and main activities

<table>
<tr><th>Week</th><th>Weekly Topics</th><th>Main Activities</th></tr>
<tr><td>Week 1</td><td>• Knowledge of ASD and Child Development
• Parental Attitude and Expectation</td><td>• Practitioners observe parent-child interactions and conduct one-on-one counselling
• Develop individualised treatment plans
• Deliver didactic presentations in groups</td></tr>
<tr><td>Week 2
Week 3
Week 4
Week 5</td><td>• Child Behavioural Problems
• Behaviour Management Techniques
• Instruction Giving, Reinforcement (Praise & Rewards), Prompting, Fading, Shaping, and Chaining
• Ignore and Redirect</td><td rowspan="6">• Training and practice sessions tailored for each caregiver group</td></tr>
<tr><td>Week 6</td><td>• Parent-Child Communication and Interaction
• Emotional Labelling</td></tr>
<tr><td>Week 7</td><td>• Fine and Gross Motor Skills</td></tr>
<tr><td>Week 8</td><td>• Brief Introduction to TEACCH – “Structured TEACCHing”
• Visual Schedules, Structures, and Choices</td></tr>
<tr><td>Week 9</td><td>• Parental Self-Regulation
• Communicate with Family Members</td></tr>
<tr><td>Week 10</td><td>• Skill Maintenance and Generalisation</td></tr>
<tr><td>Week 11</td><td>• Review and Plan for the Future</td><td>• Individual assessments
• Create individualised family action plan for future use</td></tr>
</table>

Table 3 Delivery methods

Delivery Method	Description
Individual consultation	One-on-one sessions for practitioners to understand the challenges in each family and for parents to provide information and express concerns.
Didactic presentation	Large didactic lectures to present weekly topics, which are attended by all caregivers
Practitioner observation	Practitioners observe parent-child interactions in smaller groups.
Practitioner modelling	Practitioners model in smaller groups the techniques learned in the didactic presentations.
Cases and stories	Practitioners share cases and stories to illustrate a technique. Caregivers are also invited to share their own challenges and coping strategies.
Practice in sessions and in-vivo feedback	Caregivers implement the skills with their child during the session and receive in vivo feedback from practitioners.
Role play	Practitioners and caregivers simulate a scenario to demonstrate problems and solutions.
Homework and feedback	Practitioners assign activities for caregivers to practice at home and provide feedback.
Videorecording and feedback	Caregivers are encouraged to video-record their practice at home so that practitioners can provide detailed comments and instructions.
Group discussion on skills and experiences	Caregivers discuss and share their challenges and coping strategies during sessions.
Group problem solving	Caregivers work in groups to come up with solutions to deal with a specific challenge.
Physical activity	Caregivers and children participate in activities that involve bodily movement.
Reinforcement and active listening by practitioners	Practitioners give praise and rewards to caregivers, and pay full attention to the conversations with caregivers, in order to improve caregiver learning experience.
Online group communication	Online social and messaging groups are created on WeChat for each caregiver group, including practitioners, and for all participants in the programme.
Printed and online materials	Handouts are distributed for each session and posted online for easy access.
Childcare	Volunteers look after the children while their caregiver attending didactic presentations, when there is no COVID-19 pandemic or restrictions on indoor gathering.

The programme also offers participants the option of selecting two versions of delivery which are provided concurrently with the purpose of exploring ways to reduce cost while

maintaining or improving outcomes. Both versions divide caregiver-child dyads into several groups based on children's ASD symptoms, which are assessed using the ATEC (Rimland & Edelson, 1999). Version A has four groups of dyads who attend didactic sessions together but practice sessions separately, whereas Version B has three caregiver groups and delivers all sessions separately for each group. Other than that, the two versions share the same content.

2.4.2. Sample size calculation

A power calculation was conducted prior to the evaluation study using the PWR package in R Studio (J. Cohen, 2013). Paper 1 (Chapter 2 Systematic Review) shows that parent training programmes for families of children with ASD aged one to eleven in China had an effect size of g = -1.37 (95% CI [-2.03, -0.71]) on child emotional and behavioural problems, whereas Postorino et al. (2017) found a smaller effect size SMD = -0.59 (95% CI, [-0.88, -0.30]) for disruptive behaviours in children with ASD aged between two to fourteen years in other countries. For the purpose of this thesis a decision was made to perform a power calculation based on the estimation from Postorino et al. (2017), in order to increase the statistical power. The sample size calculation shows that with a significance level of 0.05 and statistical power of 0.8 in a two-sample, two-tailed t-test, the sample size necessary to detect any significant effect is 94 (47 in each arm).

Since the study is conducted within a routine delivery context, based on the service capacity at the time of conducting the study, a sample size of 100 was initially proposed (50 in the first round serving as the treatment group and 50 in the second round as the waitlist control). This was expected to enable a minimal detectable effect size of d = -0.57 on the primary outcome

measure. Based on previous delivery of the programme, caregivers are often highly committed, resulting in a programme attrition rate of less than 2% in the three years prior to the evaluation. Allowing for this level of attrition, the proposed sample size still gives a detectable change in the region of approximately $d = 0.57$. If the attrition is increased to 5%, the sample will only be able to detect a slightly larger effect size of $d = 0.58$.

A sensitivity power analysis was also conducted when recruitment was complete and the final sample size achieved (N=111), the result of which is presented in Paper 2 (Chapter 4, section 4.4.3).

2.4.3. Evaluation study participants

2.4.3.1. Family participants

The recruitment criteria for family participants in the evaluation study followed the existing strategies used by the NGO that provides the SREIA programme. The age range of children was three to six years old, and all participating children needed to meet the diagnostic criteria for Autism Spectrum Disorder according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013); otherwise, an official letter of ASD diagnosis needed to be provided. Families were excluded if the child had been diagnosed with Cerebral Palsy. Each family had one primary caregiver and one child participating in the programme. Participating primary caregivers were those who 1) undertook the responsibility for the daily care of the child for at least five days a week and 2) provided informed consent to participate in the research. There were no additional exclusion criteria.

Despite the fact that the service was provided in Beijing, the recruitment was not restricted to families in Beijing, but open to families from every administrative division in China.

Participants were drawn from a permanent SREIA waiting list. Enrolment to the programme was on a first-come, first-serve basis. Families attending between September 2020 and November 2020 were the treatment group. Those who signed up for the delivery between November 2020 and January 2021 comprised the waitlist control group. Due to COVID-19, some families on the waiting list decided not to attend the programme and were thus also allocated into the control group. Recruitment was conducted by the implementing organisation inviting caregivers on the waiting list to the study. Research staff provided information sheets and introduced the study to families. Families were able to contact the research team for further project details or to address any concerns before they gave written consent. Participation in the study was voluntary, and no data were collected from caregivers who did not consent to participate. Reimbursements, as well as a certificate of participation and a thank you note, were provided to participants who completed all data collection.

2.4.3.2. Programme practitioners

Eight programme practitioners delivered the SREIA programme. Two practitioners had a degree in social work and the remaining practitioners had various backgrounds unrelated to healthcare. All were trained or had extensive experience of delivering parent training programmes. All practitioners provided informed consent to participate in the assessment of the programme implementation.

2.5. Selection of Measures in the Evaluation Study

Table 4 provides an overview of measures that were used to assess the outcomes in this study, as well as the time points of the assessments. For questionnaires that did not have a Chinese version (the Arnold-O'Leary Parenting Scale (PS) (D. S. Arnold, O'Leary, et al., 1993) and the Parenting Young Children (PARYC) (McEachern et al., 2012)), the translation followed the WHO guideline of *Process of Translation and Adaptation of Instruments* (World Health Organization, 2020). Items were first translated into Chinese by a native Chinese speaker who was also fluent in English. A bilingual translation panel then identified and resolved discrepancies and inadequate expressions in the translation. After the panel discussion, the items were back translated into English by a translator whose mother tongue was English and who was proficient in Chinese. Discrepancies were discussed with the panel. The translated scales were piloted with three caregivers of young children with ASD, followed by debriefs with the interviewees. The questionnaires were finalised based on the pilot interviews and feedback from the panel (see Appendix F for more details).

Table 4 Outcomes and measures.

Outcomes	Time Points*		Measures	Items
	1	2		
Demographic Characteristics	✔		A demographic questionnaire	23
Primary Outcome Child Externalising Problems	✔	✔	Child Behaviour Checklist (CBCL) for Age 1.5-5, Externalising scale	24
Secondary Outcomes ASD Symptoms	✔	✔	Autism Treatment Evaluation Checklist (ATEC), total score	77
Parenting Style	✔	✔	Arnold-O'Leary Parenting Scale (PS), Over-reactivity subscale	5
			Parenting Young Children (PARYC), Supporting Positive Behaviour subscale	7
Parental mental health	✔	✔	Depression Anxiety Stress Scale-21 (DASS-21), total score	21
Family Function	✔	✔	Adaptation, Partnership, Growth, Affection & Resolve (APGAR), total score	5
Parental Knowledge	✔	✔	A questionnaire designed for the evaluation based on an existing parental knowledge questionnaire in the programme	21
Implementation Aspects				
Programme Acceptability		✔	A satisfaction questionnaire based on the Incredible Years® Autism Programme End of Course Satisfaction Questionnaire	44
		✔	Interviews with caregivers and focus group discussions with practitioners	
Participant Involvement	✔		Attendance sheet	
			Engagement checklist	
			Routine records (dropout rates)	
		✔	Interviews with caregivers	
Implementation (Practitioners)	✔		Practitioner checklists	
			Hours of delivery	
			A quality of delivery questionnaire	24
		✔	Interviews with caregivers and focus group discussions with practitioners	

**Time point: 1—baseline, 2—immediate post-intervention*

2.5.1. Demographic characteristics

The following demographic information was collected.

1. Child: gender, age, ethnicity, services attended previously, medical history, medication history, comorbidity.
2. Caregiver: gender, age, education, annual income, work status, spouse work status
3. Family: type of Hukou (household registration), number of children

2.5.2. Primary outcome – CBCL 1.5-5 Externalising Scale

The primary outcome of the SREIA evaluation was *child externalising behaviours*. This measure is slightly different from that of the systematic review, which also included child internalising (emotional) problems. The reason for this was that *child externalising behaviours* is identified by the programme designer and practitioners as the distal outcome of this intervention (theory of change, section 2.4.1).

2.5.2.1. Justification of using the CBCL 1.5-5

This section describes the decision-making process leading to the use of the Child Behaviour Checklist 1.5-5 as the primary outcome measure in this thesis.

Several scales have been used in the existing literature to assess child externalising behaviours for children with developmental disabilities in general. For example, the Strength and Difficulties Questionnaire (SDQ, Goodman, 1997) is a validated questionnaire commonly applied in evaluations of parent training programmes for a range of developmental disabilities in high-income countries, such as the Early Bird Programme (McCauley, 2010), the Parents'

Plus Programme (Coughlin et al., 2009; Hand et al., 2013; Quinn et al., 2007), and the Video-Feedback Intervention to Promote Positive Parenting adapted to Autism (Poslawsky et al., 2015). The SDQ has been translated into Chinese. It has demonstrated good internal consistency, concurrent validity, discriminant validity, and test-retest reliability in the Chinese population (Du et al., 2008; Lai et al., 2010; S. K. Liu et al., 2013) and in children with ASD (Findon et al., 2016; R Goodman et al., 2000). However, the SDQ contains only 10 items measuring child conduct problems and hyperactivity. Due to its short length and narrow scope, its sensitivity to detect changes was of concern.

Other scales include the Aberrant Behavior Checklist (Aman et al., 1985), the Developmental Behaviour Checklist-Parent/Carer Version (Einfeld & Tonge, 2002), and the Eyberg Child Behavior Inventory (Eyberg & Pincus, 1999). The Aberrant Behavior Checklist has been used in the Research Units on Pediatric Psychopharmacology Autism Programme (Aman et al., 2009; L. Arnold et al., 2012). However, the questionnaire is designed for children aged five years and older, whereas around two thirds of the children involved in this thesis were under five. The Developmental Behaviour Checklist-Parent/Carer Version has been frequently used to assess the effects of the Parent Education and Behaviour Management Programme for ASD (Tonge et al., 2006, 2012) and the Stepping Stones Triple P (SSTP) for a wide range of developmental disabilities (Roux et al., 2013; Tellegen & Sanders, 2013). However, similar to the Aberrant Behavior Checklist, the questionnaire only targets children aged four years and older, failing to cover one thirds of the children involved in this thesis. Some evaluations of SSTP also measure child behavioural problems with the Eyberg Child Behavior Inventory

(Roux et al., 2013; Sofronoff et al., 2011; Koa Whittingham et al., 2009), the access to which, however, is cost-prohibitive. This evaluation was not a funded study, thus lacking the financial resource needed to purchase the scale.

Paper 1 (Chapter 2, section 3.5.3) also identifies four scales that are commonly used to measure behavioural problems in children with developmental disabilities in China, including the Child Behaviour Checklist (Achenbach & Rescorla, 2000), the Conners Comprehensive Behaviour Rating Scales-Parent Version (Conners, 2008), the Autism Behaviour Checklist (Krug, Arick, & Almond, 1979), and the Autism Treatment Evaluation Checklist (Rimland & Edelson, 1999). The age range of the Conners Comprehensive Behaviour Rating Scales-Parent Version is six to eighteen years, making it unsuitable for this thesis, in which the children involved were between three to six years old. The Autism Behaviour Checklist and the Autism Treatment Evaluation Checklist both contain subscales assessing internalising and externalising problems. However, these scales are primarily designed to measure ASD symptoms and focus more on ASD-induced behaviours. For instance, the Autism Treatment Evaluation Checklist includes items such as “repetitive movements” and “fixated on certain objects/topics”, which are specific to the ASD diagnosis. It does not include other behavioural issues (such as inattentiveness, quickly shifting attention, and demand for attention) that are commonly seen in children with and without developmental concerns. Therefore, a questionnaire that can capture a broader range of externalising behaviours was needed to assess the primary outcome in this thesis.

Three included studies in Paper 1 used the Child Behaviour Checklist (CBCL). This scale has also been applied in children with a range of developmental disabilities in high-income countries, such as the Incredible Years-Autism Spectrum and Language Delays Programme in the UK (McIntyre, 2008; Williams et al., 2020) and the Parents' Plus Programme for children with developmental disabilities in Ireland (Quinn et al., 2007), as well as for typically developing children in low- and middle-income countries, such as the Parenting for Lifelong Health programmes in South Africa and Lesotho (Cluver et al., 2018; Tomlinson et al., 2016). It comprises over 20 items assessing multiple types of child externalising behaviours and is more likely to be able to detect changes than the SDQ subscales. It has been translated into Chinese, and demonstrated good test-retest reliability, internal consistency, and cross-cultural validity in Chinese population (P. W. L. Leung et al., 2006; L. Liu et al., 2003; Su et al., 1996; Tan et al., 2007), as well as in children with ASD (Pandolfi et al., 2009).

There are two versions of the CBCL, with one for children aged 1.5-5 and the other for 6-18 years. Previous research showed similar levels of internal consistency of the CBCL 1.5-5 years version in children with ASD aged five and those aged six (Basten et al., 2014). Several other studies using the CBCL 1.5-5 for children with ASD of a broader age range (Kim et al., 2018) and for typically developing children slightly older than five years old (Blanken et al., 2017; Muetzel et al., 2015; Rijlaarsdam et al., 2015), have also found it sensitive to capturing psychiatric symptoms. Further, multiple items (such as "drink alcohol", "use tobacco or drugs", and "truant") in the *Externalising* scale of the CBCL 6-18 are not applicable for children with ASD aged six. Therefore, it was plausible to use the CBCL 1.5-5 for all participating families

in this thesis, who comprised 98 children between the ages of three to five and 13 between five to six, rather than administering different versions for children within different age ranges. As such, the *Externalising* scale of CBCL 1.5-5 was used to measure the primary outcome of *child externalising behaviours*.

2.5.2.2. Description of the CBCL 1.5-5

The *Externalising* scale of CBCL 1.5-5 contains two subscales: *Attention Problems* and *Aggressive Behaviours*. The *Attention Problems* subscale consists of five items (e.g. "can't concentrate", "quickly shifts", and "wanders away"), and the *Aggressive Behaviours* subscale has 19 items (e.g. "can't stand waiting" and "demands met"). Both are rated by parents based on child performance during the previous two months with a 3-point Likert-type scale (0 = not true, 2 = very true or often true). To increase the sensitivity to change, this thesis set the recall period of the questionnaire as the previous one month, instead of two (Pannucci & Wilkins, 2010; Yahaya et al., 2014). Answers to child attention problems and aggressive behaviours were summed up to create a total externalising behaviour intensity score, with lower scores suggesting fewer problems. The global cut-off scores are 0-25 for the normal range, 26-30 for the borderline range, and 31-48 for the clinical concern range (Achenbach & Rescorla, 2001a).

Although slightly lower than the Achenbach and Rescorla (2001) sample, the CBCL 1.5-5 has shown excellent internal consistency (α=.80-.93) and factorial validity (CFI=.97) with children with ASD (Pandolfi et al., 2009). A previous study found sufficient internal consistency (α=.65-.89), test-retest reliability (ICC =.73-.87), and convergent validity (r=.70-.88) of the old version CBCL 2-3 in China (L. Liu et al., 2003), but local evidence

regarding the validity and reliability of the new version for children aged 1.5-5 is limited. One study demonstrated good cross-cultural factorial validity (CFI=.92) of the Chinese CBCL 1.5-5 in children in mainland China (Jianghong Liu et al., 2011). Another study suggested excellent internal consistency (α=.93) and marginal factorial validity (CFI=.87) in Chinese girls adopted into North American families (Tan et al., 2007). However, modifications to the old version of CBCL 2-3 are in fact minimal, with only two items being changed: item 51 "overweight" is substituted with "shows panic for no good reason", and item 79 "stores up things" is replaced with "rapid shifts between sadness and excitement" (ASEBA, 2020).

2.5.3. Secondary outcomes

The proximal targets of the SREIA programme (section 2.4.1) are assessed as the secondary outcomes of the evaluation, including ASD symptoms, parenting style, parental mental health, family function, and parental knowledge.

2.5.3.1. ASD symptoms

ASD symptoms were assessed using the Chinese version of the Autism Treatment Evaluation Checklist (ATEC) (Rimland & Edelson, 1999),

The selection of questionnaires with adequate reliability and validity to detect intervention effects on ASD symptoms remains a challenge. Although there are several standardised measures of ASD symptoms—such as the Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1986), the Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994), and the Autism Behaviour Checklist (Krug, Arick, & Almond, 1979)—those tools are often

designed for diagnostic purposes and focus on the overall ASD severity, which is not likely to change during a short period of time. The Vineland Adaptative Behaviour Scales (VABS-II, Sparrow, Cicchetti, & Balla, 2005) has also been widely used. However, it emphasises adaptive behaviour skills and developmental levels that can be often delayed in children with ASD. Besides, the VABS-II survey contains 297 items, which take a longer time for parents to answer and may thus put the validity of data at risk. Further, those measures require additional financial resources to access.

The Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999) is designed to capture treatment benefits and monitor child progress. It contains 77 short items and is freely accessible online, which helps to relieve parental burden and address the financial constraints. As Paper 1 describes, the ATEC has been one of the most frequently used measures in the evaluations of parent training programmes for ASD in mainland China: of the eleven ASD studies, five administered the ATEC and showed that the questionnaire was sensible to short-term changes. Studies in high-income countries also suggest that the ATEC can successfully capture treatment effects (Geier et al., 2013; Jarusiewicz, 2002; Magiati et al., 2011). In addition, significant correlations between the ATEC and the above mentioned diagnostic tools (such as the Childhood Autism Rating Scale and the Autism Diagnostic Interview-Revised) has been found in several countries, including China (H. Fang et al., 2019; Geier et al., 2013; J. Lu et al., 2004; Memari et al., 2013). Moreover, it is a routine practice in the SREIA programme to assess child ASD symptoms using the ATEC prior to each round of

programme implementation, allowing this thesis to build on its existing resources and avoid creating extra burden for participants.

The ATEC comprises four subscales with 77 item in total: 1) The *Speech/Language/Communication* subscale has 14 items (e.g. "knows own name," "explains what s/he wants," and "carries fairly good conversation"), 2) the *Sociability* subscale contains 20 items (e.g. "no eye contact," "ignores others," and "does not imitate"), 3) the *Sensory/Cognitive Awareness* subscale consists of 18 items (e.g. "responds to praise," "plays with toys appropriately," and "looks where others are looking"), and 4) the *Health/Physical/Behaviour* subscale has 25 items (e.g. "extremely limited diet," "rigid routines," and "not sensitive to pain"). The questionnaire is scored by parents recalling child performance during the previous month. The *Health/Physical/Behaviour* subscale is rated using a 0 (not a problem)-to-3 (serious problem) point scale, whereas the other three subscales are rated using a 0 (not true)-to-2 (very true) point scale. Scores are summed for each subscale and for the entire scale, with higher scores representing more ASD symptoms.

Research has demonstrated excellent internal consistency of the ATEC. For example, the study by Magiati et al. (2011) found an α=.86-.96 and Rimland and Edelson (1999) detected a Pearson r=.82-.94. Evidence has also suggested that the ATEC is a valid and reliable measure that can be used in cross-cultural settings. For instance, the Chinese version of the ATEC has shown slightly lower but sufficient internal consistency (α=.75-.79) when applied in mainland China (H. Fang et al., 2019). A study conducted in Thailand indicates that the locally translated version of ATEC has a high inter-rater reliability (ICC=.86-.97) (Sunakarach & Kessomboon,

2018). The Hindi version shows excellent internal consistency (α=.84-.93), test-retest reliability (ICC=.99), and content validity (index=.87-1) (Sapra et al., 2016). The Persian version of ATEC also demonstrates satisfactory internal consistency (α=.86-.93) and test-retest reliability (ICC=.79-.93) (Memari et al., 2013).

2.5.3.2. Parenting style

This thesis measured *parenting style* using the *Over-Reactivity* subscale of the Arnold-O'Leary Parenting Scale (AOPS) (D. S. Arnold, O'Leary, et al., 1993) and the *Supporting Positive Behaviour* subscale of the Parenting Young Children Scale (PARYC) (McEachern et al., 2012). The *Over-Reactivity* subscale, designed for caregivers of children aged two to 16, has been used in the SSTP programmes for ASD (Schrott et al., 2019; Tellegen & Sanders, 2014; Koa Whittingham et al., 2009), the Triple P programme for typically developing children in Hong Kong (C. Leung et al., 2003b), the standard version of Incredible Years (Hutchings et al., 2011; Morpeth et al., 2017; Williams & Hutchings, 2015), and the Parenting for Lifelong Health (PLH) programmes in low- and middle-income countries, including Romania, North Macedonia, Moldova, and the Philippines (Alampay et al., 2018; Frantz et al., 2019). It contains five statements (e.g. "when I'm upset or under stress, I am picky and on my child's back, or I am no more picky than usual" and "when there's a problem with my child, things build up and I do things I don't mean to do, or things don't get out of control"). To increase the sensitivity to change, this thesis changed the recall period to the previous one months rather than two. A total score is summed, with higher scores indicating more dysfunctional parenting practices. The *PS Over-Reactivity* subscale has demonstrated in previous studies adequate internal

consistency (α=.79 to .82) and test-retest reliability (ICC=.82), as well as a significant correlation with the CBCL (D. S. Arnold, O'Leary, et al., 1993; C. Leung et al., 2003a).

The PARYC *Supporting Positive Behaviour* subscale consists of seven items (e.g. "play with your child in a way that was fun for both of you?" and "stand back and let your child work through problems s/he might be able to solve?"). Caregivers are asked to rate each question from 1 (not at all) to 7 (most of the time) according to the frequency with which they are engaged in such parenting strategies during the previous month. Each question is also followed by a Yes/No question asking caregivers whether conducting the parenting practice is problematic. However, the Yes/No question is not included in this thesis because the meaning of it can be interpreted in multiple ways. For example, caregivers may understand it as whether they agree with the parenting practice, whether it is difficult for them to use it, or whether they are satisfied with their current level of usage. Each of the five statement is rated by a 7-point Likert-type scale. Caregivers of children are asked to select the number that best describes their parenting styles during the past two months. A score is summed, with higher scores representing more positive parenting practices. This subscale has been used to examine the association between child behavioural problems and positive parenting practice for children with and without developmental disabilities in the US (Gottuso, 2014). It has also been commonly used in the PLH programmes delivered and evaluated in other LMICs, such as South Africa, the Philippines, Romania, North Macedonia, and Moldova (Alampay et al., 2018; Lachman et al., 2017, 2019; Ward et al., 2020). Although there is currently limited evidence regarding validity

and reliability in Chinese population, it has demonstrated sufficient construct and convergent validity and good internal consistency (α=.78) in the U.S. (McEachern et al., 2012).

2.5.3.3. Parental mental health

Parental mental health was assessed using the Chinese version of the Depression Anxiety Stress Scale-21 items (DASS-21) (Lovibond & Lovibond, 1995), since the DASS-21 questionnaire has been validated and widely used in Chinese populations and measures a broader range of mental health symptoms than some other tools, such as the Patient Health Questionnaire, which focuses on depression (Spitzer et al., 1999). The DASS-21 comprises three self-report subscales with each having 7 items, which are rated from 0 (not apply to me) to 3 (apply to me very much or most of the time) based on performance over the past week. The three subscales are 1) *Depression* (e.g. "I felt that I had nothing to look forward to" and "I found it difficult to work up the initiative to do things"), 2) *Anxiety* (e.g. "I was aware of dryness of my mouth" and "I experienced trembling"), and 3) *Stress* (e.g. "I tended to over-react to situations" and "I found it difficult to relax"). Scores are summed and multiplied by 2 to create a final score for each subscale and for a total score. Lower scores indicate a better emotional state. The cut-offs are 9, 7, and 14 for *Depression*, *Anxiety*, and *Stress*, respectively.

The DASS-21 has often been used in the evaluations of SSTP (such as Ruane et al., 2019; Tellegen & Sanders, 2014) and in Asian populations. Norton (2007) administered the scale in multiple ethnic groups in the U.S. and found good internal consistency (α=.74-.87) among Asian Americans. Several studies in mainland China and Chinese population in other parts of Asia also found internal consistency of the Chinese DASS-21 ranging from α=. 76 to .93 for

subscales and from .89 to .95 for the total scale (R. C. K. Chan et al., 2012; X. Gong et al., 2010; L. C. Jiang et al., 2020; Kui Wang et al., 2016; Wen et al., 2012); a test-retest reliability of .75 (Wen et al., 2012); and adequate convergent validity (Oei et al., 2013; Kui Wang et al., 2016).

2.5.3.4. Family function

Family function was briefly assessed using the Chinese version of the Family APGAR scale (Smilkstein et al., 1982). The Family APGAR consists of five statements related to five areas of family functionality—*Adaptability*, *Partnership*, *Growth*, *Affection*, and *Resolve*. Participants are asked to rate each statement from 0 (hardly ever) to 2 (almost always) based on experience during the past two weeks. A total score is summed, with higher scores representing higher level of satisfaction of their relationships with other family members. Smilkstein et al. (1982) identified an internal consistency coefficient of α=.80 for the original scale. Studies in Taiwan and mainland China also found similar results for the Chinese version, with Cronbach α ranging from .83 to .91 (H.-C. Lin et al., 2008; Nan et al., 2014; Yang et al., 2016).

2.5.3.5. Parental knowledge

Parental knowledge was measured by adapting an existing survey administered by the SREIA programme prior to the start of each delivery. The adapted questionnaire contained 21 items, covering topics of ASD symptoms, its implications on child social-communicational skills, impacts on child behaviours, interventions, and prognosis.

2.5.4. Process evaluation

2.5.4.1. Theoretical framework

Implementation science examines the facilitators and barriers to evidence-based practice, aimed at promoting the utilisation of research findings in real world settings (Durlak & DuPre, 2008). It plays a key role in increasing global access to evidence-based ASD treatments (Franz & Dawson, 2019). This thesis explored the implementation of the SREIA programme through the following three components: *programme acceptability*, *participant involvement*, and *programme delivery*, which have been identified as being critical to the effectiveness of parent training programmes in the general population (Berkel et al., 2011; Kazdin, 2000).

Participant involvement refers to the extent to which the programme maintains participants' interest and attention (Dane & Schneider, 1998). It consists of four dimensions: enrolment, attendance, engagement, and dropout. Enrolment refers to participants signing up for and being admitted to the programme. Attendance refers to participants attending the intended sessions. Engagement is the degree to which participants are involved in the activities, actively contribute to the sessions, and adhere to the strategies taught in the programme (Gopalan et al., 2010; Karver et al., 2005). Insufficient caregiver involvement may undermine the potential of programmes to produce desirable outcomes in interventions for children with and without ASD. For example, a randomised controlled trial (RCT) conducted in a low-resource setting in the U.S. found that lower treatment attendance predicted shorter duration of joint attention in a caregiver-mediated intervention for children with ASD aged two to five (T.

Carr et al., 2016b). Research in families of children without ASD, such as an RCT of the parenting programme of Incredible Years, also found that the intervention had a dose-response effect between participant engagement and improved parenting practices (Baydar et al., 2003). A study assessing the effects of parent management training for caregivers of low socioeconomic status further suggested that the quality of engagement, but not attendance, was linked to improvements in parent-child relationships and positive parenting practices in the long term (Nix et al., 2009).

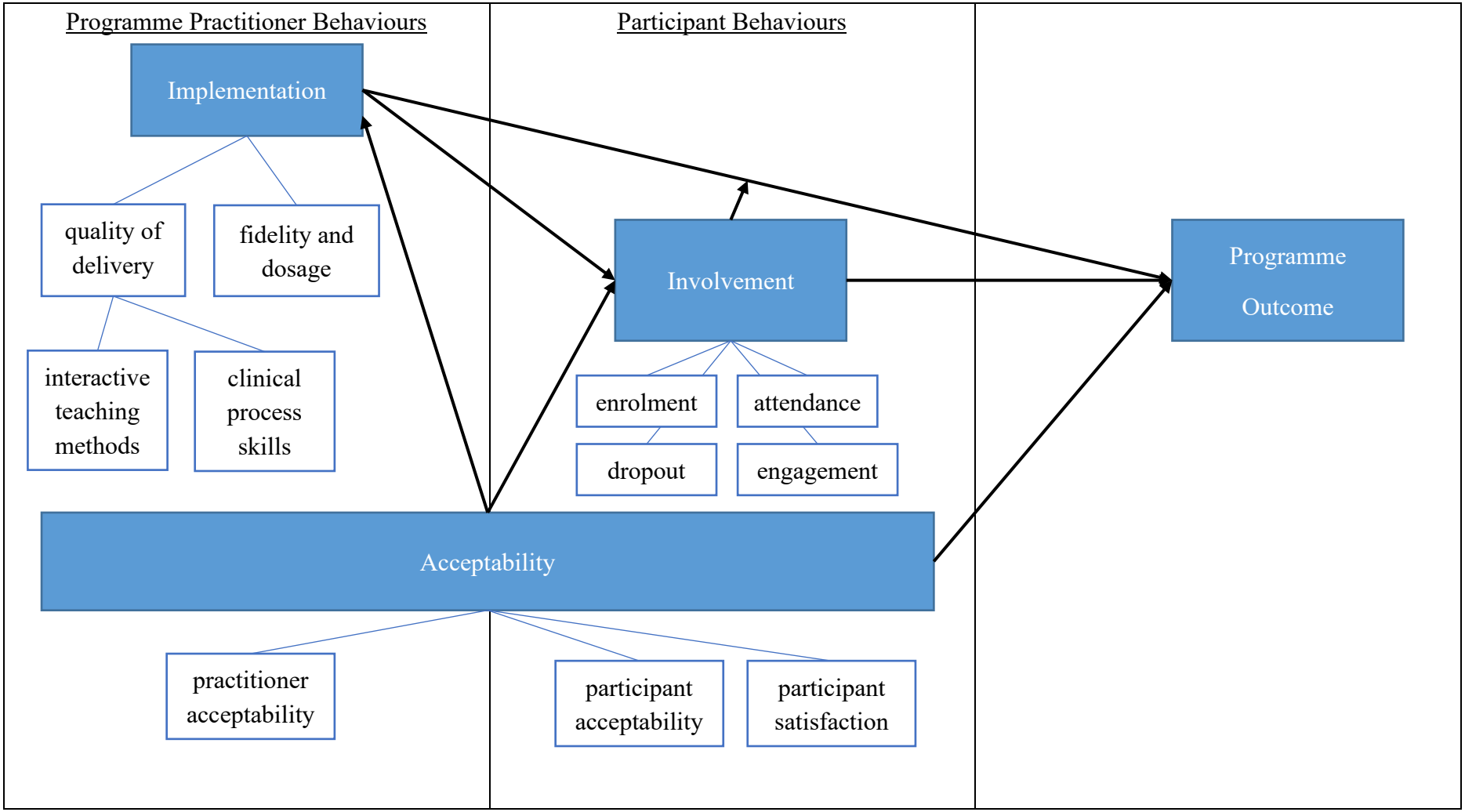
Programme acceptability refers to the extent to which participants consider the programme content and delivery methods as being acceptable and satisfactory (Proctor et al., 2011). Based on the barriers-to-treatment model (Kazdin, 1996), programme components deemed as lacking relevance to child challenges can act as significant obstacles to participant involvement, whereas those that are considered acceptable and contextually relevant are more likely to be taken up and promote change (Kazdin, 2000). As is shown in a qualitative study conducted in families of children without ASD, parents appraised the value and utility of parenting practices before deciding whether they would apply the skills (Holtrop et al., 2014). Moreover, practitioners' perceptions of programme acceptability influence the quality of programme delivery and fidelity (Allinder & Oats, 1997), which can further affect programme feasibility and outcomes. This is exemplified by a qualitative study conducted in South Africa (Makombe et al., 2019), which found that two of the major barriers to implementing early caregiver coaching interventions for ASD were the difficulty in practitioners understanding the complex programme concepts and the collaborative coaching method, which were misaligned

with their existing understanding.

The three core aspects of programme delivery are fidelity, dose, and quality of delivery. Fidelity refers to the degree to which the programme is delivered as originally intended (Dusenbury et al., 2003). Dose refers to the percentage of the programme that is delivered (Dane & Schneider, 1998), and quality of delivery refers to how well practitioners conduct the programme (Dane & Schneider, 1998; Dusenbury et al., 2003), involving a range of skills, such as presentation, interaction, group facilitation, and conflict resolution. A comprehensive review of the potential impact of implementation on outcomes in health promotion and prevention programmes found strong evidence supporting the relationship between effective implementation and improved health (Durlak & DuPre, 2008). A meta-analysis of group-based parent training programmes for early onset conduct problems in children aged three to 12 years also showed a larger effect in programmes demonstrating better implementation processes, compared to those with lower levels of fidelity and quality of delivery (Furlong et al., 2012).

A theoretical model illustrating the relationships of the three implementation dimensions and their associations with the programme outcome is adapted from Berkel et al. (2011) and presented in Figure 3.

Figure 3 Theoretical model of programme implementation, adapted from Berkel 2011



2.5.4.2. Measures

Programme acceptability was assessed at post-intervention using a questionnaire based on the Incredible Years® Autism Programme End-of-Course Satisfaction Questionnaire (Incredible Years, 2020) tailored for the SREIA programme and the Chinese context. The questionnaire contains a range of topics including overall impression; teaching format; information and techniques; practitioners; and parent groups. It consists of 42 items rated with a 3-point Likert-type scale. High scores represent higher levels of satisfaction. *Acceptability* is also explored using in-depth interviews with caregivers and focus group discussions with practitioners.

The level of *participant involvement* was captured by calculating the rates of *attendance*, *engagement*, and *programme dropout*. The *attendance and engagement rates* were assessed using an attendance and engagement registry (Appendix E.3.ii) reported by programme deliverers on a daily basis. The level of caregiver engagement was judged based on four criteria: responsiveness to practitioners, interactions with other caregivers, participation in group discussion, and completion of homework activities. *Programme dropout rate* was calculated based on families who missed at least ten days. *Participant involvement* was also investigated in the caregiver interviews and focus group discussions.

Two aspects of *programme delivery* were measured—fidelity and quality of delivery. *Fidelity* was assessed using practitioner checklists. Practitioners reported whether they delivered the core components prescribed in the manual each week. The fidelity scores comprised the overall ratio of delivered components to prescribed components (n=62). *Quality of delivery* was measured by research staff observing parent group sessions and filling out a quality of delivery survey. The survey contains 24 items, assessing the general skills of facilitating parent groups (such as knowledge of content, teaching skills, sensitivity to participants' feelings and experiences, ability to handle tension, etc.) and skills of modelling parenting techniques and facilitating practice sessions (such as appropriately setting up the

space and providing adequate support during participant practice). A total score is summed. Two sessions for each practitioner were randomly selected and recorded for research staff to rate the quality of delivery. The in-depth interviews and focus group discussions were used to understand the delivery of the programme from the perspectives of caregivers and practitioners.

2.6. Data Collection, Analysis, and Management in the Evaluation Study

2.6.1. Data collection

All data collectors were trained on a range of topics including research ethics, informed consent, research protocols, working with vulnerable families, child protection protocol, safety protocol, and interview techniques. Baseline data were collected during the two weeks prior to the start of programme, and post-intervention data were collected during the two weeks immediately after the treatment group completed the programme. There were 11 weeks between the two assessment time points. All questionnaires were converted into an online survey system that encrypted each survey when it was submitted.

Qualitative individual interviews were conducted online with 14 parents within a month after the treatment group completed the programme. Interviewees were purposively sampled; the selection of interviewees was informed by the quantitative data and involved families that exhibited both the highest and lowest overall attendance and engagement rates in each caregiver group. Each interview lasted for a maximum of 90 minutes. Two focus groups were conducted with eight SREIA practitioners in person at post-intervention, with each involving four practitioners and lasting for approximately two hours. With the permission of participants, all interviews and focus groups were audio-recorded and transcribed verbatim. Written notes were also taken during interviews and focus groups.

Semi-structured interview schedules were developed to guide the interviews and focus groups. Open-ended questions were used to stimulate reflection and discussion. The interviews with parents and practitioners covered the following topics: 1) understanding and use of skills

(parents), 2) perceived changes in child and parental outcomes (parents); 3) barriers to, facilitators of, and strategies to overcome the challenges of delivery (practitioners) and participation (parents); and 4) acceptability and appropriateness of programme delivery and content (parents and practitioners).

2.6.2. Blinding

It was not possible to blind participants or practitioners, due to the nature of parent training and the use of a waitlist control group. However, to reduce the risk of detection bias, the research staff who collected data for the baseline and immediate post-intervention assessments were blind to allocation status. Data collectors were not involved in the delivery process and were trained on the topic of risk of bias. Parents were also asked to keep their allocation condition private from outcome data collectors. Process evaluation data were collected by a separate group of research staff. Blinding was protected and monitored by data collectors reporting their knowledge about participant group status after each interview.

2.6.3. Data management

Non-electronic data were stored in a locked closet in the SREIA implementing organisation. All electronic data—including personal details of participants, questionnaire answers, audio recordings, and transcript of audio recordings—were transferred to the study's Nexus365 OneDrive for Business, which is an integrated part of University Office 365, supported by the University of Oxford, and meets the University's security requirements. Electronic data were also backed up regularly into a hard drive which is stored in the same closet with non-electronic data. All data were pseudonymised. An ID number was assigned to each participant after they gave consent. The linkage between the ID number and participant personal details was stored with other electronic data. Only the research team had access to data in the central drive and the locked closet. Audio recordings were erased immediately at the end of the study. All other data will be kept for three years after final publication. Permission from the research team and

the NGO will be necessary to obtain access to the data for future use.

2.6.4. Quantitative data analysis

2.6.4.1. Difference-in-differences with propensity score weighting

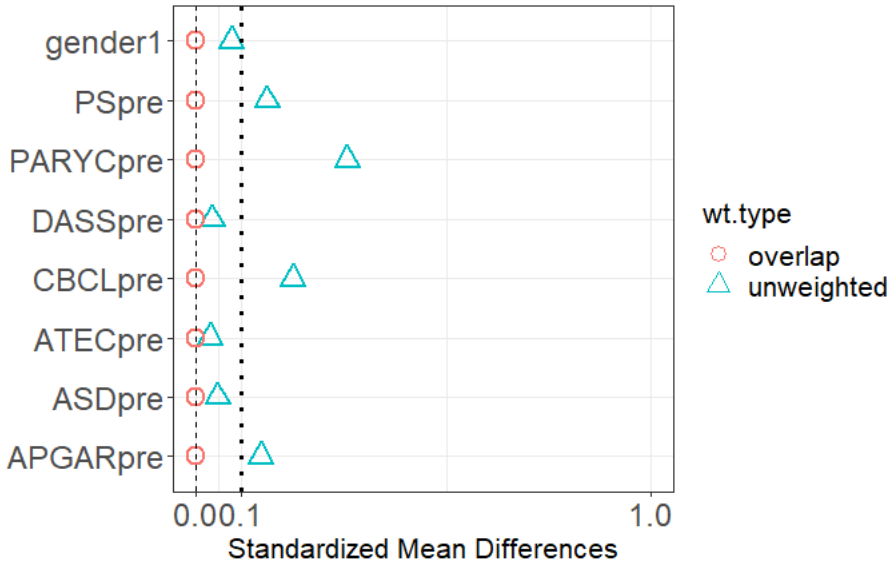
Given the small sample size (N=111) in this thesis, PS Weighting was selected over PS Matching to avoid the exclusion of observations. Also, section 2.3.1.2 shows that the Overlap Weighting (OW) scheme is more likely to produce better balance and precision than the Inverse Probability of Treatment Weighting (IPW) scheme, and that, unlike Kernel Matching (KM), it does not rely on researcher's decision-making, which can sometimes be arbitrary. Given these advantages, this thesis utilised the OW scheme as the primary propensity score method in the analysis, and employed the IPW and the KM schemes as robustness checks to verify the main results. This section describes the four steps undertaken to integrate the OW scheme into the Difference-in-Differences (DiD) design and estimate the treatment effects.

First, propensity scores and weights under the OW scheme were estimated using logistic regression, with accounting for key covariates. While adding too many covariates may overfit the model, omitting important covariates will undermine the ignorability assumption (Stuart et al., 2014). As such, the selection of key covariates was completely theory driven. Only factors measured at baseline and shown by the literature as being associated with the primary outcome of interest but not affected by the exposure to the intervention were included in the logistic model (Godard-Sebillotte et al., 2019). Adding those factors is proven to diminish the variance of treatment effect estimation without inducing bias (Brookhart et al., 2006). This thesis involved the conduct of a literature review and identified eight key covariates, including the baseline secondary outcome measures (child externalising behaviour, caregiver mental health, positive parenting style, dysfunctional parenting practice, Autism symptoms, parental knowledge, and family function) and child gender (Appendix B.1).

Second, balance within the weighted sample was checked using absolute standardised

mean differences (ASMD) for each covariate. Figure 4 shows that the post-weighting ASMDs were significantly reduced compared to the pre-weighting ASMDs, and were all close to zero, indicating an optimised balance between the treatment and control groups (T. Zhou et al., 2020). In this case, it was regarded as being plausible to proceed to the next step of analysis without modifying the logistic regression model.

Figure 4 ASMD plot – Overlap Weighting (OW) scheme

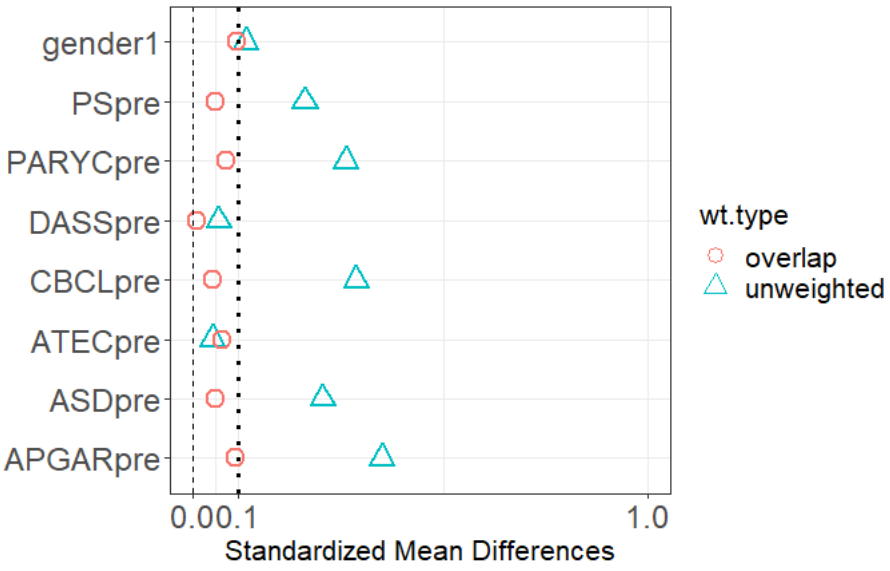


Third, the DiD model was built based on the Model 2 specified in section 2.3.1.1 by treating the pre-post difference scores as the dependent variable, creating a binary dummy variable indicating group assignment, and adjusting for all the key covariates used to estimate the PS scores. Clustering effects within different versions of delivery (there are two versions of delivery offered at two sites) and parent groups (seven groups in total) were examined using intracluster correlation coefficients (M. K. Campbell et al., 2001). Results showed that the pre-post differences of the primary outcome were clustered within each version (child externalising behaviours: ICC=0.11, 95% CI [0.01, 0.85]), and that the pre-post differences of two secondary outcomes were related within parent groups (parental knowledge: ICC=0.11, 95% CI [0.00, 0.44]; Autism symptoms: ICC=0.15, 95% CI [0.02, 0.49]). For those outcomes, random-intercept and fixed-slope linear mixed models were created to account for clustering effects, assuming that participants in the same version or group experienced the same association

between the covariates and the outcome. The dummy variable and key covariates were treated as the fixed effects and the version or parent group variable were incorporated as the random effect.

Fourth, the PS weights estimated in step 2 were extracted and incorporated into the DiD models to produce the estimation of treatment effects. For the primary outcome, the difference between the two versions of delivery in the primary outcome child externalising behaviours was also explored. A three-level dummy variable was created to reflect multiple treatment groups (version a, version b, and control). Step one to four were re-run by replacing the binary dummy variable with the new three-level dummy variable. Figure 5 suggests that the OW scheme achieves adequate balance between the three groups, with controlling all ASMDs within 0.1 (Rubin, 2001). The weights were therefore added into the new DiD model to explore the version difference.

Figure 5 ASMD plot –OW scheme, version difference in the primary outcome



2.6.4.2. Robustness checks

Two robustness checks were conducted using the DiD model with the IPW and the KM schemes, respectively. The procedure was similar to the four steps described above. The balance check shows that the IPW scheme can also successfully create comparable groups (Figure 6),

although the ASMDs are slightly larger, and the balance is less optimal than the OW scheme (Figure 7). This is likely due to the extreme weights produced by IPW, as the boxplots in Figure 8 indicates that the distribution of PS scores under IPW is skewed and has multiple outliers, whereas the scores under OW have a more normal probability density. Despite the caveats, the IPW scheme produced an estimate (b = -2.76, 95% CI [-5.08, -0.44]) similar to the OW scheme (b=-2.71, 95% CI [-5.23, -0.18]).

Figure 6 ASMD plot – Inverse Probability of Treatment Weighting (IPW) scheme

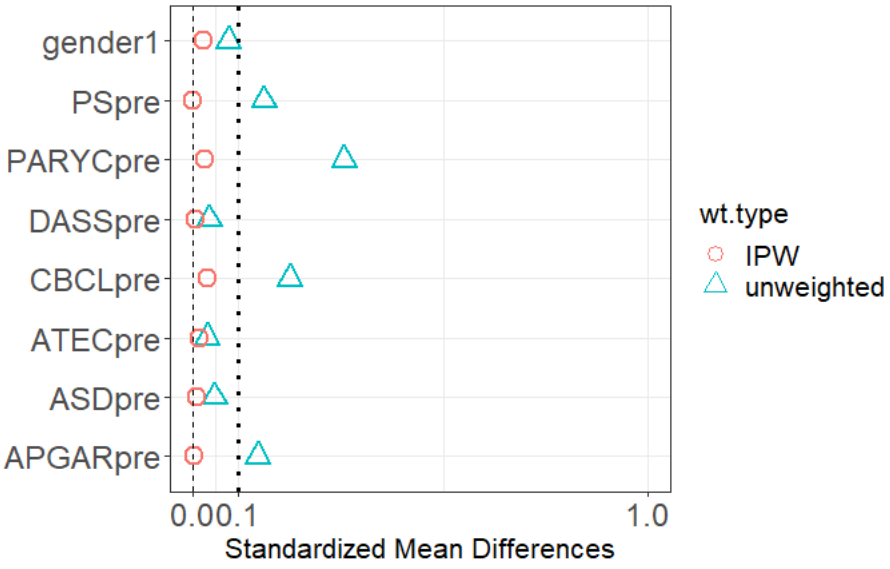


Figure 7 ASMD plot – OW versus IPW

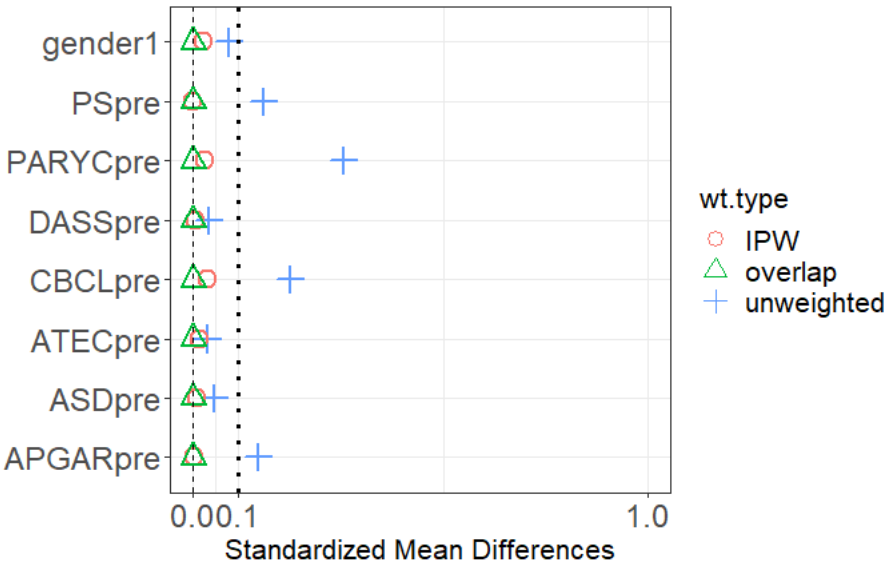
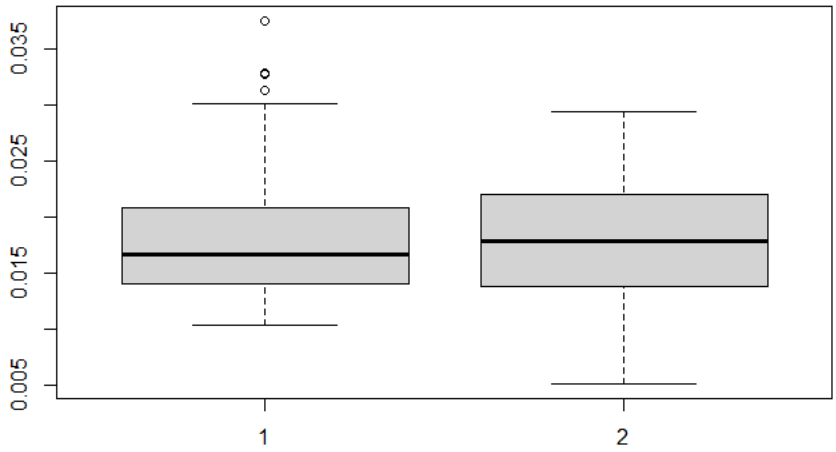


Figure 8 Boxplots – propensity scores under the IPW and the OW schemes (1-IPW, 2-OW)



The DiD with KM was conducted with a default bandwidth of 0.6. Figure 9 shows that all ASMDs were controlled within 0.1, except for the covariate of baseline family function. One observation was excluded due to the lack of common support (Figure 10). For observations remaining within the region of common support, the KM model with adjusting for clustering effect produced a slightly larger treatment effect (b = -3.28, 95% CI [-4.59, -1.97]) than the OW scheme (b=-2.71, 95% CI [-5.23, -0.18]), which may be attributed to the bias caused by suboptimal group balance.

Figure 9 ASMD plot – Kernel Matching (KM) scheme

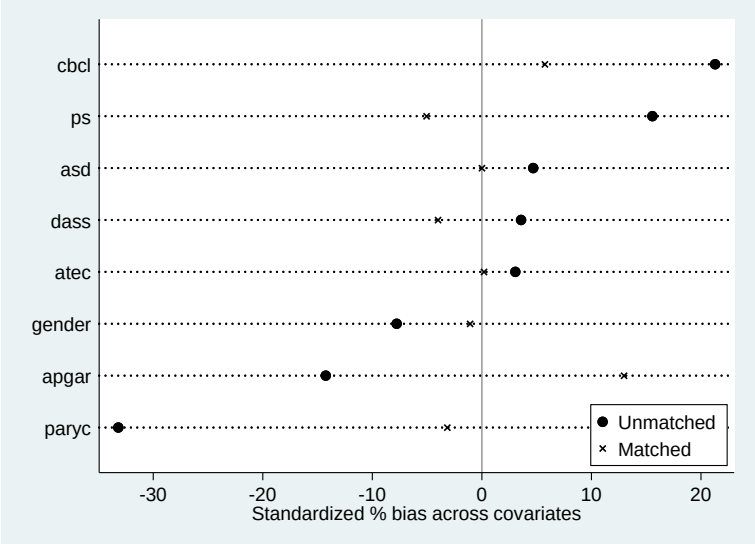
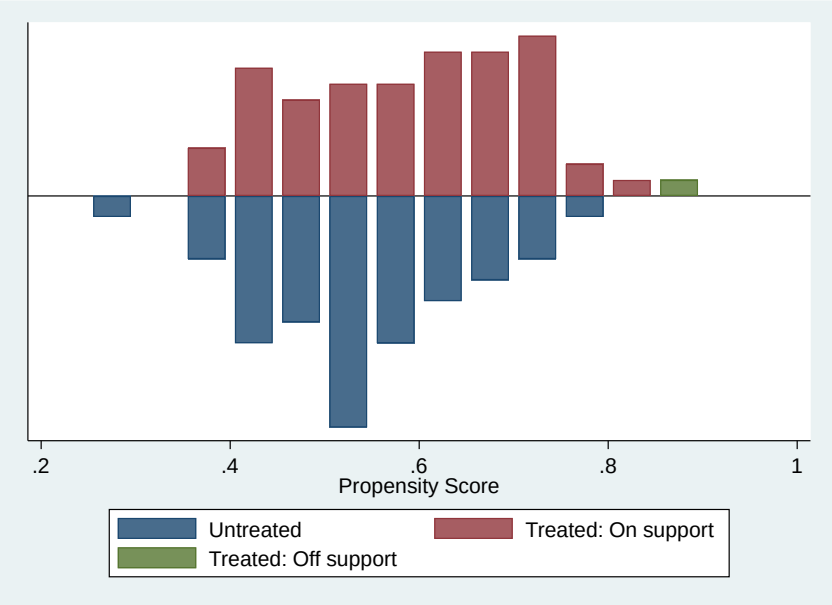


Figure 10 Common support plot – KM scheme



Overall, the results of the two robustness checks were generally in line with the main estimation of the primary outcome, suggesting a high degree of robustness of the findings.

2.6.4.3. Sensitivity analyses

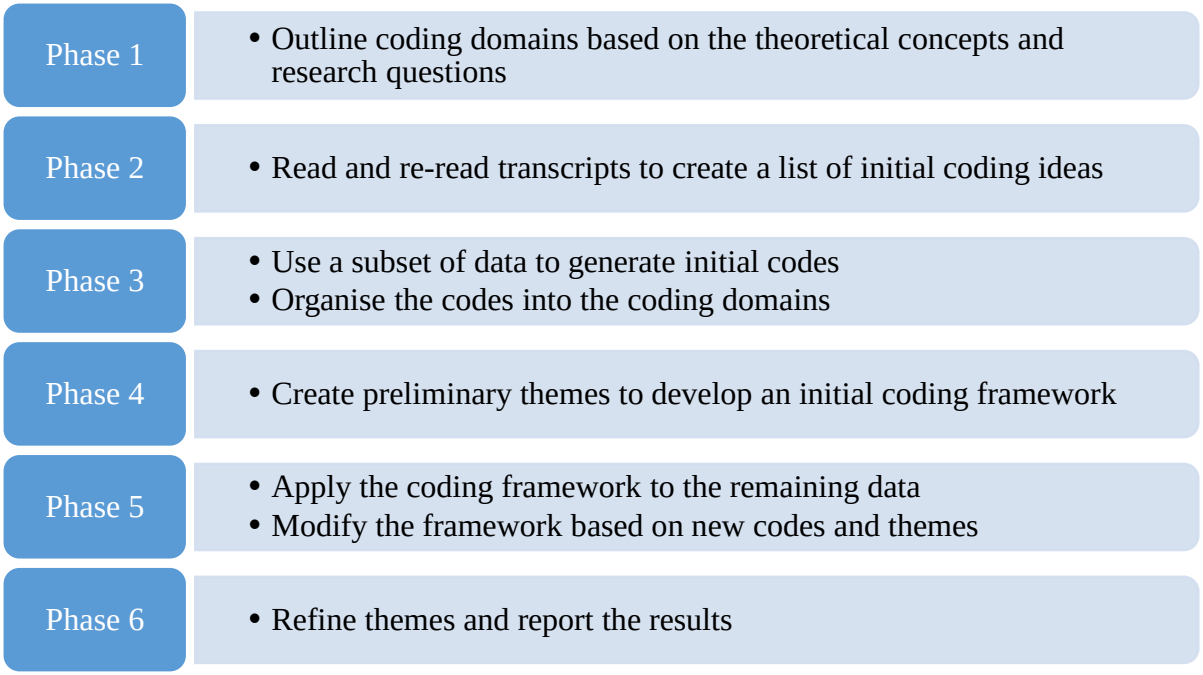
Two sensitivity analyses were conducted to check the stability of the distribution of covariates in the two groups and the impact of unobserved confounders. Due to uncertainties caused by COVID19, it was not possible in this thesis to examine the parallel trend of DiD prior to the intervention. As an alternative, the assumption was tested by treating financial health as the outcome variable in the weighted DiD model. Financial health was not expected to be affected by the treatment, which contains no family budgeting component, but is related to child behavioural concerns according to the literature (Slopen et al., 2010). Financial health was measured at both time points using eight criteria (e.g., spending less than income, having sufficient savings, and creating financial plans) with a 4-point Likert-type scale. The result suggested that there was no group difference (b = -0.09, 95% CI [-1.76, 1.93]). As such, any confounders that might have caused the outcome to differ between the two groups remained constant over time. Further, to check the impact of unobserved covariates on PSW, the effect of group assignment on the baseline measure of externalising behaviours was tested. The result indicated no violation of the ignorability of PSW (b = -0.04, 95% CI [-2.68, 2.75]). Both

sensitivity analyses provided support to the robustness of findings in the thesis.

2.6.5. Qualitative data analysis

The thematic analysis in this thesis used the codebook thematic analysis approach, combining inductive and deductive orientations. It involved the following six phases (Figure 11).

Figure 11 Six phases of the thematic analysis in this thesis



This qualitative study (Chapter 5 Paper 3) aimed to explore three main theoretical concepts - programme acceptability, participant involvement, and programme implementation - and also sought to understand the perceived changes and areas for improvement from the perspectives of caregivers and programme deliverers. Informed by Fereday and Muir-Cochrane (2006), phase one of this study outlined the coding domains according to the theoretical concepts and research questions, which consist of five broad coding domains (perceived changes, programme acceptability, participant involvement, programme implementation, and areas for improvement) and several subdomains under each domain (such as caregivers, children, parent-child relationships, and family members under the domain of perceived changes; programme content and delivery methods under the domains of programme

acceptability and areas for improvement; facilitators and barriers under the domains of participant involvement and programme implementation).

In phase two, familiarisation with the data was gained by listening to the audio recordings of the conversations and reading the transcripts repeatedly. Casual notes were taken to reflect the overall impression, initial coding ideas, possible connections between data, and issues that may need to be addressed at later stages (Braun & Clarke, 2013). The notes were primarily shaped by the coding domains but also paid close attention to the unique ways by which participants explained their own situations (Brooks et al., 2015).

In phase three, preliminary coding of data was conducted using transcripts from four out of the 14 caregiver interviews and one of the two focus group discussions. The initial coding generated as many codes as possible. Brief labels that contained only one or two words were avoided to make sure that the codes were sufficiently descriptive. Extracts were quoted inclusively to show the context of the codes. Each extract may have been quoted multiple times to produce several codes (Braun & Clarke, 2013). The codes were then organised into relevant domains and individual codes may have been arranged into more than one domain. New potential domains (experience of having a child with ASD in China prior to the programme) and subdomains (such as support to practitioners under the domain of areas for improvement) were created for codes that did not fit into the existing domains. No codes were discarded at this stage.

Phase four involved searching for themes and developing the coding framework. In this phase, relevant codes under each domain were collated into candidate themes and subthemes. Possible links between themes were established to tell the story about the domains. The software ATLAS.ti was used to create a map of codes and themes and their inter-relationships for each domain. Based on these themes, a preliminary coding framework was formed (Brooks et al., 2015). In the following phase, the remaining data were coded, and the initial framework was applied to the new codes. When the candidate themes could not represent the meaning of

the new codes, the framework was revised with existing themes being modified and new themes being incorporated. The process was iterated to ensure that the framework allowed for a comprehensive representation of the data. However, the finalisation of the coding framework was less straightforward, as the data always provided new ideas to refine the codes and themes. The decision on the final version of framework was made by considering time and the extent to which it answers the research questions (Brooks et al., 2015; Fereday & Muir-Cochrane, 2006; J. Smith & Firth, 2011).

In the final phase, the themes were refined, and an analysis report was produced. All transcripts were re-read at this stage, with the purposes of confirming that the themes were relevant to the dataset and identifying additional codes that were missed in previous steps (Braun & Clarke, 2013). Also, extracts in each theme were reviewed to examine whether the theme adequately reflected the meaning of those accounts. In addition, themes under each domain were modified and merged to avoid conceptual overlap (Braun et al., 2019). Last, shorter and more succinct names were assigned to the themes for the report of results.

In the analysis report, themes were presented in a way that shows the flow of the overall story (Braun & Clarke, 2013). They started from participant situations prior to the programme to perceived changes upon the completion of learning, and then moved from their experiences of participating or delivering the programme to views on how the programme could be improved. All deviant cases have been presented to prevent selective reporting. Quotes were provided to demonstrate the themes, which also enabled a thick description of contextual information (Braun et al., 2019; Kuper et al., 2008).

The qualitative data analysis was conducted with another bilingual researcher being the second coder, who checked 50% of the initial codes in each domain during phase three, reviewed all the candidate themes in phase four, and continued to examine all codes and themes before they were finalised in phase six (Lincoln & Guba, 1986). The qualitative data were collected in Chinese. To avoid the loss of meaning, data analysis was conducted in the source

language, the results of which were then translated into English for the purpose of the report. The translation process can often involve additional interpretation of the raw data, especially when the socio-cultural contexts of the two languages are distinct, thereby increasing the risk of bias (van Nes et al., 2010). In order to improve the internal validity, the themes and quotes were translated literally, maximising the faithfulness to the data. Paraphrases and metaphors were avoided. Further, several quotes were presented for each theme to increase the credibility of the results.

Qualitative findings are results of the interactions between the participants, the data, and the researcher (Lincoln & Guba, 1986). Patterns of data are constructed by researchers who cannot be free from previous experiences. As such, it is particularly important to be reflexive and acknowledge the influence a researcher brings to data collection and analysis (Kuper et al., 2008). Reflexivity of this study was improved by recognising and addressing power differentials between the researcher and participants. All interviews were conducted in a friendly and empathetic manner. Rapport was built prior to asking any questions. The interviews started with casual conversations, informing participants what to expect in the interview and addressing their concerns about confidentiality. The interviews were conducted in a space that was familiar to the participants. The purpose and anonymisation of recording, as well as their rights to erase the recording and/or withdraw the data, was fully explained. Light refreshments were also provided to create a welcome and relaxed environment. Further, the coding software ATLAS.ti was used to document the entire coding procedures, including any evolving perceptions and critical decision points. The involvement of second coder and the discussion of discrepancies also facilitated the introspection process. Moreover, this study leans toward positivism, with the overall purpose of testing hypotheses. This may also contribute to the reduction of potential influence caused by researcher experience.

2.7. Ethical Considerations of the Evaluation Study

The planning of procedures for informed consent, data collection, and data management

was informed by the following ethics guidelines: the Best Practice Guidance of Management and Protection of Data Collected for Research Purposes (BPG 9), the Best Practice Guidance of Studies where there is a Possibility of Identifying Psychological Distress or Disorder in non-NHS Participants (BPG 8), and the Ethics Issues Checklist for International Research in the Best Practice Guidance on Ethical Review of Social-Sciences Based Research Conducted Outside the UK (BPG 16), as well as the national child protection guidelines in China and 1989 UN Convention on the Rights of Children and Persons with Disabilities (Assembly, 1989; United Nations, 2008).

2.7.1. Informed consent

Information sheets and consent forms (Appendix H.4) were sent online by the organisation delivering the intervention. Potential participants were then contacted online via telephone or WeChat. During the call, a staff member talked through the information sheet and answers questions from participants, so as to ensure that the participants were aware of the purpose of the research, how they would be contributing to it, and how their data would be used and managed. The research staff presented the information in a simple and clear manner and in a participant's preferred language to prevent poor literacy or illiteracy from hindering a participant's understanding about the methods and purpose of the research. They emphasised that participation in the research was completely voluntary, and participants could also withdraw themselves from the study at any time, without giving a reason, by advising the research team of this decision. The deadline to withdraw data was 3 months post-intervention (for qualitative interviews, it is 3 months after the follow-up interviews) if participants wished to do so. Caregivers were informed that there were no implications in terms of their attending the programme if they chose not to participate or withdraw data at any point, such that if they decided to cease participation during the research, they could continue attending the SREIA sessions and receive a certificate of completion when they finished the programme.

Caregivers were made aware of the confidentiality of their information, including how

the data they provided would be used and stored, how their identifies would be masked using ID numbers on research materials, and how documents used to track and contact families for follow-up interviews would be kept separately from research data to protect participant's confidentiality. Caregivers also had the opportunity to ask questions about the research before deciding whether to take part. They were given a contact number and WeChat ID to discuss any further concerns. The research staff also asked the caregivers whether they felt any pressure or coercion to take part. No caregivers expressed feeling pressurised to participate.

The caregivers had up to a week to decide whether to participate in the study. They were also given 24 hours to decide to provide consent to participate, once they have received all the information about the study. If they agreed to take part in the study, they were asked to provide oral consent. A research staff recorded the oral consent using the form in Appendix H.4. All participants had to be capable of giving their own consent. No caregivers were identified as having difficulty completing the informed consent procedure.

Practitioners who were invited to the research also received an information sheet and a consent form (Appendix H.5). Oral consent was obtained from them using the same procedure as with family participants. They were reassured that participation was voluntary and that there were no negative consequences of their choosing not to participate or withdraw. They were also given one week to make a decision.

2.7.2. Data collection and confidentiality

Data collection was conducted using online video or audio conferencing (through Microsoft Teams). Caregivers were asked to complete the outcome assessments with assistance from trained research staff. The staff read the questions or items out loud to the participants, made sure the questions were understood, and entered participants' answers into encrypted online surveys. The participants were asked to stay in a private setting with no one else present during the online interview. Data collectors also confirmed with participants whether they were in a private setting before they started to administer the questionnaires. Participants did not

have to answer any questions they feel uncomfortable answering. The data collection interviews took no more than one hour for each caregiver. There was a short break after the first 30 minutes. Participants could also ask to pause or stop at any time. The qualitative interviews were similarly conducted in private. Caregivers could choose to stop the interview at any time, and if they wanted, they could ask the research staff not to use any part of the information that they provided.

For programme practitioners, the attendance and engagement registry and the fidelity checklist were both designed to take only a few minutes to complete. The checklists were converted online so that practitioners could access the form any time convenient for them. The practitioners were notified in advance if their sessions were selected for observation. They could choose to refuse to be observed if they were uncomfortable with it. The focus group discussions with practitioners were also held online via Microsoft Teams at a time that was agreed on by consensus. The discussions took about two hours. If more time (less than 20 minutes) was needed, all practitioners were asked for their consent to extend. There was a ten-minute break after the first hour. Participants had the right not to answer any question without giving any reasons. They were informed that they could opt out of the discussion at any time they felt like doing so and could request to remove any part of the recording if they wished to do so.

Confidentiality was maintained in all conversations, unless the participant indicated that they would conduct self-injurious behaviours, or there were any concerns about possible child abuse, for which appropriate action would be taken in accordance with the Child Protection Protocol (Appendix H.7) and in terms of informing the relevant authority. All research staff were also required to sign a confidential agreement (Appendix H.9) to protect the identify of respondents and the data collected.

My role in the quantitative data collection was to train the data collectors in administering the standardised questionnaires, setting up the online venue, connecting the data collectors with

the participants, monitoring the process, and providing supervision to the data collectors. My role in the qualitative data collection was to conduct half of the individual in-depth interviews with caregivers and facilitate the two focus group discussions with practitioners. I also trained and supervised a data collector to conduct the remaining half of the interviews with caregivers.

2.7.3. Potential harm and ways to resolve

This thesis investigated whether the SREIA parent training programme could improve parental mental health status and familial relationships with the purpose of promoting child development. However, caregivers in China may not feel comfortable talking about private issues such as mental health status or familial relationship. Therefore, asking them questions about whether and how they feel depressed, anxious, or stressed, could have potentially distressed them. In addition, children with ASD often have emotional and behavioural problems that are difficult for caregivers to cope with. As a result of having limited support, the caregivers may not have been using the most effective parenting strategies to interact with their children with ASD. As such, asking about their parenting styles may have made them wonder if they were being judged. Some caregivers may also have felt guilty if the questions made them feel that they could have done better.

To mitigate the risks, caregivers were informed during the consent procedure and during interviews that all conversations were private and any information they provided was confidential, unless there was risk of significant harm to them or their child or they were putting anyone else at risk of harm. They were also made aware that they did not have to answer any questions that they were uncomfortable with, and they had the right to cease the interview at any time without any repercussions. The interviews were conducted in a friendly environment. Research staff validated parents' feelings and normalised their parenting challenges. Caregivers were reassured that they would not be judged by the research staff, that their responses would only be used for research purposes, and that the research team would not be able to know their identities when accessing the data. In addition, all fieldwork staff had obtained or were working

on a master's degree in social work. They had been trained in research ethics and working with vulnerable families. They were able to use social work counselling techniques and discuss any issues the caregivers may have had if the caregivers were willing to. Staff could then provide information regarding mental health services or make referrals with the assistance from the implementation organisation, if required by the caregivers.

2.7.4. Child protection

All research staff, practitioners, and organisation managers were required to attend a training, conducted by me, on the Child Protection Protocol (Appendix H.7), which was created in case caregivers or programme practitioners disclosed any case where a child was being or was at risk of being abused or neglected. In those situations, research staff followed the following procedure:

1) If the child is at risk of harm and the caregiver is not the source of the risk, discuss with the caregiver the possibility of preventing harm and reporting to the Child Welfare and Protection Unit in Beijing if harm occurs.

2) If the child is at risk and the caregiver is the source of harm, inform and collaborate with the designated person in the organisation to investigate the situation. A Child Protection Referral Form will be completed in confidence with the Child Welfare and Protection Unit in Beijing.

3) If the child has been severely harmed, the staff member will be asked to assess the situation and call the Child Welfare and Protection Unit in Beijing who will advise on whether to call the police. The child will be sent to a hospital and the family will be excluded from the research.

Issues concerning potential risks of harm were discussed in training and supervision with research staff. The implementation organisation was also advised to discuss the topic during their supervision sessions. Participants were informed about this protocol during consent procedure.

2.7.5. Staff safety

The physical and psychological safety of research staff was prioritised. They were trained on the personal safety protocol (Appendix H.8) and advised against travelling during COVID-19. All data were collected online, which minimised the risk of being infected. Staff were asked to stop the interview whenever they felt uncomfortable or emotionally disturbed. In addition, working with vulnerable populations and hearing about their adverse experiences can be distressing. Although all research staff were social work graduate students who had received training on preventing vicarious trauma, time was set aside in each supervision to discuss any issues and distressing events. All staff were provided with the contact details of the psychological support and counselling services in the student counselling centre of the Beijing Normal University.

2.7.6. Approval

Ethical approval was granted by the Social Science and Humanities Inter-Divisional Research Ethics Committee at University of Oxford in the UK (R67619/RE001) and the Research Ethics Committee at the School of Social Development and Public Policy of the Beijing Normal University in China (SSDPP-HSC2020001).

The next chapter presents the methods and findings of the systematic review of parent training programmes that address physical abuse in childhood and associated factors (child emotional and behavioural problems and parent-child relationships) for families of children with developmental disabilities in mainland China.

CHAPTER 3. PAPER 1 Parent Training Programmes that Address Physical Abuse in Childhood for Families of Children with Developmental Disabilities in Mainland China: A Systematic Review and Meta-Regression

A version of this paper has been published in *Trauma, Violence, & Abuse:*

Fang, Z., Barlow, J., & Zhang, C. (2020). Parenting programs that address physical abuse in childhood for families of children with developmental disabilities in mainland China: Systematic review and meta-regression. *Trauma, Violence, & Abuse*, 1524838020915599.

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Word Count: 9811

3.1. Abstract

Millions of children in China are diagnosed with Developmental Disabilities (DD), many of whom are subject to physical abuse. While a significant body of research suggests that parenting interventions can reduce the incidence and risk of such abuse, there is currently limited evidence of their effectiveness for this population or from non-English-speaking countries. This review involved searches in both English and Chinese databases to identify randomised controlled trials and quasi-experimental studies of parent training programmes for families of children with DD in mainland China. Multi-level meta-analyses were undertaken to examine the effectiveness of parent training programmes. Subgroup analyses and meta-regression were conducted to investigate heterogeneity and identify potential moderators with a focus on intervention and delivery components. Risk of bias was assessed for each study. Thirty-one studies were included. The results showed that parent training programmes could reduce child emotional and behavioral problems (CEBP), and improve the parent-child relationship, although only one study directly measured the actual incidence of abuse. Programmes for Autism and Epilepsy had stronger treatment effects. Teaching knowledge about CEBP, skills to improve parental mental health, and techniques to cultivate empathy, were associated with programme success; however, positive reinforcement was associated with more problems. The results also supported the delivery of programmes with longer duration; a combination of group and individual sessions; efforts to build rapport; ongoing communication outside the programmes; and delivery in hospitals or service agencies. Further research is needed, however, in addition to improvements in the quality of research and reporting.

Keywords: Physical Abuse in Childhood, Parent Training Programmes, Developmental Disabilities, Multi-Level Meta-analysis, Meta-Regression, Moderator Analysis, Intervention and Delivery Components

3.2. Introduction

Physical abuse in childhood is defined as all corporal punishment and all other forms of torture, cruel, inhuman or degrading treatment or punishment against children under 18 by parents or other adult caregivers (United Nations Children's Fund, 2014). It is one of the most serious factors undermining healthy child development and its negative impacts have been documented across a range of domains including cognition, language, socio-emotional development, and mental and physical health (World Health Organisation, 2014). Child emotional and behavioral problems (CEBP) are characterised by: 1) inappropriate behaviors or feelings under normal conditions; 2) a pervasive mood of unhappiness or depression; 3) an inability to establish or maintain satisfactory relationships; 4) difficulty in learning that cannot be explained by intellectual, sensory, or health factors; or 5) a tendency to develop physical symptoms, pains, or fears with individual issues (United States Congress, 1990). There is substantial research showing that children with Developmental Disabilities (DD) (e.g. Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability, Cerebral Palsy, Epilepsy, Down Syndrome, and Tourette's syndrome), are much more likely to present with a wide range of CEBPs than children without such diagnoses (Herring et al., 2006a). Problems of this nature, combined with other disability symptoms, compound the DD condition, creating further activity limitations in children's daily functioning and imposing more challenges to parenting, such as the inability to communicate with children and difficulty in managing disruptive behaviors and noncompliance. Indeed, research consistently demonstrates a higher risk of parental stress among parents of children with DD, as well as a greater exposure to other mental health problems and chronic diseases(Richard Patrick Hastings et al., 2012). Additionally, as a result of the parenting challenges and frustration such child problems can cause, there is an increased likelihood of such parents becoming less responsive, supportive or affectionate to their child, and less engaged in positive parent-child interactions, which ultimately leads to impaired parent-child relationships (Belsky, 1993). CEBP and

dysfunctional parent-child relationships have historically been important predictors for physical abuse against children (Patterson, 1982; Tolan et al., 2006). As such, compared with typically developing cohorts, children with DD are at a considerably higher risk of experiencing such abuse (Jones et al., 2012).

In accordance with global data, epidemiological studies in China have shown that there are increasing numbers of children with DD diagnoses, with an estimate of 0.8 million children diagnosed with Autism (X. Sun, Allison, Matthews, et al., 2013), 17 million children diagnosed with ADHD (A. Liu et al., 2018; UNICEF et al., 2017), 1.98 million children diagnosed with Intellectual Disability (China Disabled Persons' Federation, 2012), and 1.83 with Epilepsy (Song et al., 2017). In addition to CEBP and parental health issues, Chinese parents are also affected by a range of other challenges. Traditionally, parents in China believe that corporal punishment is an effective, and legitimate, parenting practice that promotes attributes such as diligence, integrity, and obedience (M. Wang & Liu, 2014), and that such disciplinary practice reflects a parent's affection towards their child (Qiao & Xie, 2015). Also, the general lack of understanding regarding the implications of DD diagnoses, and a lack of reliable information for parents of children with DD in China, contribute to parents having expectations of children and attributions of behavioral intent, that are not appropriate to their children's developmental capacity (X. Hu et al., 2015). These inappropriate expectations and misunderstandings may increase the use of physical discipline (Dix & Grusec, 1985; Weisleder, 2011).

Parental stress in Chinese parents is further exacerbated by social isolation, restricted access to state financial supports, and the limited provision of education and rehabilitation services, which are geographically unevenly spread (X. Hu et al., 2015; State Council, 2012). A high level of stress is recognised to contribute to low parental warmth and dysfunctional disciplinary practices, which intensifies CEBP and increases the likelihood of physical abuse (Belsky, 1993; Pinderhughes et al., 2000). Despite the elevated risk of physical abuse, a comprehensive detection and reporting system for child abuse has yet to be established. As a

result, the situation of children with DD in mainland China is of concern.

3.2.1. Parent training programmes

Parent training programmes are interventions that are aimed at reducing the incidence and risk of physical abuse against children and promoting the parent-child relationship, by improving emotional and behavioral adjustment, reducing parental stress, changing parenting attitudes, and increasing positive parenting knowledge and skills (J Barlow et al., 2006; Montgomery et al., 2009). They are underpinned by a range of theoretical frameworks but are usually grounded in social learning theory (Bandura, 1971), operant learning theory (Skinner, 1950), the coercion model of interaction (Patterson, 1982), and attachment theory (Bowlby, 1969). Despite different theoretical models, such programmes often share common strategies such as positive reinforcement, parent-child play, and emotion coaching, in addition to having unique components to address particular concerns (Leijten et al., 2019). A variety of delivery techniques can be used including modelling and role play. The duration and intensity of parent training programmes vary, although they are typically provided on a weekly basis over the course of 8-12 weeks. They can be delivered individually and/or on a group basis, by professionals and/or trained non-professionals. Manuals are typically available to guide the sessions.

A significant body of evidence has shown the effectiveness of parent training programmes in reducing the incidence of physical abuse against children and modifying risk and/or protective factors associated with such abuse among typically developing children (e.g., Altafim & Linhares, 2016; Knerr, Gardner, & Cluver, 2013; Mejia, Calam, & Sanders, 2012; van der Put, Assink, Gubbels, & van Solinge, 2018). As such, parent training programmes are recommended as one of the seven critical strategies for preventing abuse by WHO (2016).

Despite the specific issues that children with DD may experience, the core principles of the above theories still apply. For instance, research shows that the associations between reinforcement and behavior among children with Autism and Intellectual Disability are

consistent with operant theories of the establishment and maintenance of behavior (Baghdadli et al., 2003; Oliver et al., 2012). Children with Autism can also benefit from interventions underpinned by behavioral and attachment-based models of working (Rutgers et al., 2004).

To address the challenges resulting explicitly from DD (such as disability-related emotional and behavioral problems, repetitive and stereotyped behaviors in children with Autism, and delayed language skills in children with Down's Syndrome and Cerebral Palsy), parent training programmes directed at parents of children with DD also incorporate principles from a number of other sources: 1) behavioral interventions characterised by Applied Behavioral Analysis (ABA) which is grounded in operant learning theory (Cooper et al., 2007); 2) child development theories, which lead to a focus on skill acquisition and inform the creation of developmentally appropriate learning experience (Harvey et al., 2009); and 3) educational frameworks (such as TEACCH), which encourages the development of individualised treatment plans and a structured teaching environment, to maximise learning opportunities (Mesibov & Shea, 2010).

Three systematic reviews have been conducted to assess the effectiveness of parent training programmes for parents of children with DD (Singer et al., 2007; Skotarczak & Lee, 2015; Tellegen & Sanders, 2013). Skotarczak and Lee (2015) and Tellegen and Sanders (2013) showed that Stepping Stones Triple P—a parent training programme underpinned by ABA principles with a focus on behavioral change (Sanders et al., 2004)—had a significant effect on changing children's behaviors and promoting positive parenting skills for a broad range of DD diagnoses. Skotarczak and Lee (2015) found that the programme Parents' Plus appeared to improve the behavior of children with Autism, although the results failed to achieve statistical significance. Singer, Ethridge and Aldana (2007) found that behavioral parent training programmes were effective in reducing parental psychological distress.

There have been no further reviews of the effectiveness of other parent training programmes for DD, and notably existing evidence is primarily gathered from high-income

countries. Although an increasing number of parent training programmes for DD have been evaluated in other countries such as China, prior reviews commonly miss these studies, mostly due to language and database biases (Shenderovich et al., 2016). This systematic review aims to address this gap by including Chinese studies in an update of the evidence-base more generally, and through the inclusion of a moderator analysis.

3.3. Objectives

This review aims to:

1) assess the effectiveness of parent training programmes for families of children aged 0 to 18 years of age with developmental disabilities in mainland China in:

a) reducing the incidence of physical abuse in childhood,

b) decreasing child emotional and behavioral problems (CEBP) (risk factor), and

c) improving parent-child relationships (protective factor);

2) investigate potential moderators of such interventions, with a focus on the most effective intervention and delivery components.

3.4. Methods

3.4.1. Inclusion criteria

Studies of parent training programmes were eligible for inclusion if they were delivered to adult primary caregivers of children with DD in mainland China and aimed at 1) reducing physical abuse in childhood; 2) reducing child emotional and/or behavioral problems; or 3) improving parent-child relationships or creating healthy parent-child attachment, by increasing parental knowledge, improving parenting skills, changing parental attitudes, reducing parental stress, or improving parental self-efficacy. There were no limits in terms of the following criteria: underpinning theoretical framework, intervention duration, intensity, setting, format, year of delivery, or qualification of facilitators. Only RCTs and quasi-experimental studies with control conditions of treatment-as-usual (including waitlist treatment and no treatment) were

selected. The outcomes could be measured at different time points, but the primary time point of interest was post-intervention (section 2.2.1).

Intervention and delivery components included in the review were identified using a thematic analysis. Due to the fact that the included studies provided very limited and inconsistent descriptions of the interventions, exhaustive inductive coding of the reports was conducted to capture features of the interventions (Sutcliffe et al., 2015). Word-by-word coding was first performed to identify all available information regarding the interventions. Codes were then categorised into intervention components and delivery components.

3.4.2. Search methods

Electronic searches were carried out in August 2018 using the four major Chinese databases (China National Knowledge Infrastructure, China Science and Technology Journal Database, Wanfang Database, and Chinese Electronic Periodical Services) and four English databases (Cochrane Central Register of Controlled Trials, MEDLINE, Embase, and PsyINFO). Search terms were structured around three concepts: 1) child abuse, 2) parent training, and 3) developmental disabilities. Sensitive searches were conducted by using multiple search terms for each concept. Twelve sources of grey literature were also explored, the reference lists of all included studies were hand searched, and experts were consulted to identify additional studies.

3.4.3. Selection of studies and data extraction

The first author screened all titles and abstracts to determine whether they met the inclusion criteria. A random 30% of the titles and abstracts were selected using a random number generator and double-screened by the third author. Full-texts were retrieved if titles and abstracts appeared to meet the criteria. The first author reviewed all retrieved full-texts and the third author independently screened a random 30% of texts. Any disagreements were reconciled by the second author.

Data were extracted and coded by the first author, with the third author also independently

extracting data for a random 30% of included studies. Authors of the included trials were contacted via phone calls and/or emails to obtain information regarding study methods or missing data if the reasons for missing data were not specified.

A data extraction and coding form was created to collect data for narrative and quantitative synthesis, and for quality assessment of each included study. The spreadsheet included the following information: publication information (author, title, year, and study design), participant demographics (screening strategy, number of children and girls, child age, diagnosis, comorbidity; caregiver type, age, economic status, education level; and any other participant characteristics), intervention and comparison data (brand, transported or homegrown, origin, adaptation, content description, delivery mode and format, duration of the programme and each session, number and frequency of sessions, facilitator qualification, setting, incentives for participants and staff, fidelity control methods), and design/outcome data (total sample size; subgroup and sample size; outcome; measurement tool and validation; type of outcome data; respondent type; unit of analysis; response rate; number of participants and dropouts in each arm; mean and standard deviation in each arm at baseline, postintervention, and follow-ups).

3.4.4. Assessment of risk of bias

The risk of bias was examined in each included study using the Cochrane Collaboration's tool (Higgins & Green, 2011). Seven domains were assessed including random sequence generation, allocation concealment, blinding (of participants and personnel and outcome assessment), incomplete outcome data, selective reporting, and other sources of bias, particularly the baseline comparability of treatment groups.

3.4.5. Unit of analysis

No cluster-RCTs were identified. The unit of analysis was individual participants.

3.4.6. Assessment of heterogeneity

Clinical heterogeneity was explored by comparing the characteristics of participants and programmes. Methodological heterogeneity was assessed by comparing study designs. Statistical heterogeneity (between-study variance) was assessed using the Q statistic, which contrasts observed variance between studies and within-study error, and the I^2 statistic which quantifies the amount of the variability that is caused by residual heterogeneity, with P-values reported (Borenstein et al., 2011).

3.4.7. Assessment of reporting bias

Publication bias was investigated by examining the asymmetry of a funnel plot of the intervention effect estimates against the standard error of the intervention effect estimates (Higgins & Green, 2011). An Egger's test was combined with the funnel plot to test the asymmetry (Egger et al., 1997). Publication bias was assessed for CEBP only because the other outcomes were measured by fewer than ten trials.

3.4.8. Data synthesis

The included studies assessed the outcomes using a variety of tools and reported subscales and/or total scores. When a study provided both a total score and subscale scores, the total score was used if all subscales were associated with the same outcome of interest. However, if the subscales were measuring several outcome domains relevant to this review, they were extracted and analysed separately, and the total score was not used.

The effect size for each outcome domain was assessed using SMD-Hedges' *g* with a 95% confidence interval. The mean, standard deviation, and number of observations in each arm was extracted from the included trials to calculate Hedges' *g* in R Studio. A meta-analysis was conducted to combine the effect sizes for each outcome domain, when appropriate. Given the inclusion of studies reporting more than one subscale for the outcome(s) of interest, three-level mixed-effect models were used to account for the data dependency (section 2.2.2). The

Restricted Maximum Likelihood (REML) estimator was incorporated into the multi-level models to reduce bias (Hartung et al., 2008).

3.4.9. Subgroup analysis and meta-regression

Subgroup analyses were conducted to assess whether and how the origin of the programme, child diagnosis, comorbidity, and comparison conditions contributed to a reduction of heterogeneity and affected treatment effects for two outcomes—CEBP and the parent-child relationship. For parent-report CEBP at postintervention, intervention and delivery components of the included programmes were: 1) individually assessed to investigate whether group differences existed; and 2) included in multivariate meta-regression models to explore moderation effects. It was not possible to assess child age and gender because all trials included children with a wide age range and a mix of boys and girls. Parental characteristics were not well reported in most of the included trials and thus not investigated.

The review compared differences in the effects of subgroups by testing interactions between treatment and subgroup, instead of conducting separate meta-analyses for each subgroup, which can increase the likelihood of type I errors (identifying positive treatment effects when there is not a genuine effect) (Brookes et al., 2004). Two main multi-variate meta-regression models were fitted to further examine moderating effects. One model incorporated all intervention components, while the other included all delivery components. To improve precision, an additional meta-regression model was created for each original model by removing outliers. Outliers were defined as studies for which the upper confidence interval (CI) was smaller than the lower CI of the pooled effect or for which the lower CI was larger than the upper CI of the pooled effect (Viechtbauer & Cheung, 2010). All quantitative data analyses were conducted using the `meta`, `metafor`, and `car` packages in R Studio.

3.4.10. Sensitivity analysis

Sensitivity analyses were conducted to assess the impact of study quality on the outcomes

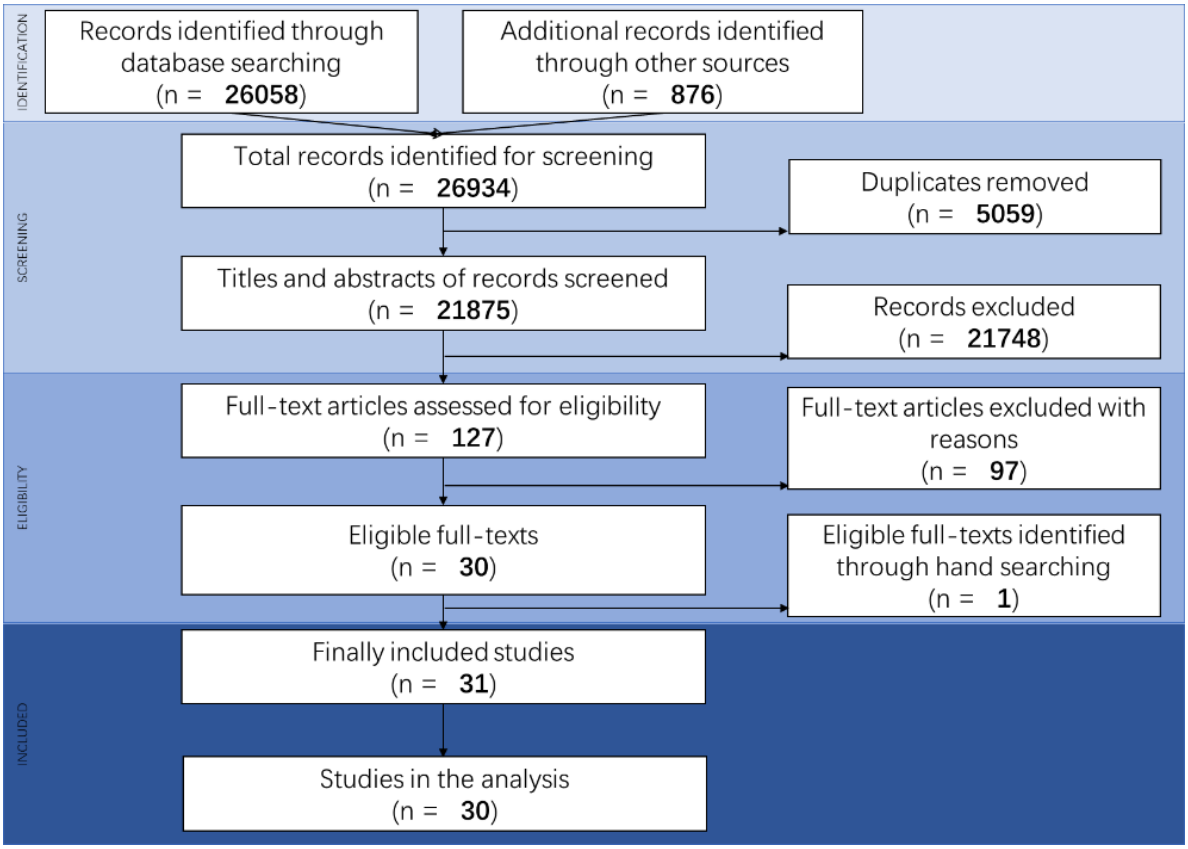
CEBP and parent-child relationships. The impact of study quality was assessed by: 1) removing quasi-experiments; 2) removing studies with overall high risk of bias; and 3) removing outliers. Studies with high risk of bias were those for which at least five out of the seven domains were rated at high risk of bias or unclear risk of bias.

3.5. Results

3.5.1. Search results

The search resulted in 26934 records. Following assessment of eligibility, thirty-one studies (evaluating 31 parent training programmes and involving 2410 primary caregivers) were included in this review; 29 were published in Chinese and two in English. Due to missing data in one report (H. Huang & Du, 2005), 30 studies were included in the analysis. A PRISMA flow chart is presented in Figure 12.

Figure 12 PRISMA flow chart



3.5.2. Study design

Twenty trials randomised individual participants into treatment and control groups, and the remaining eleven studies used a quasi-experimental design. The treatment-as-usual (TAU) conditions in the included studies can be classified into three broad categories: 1) regular services only (16 studies); 2) medication only (nine studies), providing children of parents in both treatment and control groups with the same dose of medication; and 3) a combination of both (six studies). There were three studies having more than one control group, and data from these additional comparison groups were not included in this review. Table 5 provides further details about the sample sizes, designs, participant characteristics, and intervention types.

Table 5 Included Studies

Study ID	Design	Sample	Diagnosis	Child Age	Programme Origin	Outcome Measures
Cen, 2016	RCT	60	Autism	5-11 years old	Homegrown	unvalidated questionnaire
Chu, Yan, & Wei, 2007	RCT	112	Epilepsy	4-18 years old	Homegrown	CBCL; FES-CV
Gong, Huang, & Wu, 2009	RCT	60	ADHD	6-12 years old	Homegrown	CBCL
Hang, Wu, Li, & Yang, 2012	Quasi-RCT	100	ADHD	8-12 years old	Homegrown	Conners CBRS-P; FAD
Hu, Xie, Mao, & Song, 2010	Quasi-RCT	116	ADHD	6-14 years old	Homegrown	Conners CBRS-P
Huang & Du, 2005	Quasi-RCT	60	ADHD	mean 9.06 years	Homegrown	Conners CBRS-P
Huang, 2018	Quasi-RCT	78	Autism	2-11 years old	Homegrown	PEP and ABC
Ji, Sun, Yi, & Tang, 2014	Quasi-RCT	50	Autism	mean 5.26 years	Homegrown	FAD
Jiang & Zhu, 2017	RCT	80	ADHD	6-11 years old	Homegrown	Psychological Scale; unvalidated questionnaire
Lin et al., 2013	Quasi-RCT	100	ADHD	mean 8.20 years	Homegrown	Conners CBRS-P
Liu, Xiang, Zhang, Wen, & Wang, 2007	RCT	62	ADHD	7-11 years old	Homegrown	EMBU
Liu et al., 2017	Quasi-RCT	68	Autism	0.6-3 years old	Homegrown	ABC
Liu, Su, & Gong, 2009	RCT	31	ADHD	6-13 years old	Homegrown	Conners CBRS-P
Lu, Xie, Liang, Huang, & Chen, 2006	RCT	67	ADHD	6-13 years old	Homegrown	CBCL

Luo & Wang, 2011	Quasi-RCT	88	ADHD	6.5-14 years old	Transported	Conners CBRS-P
Nie, Liu, Zhang, & Han, 2016	RCT	80	ADHD	7-12 years old	Transported	Conners CBRS-P
Qian, Hua, & Xu, 2015	RCT	60	ADHD	6-13 years old	Homegrown	SNAP-IV
Sun & Li, 2015	RCT	100	Autism	mean 5.8 years	Homegrown	ABC; ATEC
Sun, 2015	Quasi-RCT	60	Autism	1-11 years old	Homegrown	ATEC
Wang & Chu, 2015	RCT	98	Epilepsy	6-18 years old	Homegrown	FES-CV; FAD
Wang, 2005	RCT	34	Autism	3-9.6 years old	Homegrown	PSI/SF; MBRS
Wu, 2016	Quasi-RCT	26	Autism	3-7 years old	Homegrown	DCS; Parent-Child Interaction Behaviors Coding Scales
Xiao, Yang, & Cui, 2015	RCT	50	Autism	4-7 years old	Homegrown	ABC; ATEC
Xue, 2014	RCT	60	ADHD	6-13 years old	Homegrown	PHCSS
Yan, Ding, & Zhu, 2011	Quasi-RCT	66	ADHD	mean 9.83 years	Homegrown	PHCSS
Yan, Xing, & Deng, 2012	RCT	200	Tourette Syndrome	7-14 years old	Homegrown	PedsQL 4.0; unvalidated questionnaire
Zhang & Qiu, 2016	RCT	94	Autism	4-7 years old	Homegrown	ABC; ATEC
Zhang et al., 2011	RCT	75	ADHD	6-12 years old	Transported	DBDRS
Zhang & Qiu, 2016	RCT	90	Autism	2-8 years old	Homegrown	ABC; ATEC
Zhang, Jin, & Zhang, 2009	RCT	280	ADHD	mean 8.10 years	Homegrown	unvalidated questionnaire
Zhou, Nie, & Chu, 2014	RCT	98	Epilepsy	8-16 years old	Homegrown	PHCSS; FES-CV

CBCL: Child Behavior Checklist; FES-CV: Family Environment Scale-Chinese Version; Conners CBRS-P: Conners Comprehensive Behavior Rating Scales; FAD: Family Assessment Device; PEP: Psychoeducational Profile; ABC: Autism Behavior Checklist; EMBU: Egna Minnen Beträffande Uppfostran; SNAP-IV: Swanson, Nolan, and Pelham ; ATEC: Autism Treatment Evaluation Checklist; PSI/SF: Parenting Stress Index; DCS: Dyadic Coding Scales; MBRS: Maternal Behavior Rating Scale; PHCSS: Piers-Harris Children's Self-Concept Scale; PedsQL 4.0: Pediatric Quality of Life Inventory; DBDRS: Disruptive Behavior Disorder Rating Scale.

3.5.3. Outcomes

Outcomes were predominantly reported by parents. Three trials (P. Wang, 2005; Z. Wu, 2016; L. Yan et al., 2012) also used observational measurements (i.e. videotaping), and four studies (Xue, 2014; G. Yan et al., 2011; L. Yan et al., 2012; YN Zhou et al., 2014) obtained children's self-report data. All included studies measured outcomes at postintervention. Only one study (L. Zhang et al., 2009) measured child abuse using a questionnaire developed for the evaluation. It asked parents whether or not they "often used verbal and corporal punishment"; however, it did not provide the data for corporal punishment only. Twenty-five studies measured CEBP and nine studies measured the parent-child relationship.

3.5.4. Risk of bias

Figure 13 and Figure 14 present an overview of the methodological quality of the included studies. Figure 14 presents the result of an assessment of the risk of bias (RoB) items across all included studies. The risk was rated low for nine out of the 31 studies with regard to random sequence generation. In terms of allocation concealment, 20 studies were rated high risk of bias, and the remaining 11 studies did not provide adequate information. Due to the nature of parent training programmes, all included studies were rated as being at high risk of performance bias. The outcome assessments predominantly relied on data reported by caregivers or children, which could be compromised in a variety of ways including detection or social desirability bias (R. J. Fisher, 1993); all studies were therefore rated as posing a high risk of bias in relation to blinding. Twenty studies were rated as being at low risk of attrition bias, while the remaining 11 studies excluded dropouts in the analyses and were consequently rated high risk of bias. Two studies posed a high risk of reporting bias, while there were no indications of selective reporting in the remaining trials. Eighteen studies did not adequately assess baseline balance; those studies were consequently judged to be at high risk of other bias. Figure 13 shows the details of our judgements about each RoB domain for each included study.

Figure 13 Risk of bias graph

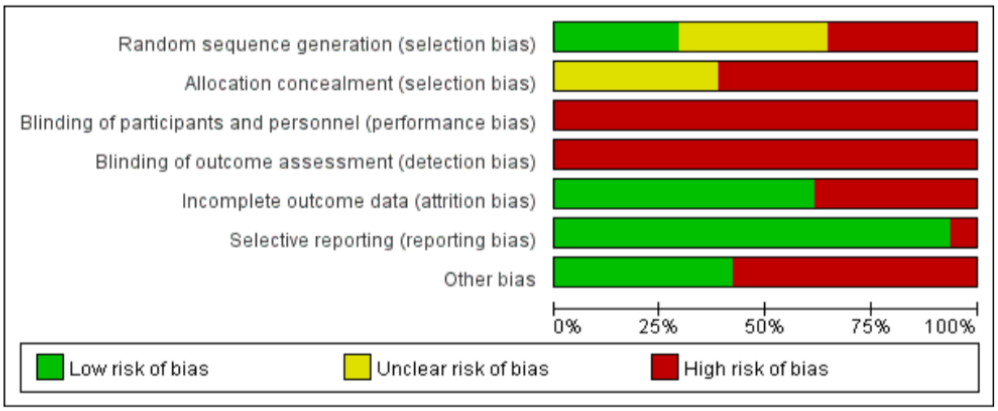


Figure 14 Risk of bias summary



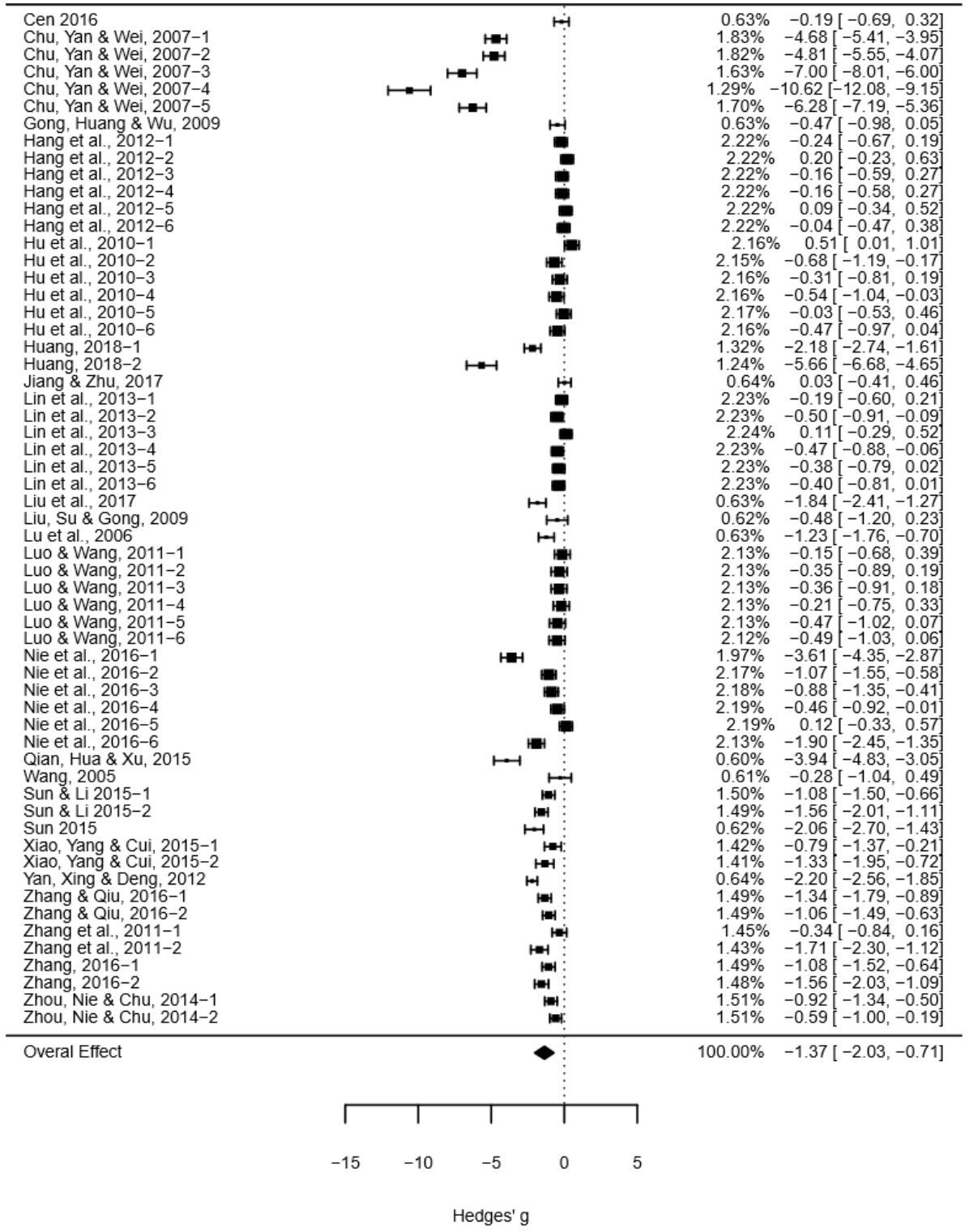
3.5.5. Effects of interventions: Multilevel meta-analyses and single study results

Physical abuse in childhood. An analysis of the data extracted from the one trial measuring child abuse indicated that parents who received the parent training programme were less likely to verbally or physically punish their children than parents in the control group at

postintervention (RR = 0.51, 95% CI [0.28, 0.92]).

CEBP. A variety of scales were used to measure CEBP including the CBCL (Achenbach & Rescorla, 2001b), the Conners CBRS-P (Conners, 2008), the ABC(Krug et al., 1979), the ATEC (Rimland & Edelson, 1999), the PHCSS (Piers & Harris, 1963), the DBDRS (Friedman-Weieneth et al., 2009), the PedsQL 4.0 (Varni et al., 2001), the SNAP-IV (Swanson et al., 2001), the PSI/SF (Abidin, 1990), the PEP (Schopler & Reichler, 1976), and a psychological scale developed by Beijing Normal University (no reference provided). Parent-reported data showed that parent training programmes were more effective than control groups at postintervention (g = -1.37, 95% CI [-2.03, -0.71]; Figure 15). There was substantial heterogeneity (I^2 = 75.40%, Q(df = 58) = 1262.86, p < .0001). For child-reported scales, there was no statistically significant group difference (g = -0.68, 95% CI [-1.82, 0.46]; I^2 = 90.06%, Q(df = 4) = 35.81, p < .0001).

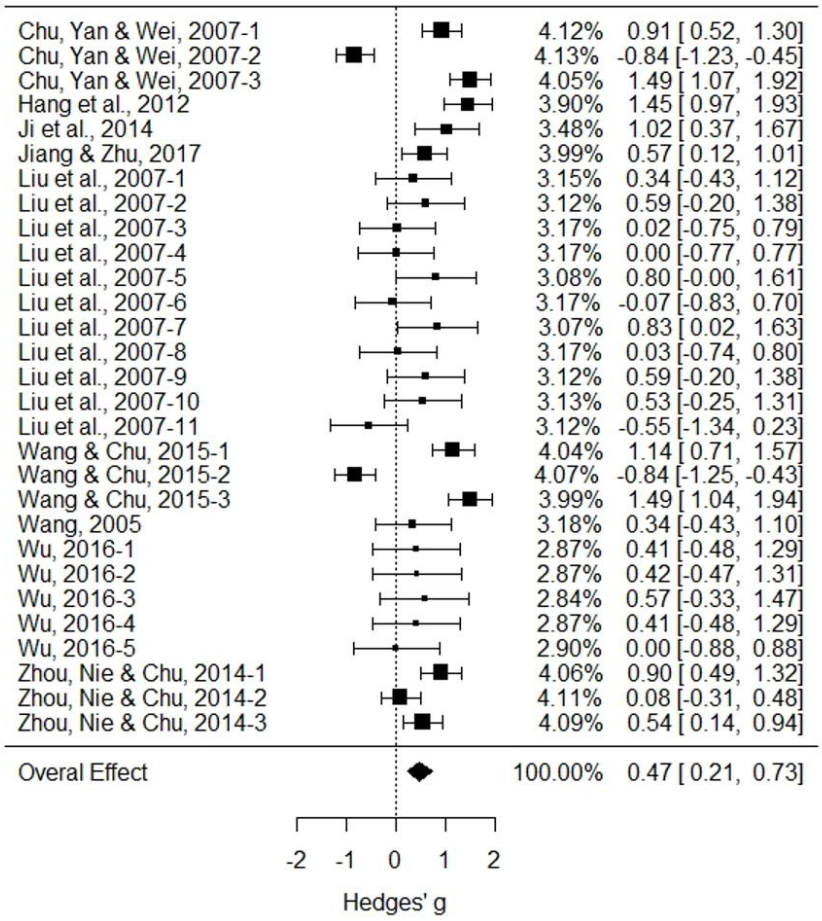
Figure 15 Analysis: child emotional and behavioral problem (CEBP), parent-report, at postintervention



Parent-child relationship. The following scales were used to measure the parent-child relationship: the FES (Moos, 1990), the FAD (Epstein et al., 1983), the EMBU (Arrindell et al., 1999), the MBRS (Mahoney et al., 1986), PSI/SF (Abidin, 1990), the DCS (Humber & Moss, 2005), and two scales designed by the trialists. The analysis showed a small effect favouring the parent training programmes at postintervention as reported by parents (g = 0.47, 95% CI

[0.21, 0.73]; Figure 16). There was low level of inconsistency (I^2 = 00.00%, Q(df = 28) = 181.30, p < .0001). Two studies used observational measurements and also found a similar effect size in improving the parent-child relationship (g = 0.49, 95% CI [0.17, 0.81]; I^2 = 00.00%, Q(df = 16) = 30.77, p = 0.0144).

Figure 16 Analysis: parent-child relationship, parent-report, at postintervention



3.5.6. Sensitivity analyses

CEBP. The treatment effect was slightly larger when seven quasi-experiments were removed (g = -1.53, 95% CI [-2.47, -0.60]; I^2 = 61.79%, Q(df = 30) = 833.87, p < .0001) and when seven studies with high risk of bias were removed (g = -1.56, 95% CI [-2.52, -0.61]; I^2 = 64.49%, Q(df = 25) = 735.14, p < .0001). The treatment effect was maintained, although was smaller, when outliers were excluded (g = -0.99, 95% CI [-1.31, -0.65]; I^2 = 77.14%, Q(df = 31) = 215.16, p < .0001).

Parent-child relationships. The pooled effect was maintained although slightly smaller with the three quasi-experiments removed (g = 0.42, 95% CI [0.11, 0.72]; I^2 = 00.00%, Q(df = 21) = 161.69, p < .0001), with four studies with high risk of bias excluded (g = 0.42, 95% CI [0.13, 0.72]; I^2 = 00.00%, Q(df = 18) = 96.65, p < .0001), and with three outliers removed (g = 0.41, 95% CI [0.23, 0.59]; I^2 = 30.52%, Q(df = 21) = 25.99, p = 0.2067).

3.5.7. Subgroup analyses and meta-regression

CEBP. The subgroup analysis detected a significant difference among subgroups based on diagnosis (Qm: F(df1 = 3, df2 = 55) = 2.85, p = 0.0457) and a small reduction in heterogeneity (I^2 = 68.01% Qe(df = 55) = 850.25, p < .0001). The results indicated that the parent training programmes had more significant effects for Autism (g = -1.47, 95% CI [-2.42, -0.52]) and Epilepsy (g = -3.69, 95% CI [-5.57, -1.81]) than for ADHD (g = -0.78, 95% CI [-1.61, 0.05]) and Tourette's (g = -2.20, 95% CI [-5.16, 0.76]). However, there were no statistically significant group differences or heterogeneity reduction in terms of the origin of the programme (Qm: F(df1 = 1, df2 = 57) = 0.39, p = 0.54; I^2 = 75.95%, Qe(df = 57) = 1258.65, p < .0001), child comorbidity (Qm: F(df1 = 2, df2 = 56) = 0.60, p = 0.55; I^2 = 76.17%, Qe(df = 56) = 1240.77, p < .0001), or control condition (Qm: F(df1 = 2, df2 = 56) = 1.62, p = 0.21; I^2 = 73.95%, Qe(df = 56) = 1047.04, p < .0001).

Parent-child relationship. The subgroup analysis showed that there were no statistically significant subgroup differences or heterogeneity reduction in terms of child diagnosis (Qm: F(df1 = 2, df2 = 26) = 0.09 p = 0.9137; I^2 = 00.00%, QE(df = 26) = 181.29, p < .0001) or comparison (Qm: F(df1 = 1, df2 = 27) = 0.20 p = 0.6612; I^2 = 00.00%, QE(df = 27) = 181.30, p < .0001). Subgroup analysis was not conducted for programme origin or child comorbidity, due to the small number of studies.

Intervention components. Statistically significant differences were found between programmes with and without components focusing on *cultivating empathy* to enhance the parent-child relationship (Qm: F(df1 = 1, df2 = 57) = 5.09, p = 0.0280) and between

programmes with and without components teaching parents *techniques to reduce stress* (Qm: F(df1 = 1, df2 = 57) = 5.70, p = 0.0203). However, neither contributed to the reduction of between-study variance (*empathy*: Qe(df = 57) = 1212.41, p < .0001, I^2 = 71.32%; *stress reduction*: Qe(df = 57) = 1185.08, p < .0001, I^2 = 70.69%)

The multi-variate meta-regression model (Table 6) found a weak association for *stress reduction*. *Offering knowledge of CEBP* was associated with stronger treatment effects (*b* = -3.69, 95% CI [-6.97, -0.40], p < .05), whereas the *use of positive reinforcement* (*b* = 2.74, 95% CI [0.27, 5.21], p < .05) and *establishing household rules* (*b* = 5.53, 95% CI [0.61, 10.45], p < .05) appeared to contribute to an increase in CEBP.

With seven outliers removed, the reduced meta-regression model (Table 6) showed that the moderation effects of *increasing parental knowledge of CEBP* were stronger (*b* = -4.60, 95% CI [-8.09, -1.10], p < .05), and the effect of the *use of positive reinforcement* was maintained (*b* = 2.41, 95% CI [1.13, 3.69], p < .001). The moderation effects for the component *establishing household rules* no longer existed. Moderation effects were captured for *cultivating empathy* (*b* = -1.85, 95% CI [-3.14, -0.56], p < .01), as well as *developing social and communication skills* (*b* = -0.96, 95% CI [-1.76, -0.16], p < .05). The two components were both associated with stronger effects in reducing CEBP. *Play* was potentially associated with less CEBP (only significant at p-value < 0.1), while *paying positive attention* could potentially increase CEBP (only significant at p-value < 0.1). The results should be interpreted with caution, because the insufficient reports could have led to the lack of power in the models.

Delivery components. The analysis showed a statistically significant difference between subgroups in term of *rapport building* (Qm: F(df1 = 1, df2 = 57) = 6.71, p=0.01) but no reduction in between-study heterogeneity (QE(df = 57) = 1048.4402, p < .0001, I^2 = 68.55%). The multi-variate meta-regression model (Table 6) indicated that *institutional delivery setting* (*b* = -7.77, 95% CI [-14.58, -0.95], p < .05) and *maintaining ongoing communication* (*b* = -3.17, 95% CI [-5.42, -0.92], p < .01) were associated with stronger effects in reducing CEBP. In

contrast, the component *individual sessions only* was likely to increase CEBP (*b* = 10.04, 95% CI [0.40, 19.69], p < .05). With outliers removed, the moderation effects captured by the original model were no longer sustained (Table 6). However, the new model showed that *shorter programmes (one to four sessions)* could contribute to an increase in ECBP (*b* = 1.88, 95% CI [0.40, 3.36], p < .05); so were potentially programmes with *five to eight sessions* and programmes with *exclusively group sessions* (both only significant at p-value < 0.1). The results of subgroup analyses and meta-regressions could again be underpowered by insufficient reports of techniques used during programme implementation.

Table 6 Meta-regression: intervention and delivery components

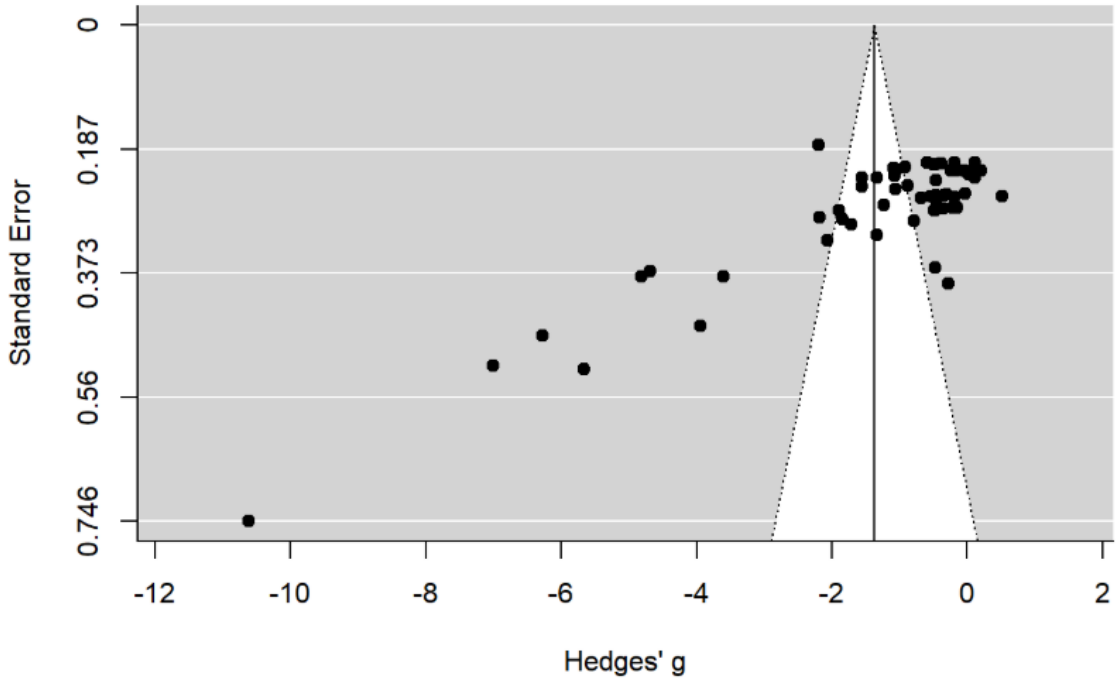
Intervention Components	Full Model		Reduced Model		Delivery Components	Full Model		Reduced Model	
	b	**95%CI**	***b***	**95%CI**		***b***	**95%CI**	***b***	**95%CI**
Intercept	-0.05	[-1.68, 1.59]	-0.17	[-0.80, 0.45]	Intercept	*-1.57`*	*[-3.27, 0.13]*	***-1.86******	***[-2.84, -0.87]***
Knowledge of CEBP	***-3.69****	***[-6.97, -0.40]***	***-4.60****	***[-8.09, -1.10]***	1-4 sessions	1.46	[-1.76, 4.68]	***1.88****	***[0.40, 3.36]***
Reinforcement	***2.74****	***[0.27, 5.21]***	***2.41******	***[1.13, 3.69]***	5-8 sessions	1.38	[-0.73, 3.49]	*1.37`*	*[-0.23, 2.98]*
Positive attention	0.52	[-3.32, 4.37]	*1.89`*	*[-0.27, 4.06]*	9 or more sessions	-1.69	[-6.21, 2.84]	-0.78	[-3.67, 2.11]
Ignore	-0.14	[-5.22, 4.94]	-0.61	[-2.17, 0.95]	Institution	***-7.77****	***[-14.58, -0.95]***	-1.39	[-4.49, 1.71]
Time-out	-0.39	[-3.18, 2.40]	-0.12	[-1.08, 0.84]	Institution and home	-10.30	[-25.29, 4.68]	0.79	[-3.21, 4.79]
Household rules	***5.53****	***[0.61, 10.45]***	0.16	[-0.86, 1.18]	Professional facilitator	0.78	[-1.01, 2.57]	0.66	[-0.32, 1.64]
Effective instructions	0.50	[-2.13, 3.13]	-0.18	[-1.02, 0.65]	In person	4.79	[-2.17, 11.76]	-1.24	[-5.25, 2.77]
Emotion coaching	-4.74	[-14.04, 4.55]			In person and online	*11.94`*	*[-1.26, 25.14]*		
Establish routines	-1.53	[-5.82, 2.77]	1.15	[-0.41, 2.71]	Group and individual sessions	2.64	[-2.71, 7.99]	-0.24	[-2.29, 1.81]
Show affection	-0.49	[-2.65, 1.68]	0.75	[-0.40, 1.91]	Group sessions only	-1.86	[-9.75, 6.03]	*2.93`*	*[-0.39, 6.26]*
Play	1.25	[-0.79, 3.29]	*-0.93`*	*[-2.00, 0.13]*	Individual sessions only	***10.04****	***[0.40, 19.69]***		
Empathy	-0.05	[-4.35, 4.26]	***-1.85*****	***[-3.14, -0.56]***	Didactive and interactive mode	-0.14	[-3.10, 2.81]	0.14	[-1.45, 1.73]
Parental self-regulation skills	-0.73	[-3.20, 1.74]			Didactive mode	0.48	[-2.24. 3.20]	0.62	[-0.89, 2.14]
Stress reduction skills	*-4.64`*	*[-9.59, 0.32]*			Flexibility	0.46	[-1.40, 2.32]	0.23	[-0.75, 1.21]
Techniques to improve child social skills	0.47	[-3.02, 3.96]	*-0.96**	*[-1.76, -0.16]*	Fidelity promotion	*3.08`*	*[-0.44, 6.59]*	2.03	[-0.87, 4.93]
Techniques to improve child language and communication skills	-2.24	[-5.55, 1.06]			Rapport building	0.82	[-9.41, 11.05]		

	Methods to promote skill acquisition	-0.69	[-4.23, 2.85]	-0.49	[-2.36, 1.38]
	Ongoing communication	***-3.17*****	***[-5.42, -0.92]***		
*P-value: ***, <0.001; **, <0.01; *, <0.05; `, <0.1*					

3.5.8. Publication bias

The funnel plot for CEBP (Figure 17) is highly asymmetrical, with the small studies with a lower effect size missing in the bottom right corner. It is likely that only small studies with a large effect size were published, whereas small studies without a significant effect were not. The Egger's test also showed a score of -14.42 (p = 0), indicating substantial asymmetry that could have been caused by publication bias.

Figure 17 Funnel plot, outcome: child emotional and behavioral problems (CEBP)



3.6. Discussion

3.6.1. Summary of findings

The review identified 20 RCTs and 11 quasi-experimental studies evaluating the effectiveness of parent training programmes for families of children with Developmental Disabilities (DD) compared to treatment-as-usual in reducing the incidents and associated

factors of physical abuse in Chinese children. A single study showed that parents in the parent training programme were less likely to verbally or physically punish their children. The findings of the multi-level meta-analyses provide provisional evidence that parent training programmes for DD (specifically ADHD, Autism, Epilepsy, and Tourette's) can reduce child emotional and behavioral problems (CEBP) and improve the parent-child relationship. The treatment effects were maintained in the sensitivity analyses, suggesting a high degree of certainty.

The subgroup analyses suggested that child diagnoses contributed to the heterogeneity such that parent training programmes had a stronger effect in reducing CEBP in families of children with Autism and Epilepsy, but not in terms of the parent-child relationship. For both outcomes, there were no statistically significant group differences in terms of treatment-as-usual conditions. Neither the origin of the programme (China versus the U.S.) nor child comorbidity had a significant impact in terms of reducing CEBP. The findings should be treated with caution, however, given the limited numbers of studies in the subgroups

With regard to the outcome CEBP, the analysis of intervention components showed that programmes with content to reduce *parental stress* and *cultivate empathy* appeared to have a stronger effect on reducing CEBP than those without such content; heterogeneity was reduced in both cases. The meta-regression models detected two additional moderators: *teaching parental knowledge of CEBP* (reduced CEBP) and *use of positive reinforcement* (increased CEBP). As regards delivery components, the subgroup analysis showed that programmes with components to *build rapport* were associated with greater success than those without such components; the heterogeneity was also diminished in the analysis. The meta-regression also

indicated that *maintaining ongoing communication* and the use of *institutional delivery setting* can potentially promote programme effects, while short duration (with less than eight sessions) and the exclusive use of group or individual sessions appear to increase CEBP. The investigation of moderators was exploratory, and the results should be interpreted with caution due to the suboptimal reporting and the consequently underpowered regression models.

3.6.2. Agreements/Disagreements with other studies

Overall effectiveness. In terms of the incidence of physical abuse against children, this review found results that were consistent with reviews on families of typically developing children (Altafim & Linhares, 2016; van der Put et al., 2018; Vlahovicova et al., 2017); however, the evidence is more limited in this review and further research is needed. As with CEBP, which is a significant risk factor for physical abuse, the effect found in this review was much stronger (g = -1.37, 95% CI [-2.03, -0.71]) compared with the two existing reviews—Skotarczak and Lee (2015) (g = -0.39, 95% CI [-0.15, -0.63]) and Tellegen and Sanders (2013) (d = -0.54, 95% CI [-0.37, -0.70]). There are three potential explanations. First, there is an overall high risk of bias across the included studies. Nonetheless, the sensitivity analyses produced even larger effects with quasi-experimental studies and those with high risk of bias removed, which indicated that there might be a genuinely strong effect. Second, given a dearth of services for DD in mainland China, participating parents could be more engaged and receptive, with more potential for change. This is consistent with previous reviews of programmes for families of typically developing children, which showed that the effect sizes were larger for those living in low-resource settings and having urgent needs for tackling disruptive behaviors (Gardner et al.,

2015; Leijten et al., 2013). Third, Leijten et al. (2019) found that targeted parent training programmes for those with emergent behavioral issues have a stronger effect than universal (for all families) and selective programmes (for families at higher risk). Programmes in this review were all targeted interventions, which may also have augmented the treatment effect.

Neither of the two previous reviews on DD examined the effectiveness of programmes in improving the parent-child relationship, which is an important protective factor for physical abuse. However, results of this review were similar to those of Knerr et al. (2013), which focused on parent training programmes for children without DD in low- and middle-income countries (LMIC) and found that all studies reported significant improvements in the parent-child interaction with a wide range of effect sizes. The pooled effects in this review are consistent with the synthesised results in Barlow et al. (2016), which reported a significant increase in positive interactive behaviors (d = 0.48, 95% CI [0.17, 0.79]) among families of young children in high-income countries (HICs).

With regard to the effects of transported versus homegrown programmes, this review found comparable results to those of Leijten et al. (2016), which included trials mostly from HICs and found no significant group differences between transported and homegrown programmes. However, this review identified only three imported programmes and the subgroup analysis should be treated with caution. In addition, little documentation of adaptations was found in this review and thus it was difficult to determine the extent to which the cultural adaptations contributed to the treatment effects.

Overall, the results of treatment effects in this review are mostly consistent with existing

evidence drawn from reviews conducted for families of children with or without DD. This indicates that, despite the diverse contexts, the mechanisms hypothesised to underlie parent training programme effectiveness are also relevant for families of children with DD in Chinese settings.

Intervention components. Existing research investigating parent training programme components have mostly been conducted based on trials for families of typically developing children in HICs. It was striking that this review consistently identified the *use of positive reinforcement* as a moderator that potentially increased CEBP in Chinese settings. Although some research highlights the fact that reinforcements might result in negative child outcomes (such as preventing children from developing prosocial behaviors) (Eisenberg et al., 2015), evidence generally suggests that positive reinforcement is effective in reducing child behavioral problems for typically developing children (Leijten et al., 2019), as well as for children with DD (Baghdadli et al., 2003; Cooper et al., 2007; Oliver et al., 2012).

If there is a genuine negative moderation effect of positive reinforcement for children with DD in mainland China (i.e. as opposed to the result being a Type I error resulting from the underpowered meta-regression), there can be four explanations. First, as suggested by Eisenberg et al. (2015), the frequent use of positive reinforcement may undermine children's intrinsic motivation for empathy-associated responding and prosocial behaviors; this could consequently restrain parent-child interactions and social development for children with DD. Second, praise needs to be tailored to the child's characteristics, behaviors, and contexts (Hattie & Timperley, 2007; Mueller & Dweck, 1998); inappropriate use of positive reinforcements

would not reduce CEBP but cause further frustration among parents. Third, before behavior problems improve, they can sometimes be temporarily intensified—a recognised side-effect of behavioural interventions (Lerman et al., 1999). Fourth, it is traditionally less common for Chinese parents to praise children and as such, it can take longer for these techniques to become established. Most programmes lasted for less than six months despite the fact that were trying to teach parents a wide range of skills; there were thus limited opportunities for parents to practice such skills, which could have also led to the misapplication of techniques in actual parent-child interactions.

Delivery components. The findings of this review are consistent with those of Tellegen and Sanders (2013), in identifying a potential pattern for parent training programmes with more sessions to have a stronger effect in reducing CEBP. The reason may again be that there is generally a lack of service provision for DD in mainland China, with parents thereby benefiting from extended provision.

This review also revealed that the sole use of individual sessions or group sessions were less likely to reduce CEBP than a combination of individual and group sessions, a finding that is consistent with those of the two previous reviews (Skotarczak & Lee, 2015; Tellegen & Sanders, 2013). This indicates that, while tailored strategies and individualised sessions are necessary to recognise the diversity of CEBP, group sessions are also important, especially in terms of gaining peer support and promoting social integration.

While Skotarczak and Lee (2015) suggested that facilitators with a higher educational level can yield larger effects, this review found that the programmes were effective irrespective

of facilitator qualification, perhaps because the included programmes were mostly delivered in hospitals, which parents already perceived as having authority. This is of particular importance because there is a shortage of well-trained health professionals for DD in mainland China and the use of alternative professionals or laypersons can maximise access to interventions.

3.6.3. Generalisability

Programmes included in this review were all behavioral (or cognitive-behavioral) and attachment-based interventions. Despite some variation in terms of delivery mode and format, the programmes were predominantly implemented in hospitals with a duration less than six months.

The programmes included both male and female caregivers where specified, suggesting that the findings can be generalised to both parents. The included programmes were mostly delivered to families with diverse socio-economic status, which suggests that the findings can be applied to families from diverse backgrounds, including those living in low-resource settings. Child age ranged from 8 months to 18 years old. While this wide range could have contributed to the between-study heterogeneity, it may also indicate that such programmes can be suitable for children of all ages; this is important for areas with insufficient resources to offer separate programmes for different age groups.

The included programmes only involved four types of DD, which may mean that the findings are not applicable to other diagnoses. However, there was a mixture of studies recruiting parents of children with and without comorbid DD diagnoses, physical impairments, or mental health symptoms. The subgroup analysis also suggested that the presence of

comorbidities did not have a statistically significant impact on the level of heterogeneity or treatment effects. Therefore, the findings of this review can potentially be generalised to children with diverse clinical conditions. Furthermore, given that there is a lack of research on families of children with other diagnoses and that parents of children with DD share common challenges, this review may be the most relevant evidence for developing and implementing parent training programmes for a broader range of DD in mainland China, or in other low- and middle-income countries (LMICs) with similar contexts.

3.6.4. Limitations

One important source of bias in this review is the limited number of included studies (k=31). Since the sample sizes of the included studies were generally small, the quantitative analyses were based on an inadequate number of participants, especially for the outcomes of physical abuse in childhood (k=1, n=280) and the parent-child relationship (k=8, n=507). The small number of studies and participants could also have underpowered the subgroup analyses and meta-regression models. As such, the non-statistically significant group differences detected in subgroup analyses may not always indicate that the components did not have any impact in terms of reducing the high level of heterogeneity. Similarly, the non-significant coefficients in the meta-regression models should not always be interpreted as a true absence of relationships between components and treatment effects. Multiple covariates were included in the meta-regression models, which may better adjust for confounding and increase the accuracy of estimates. Nonetheless, the suboptimal reporting of the included studies could limit the ability to properly control for confounders.

Although the review included control conditions of treatment-as-usual (including waitlist treatment and no treatment), there was variation in the definitions of treatment-as-usual in each study, with some studies not explicitly specifying what constituted the services in the control groups. The subgroup analyses of the comparison conditions also revealed that the effect sizes of parent training programmes appeared to vary according to the nature of the control condition, although the differences were not statistically significant. As a result, it was difficult to determine to what extent the potential heterogeneity among the comparison groups may affect the results of meta-analyses. This limitation is not unique to the current review, but a common concern in all meta-analyses; however, as long as over-generalisation and extrapolation of review findings can be avoided, this method (once carried out in a valid and reliable way) can still provide the best evidence regarding intervention effectiveness.

The review was also affected by the manner of reporting. The length of reports varied from full descriptions of techniques delivered in each session to a short introduction of the programmes using no more than a couple of sentences. Despite the robustness of the findings shown in the sensitivity analyses, the suboptimal reporting style resulted in substantial unexplained heterogeneity and the underpowering of moderator analysis. However, it should also be pointed out that even with detailed programme descriptions, it would still be difficult to determine whether the programme facilitators delivered all the prescribed components and whether any components absent in the manuals were in fact also absent in the actual sessions. The inadequate reporting also raised concerns about the internal validity of the included studies as some studies did not provide enough information about critical quality indicators.

3.6.5. Implications for policy and practice

This review has confirmed that parent training programmes are an important strategy for the prevention of physical abuse in childhood for families of children with DD. The findings are relevant to local social service agencies, non-governmental organisations, people's organisations (such as the China Disabled Persons' Federation), and child welfare centres in urban and rural communities in China, as well as to international organisations that aim to address global violence against children in LMICs for achieving the Sustainable Development Goals (General Assembly, 2015). The review supports the use of both homegrown and transported programmes, as well as the use of professional or non-professional facilitators. It also suggests that such programmes should teach parents about CEBP, how to reduce parental stress, and how to cultivate empathy. It calls attention to the use of positive reinforcement, which can have adverse effects when not applied appropriately. In addition, this review provides some support for delivering parent training programmes that have more than eight sessions; have a delivery setting in hospitals or social service agencies; build rapport between facilitators and participants; combine sessions delivered in groups and on an individual basis; and maintain ongoing communication between facilitators and participants outside programme sessions.

Parent training programmes for families of children with DD can be used a part of a range of policies in mainland China. China faces mounting pressure in terms of service provision for children with disabilities. However, the current policy is limited to offering auxiliary equipment and rehabilitation trainings that aim to promote daily functioning and social participation, to

children between the ages zero-six who have vision, hearing, language, physical, intellectual impairments or Autism Spectrum Disorder and live in impoverished households or foster care agencies (State Coucil of the People's Republic of China, 2018). The findings of this review suggest that, for children with DD but not meeting the eligibility criteria of the current policy, parent training programmes can be offered to their primary caregivers, in order to promote equity and create more opportunities for those children to reach their potential. Such interventions could also fit into the 2016-2020 Five-Year Plan to Promote Family Education in China (All-China Women's Federation, 2016; Ministry of Education, 2015), which set a range of goals, such as the promotion of positive parenting practices on a national scale and the provision of regular services for families of vulnerable children (affected by disabilities, poverty, diseases, and child abuse) to create a nourishing family environment that fosters child development.

Further, parent training programmes for families of children with DD are relevant to the Minors' Social Protection Pilot Scheme in China, which was launched in 2014 as a response to the burgeoning concern regarding child abuse (Ministry of Civil Affairs, 2014). Such interventions could be integrated as part of the preventative services. Although direct evidence is limited in the current review, parent training programmes have shown promise in reducing rates of child abuse perpetrated by primary caregivers across countries (van der Put et al., 2018; Vlahovicova et al., 2017); given their success in reducing risk factors for children with DD in Chinese settings, such interventions could also be one of the potential solutions to child abuse in mainland China.

The implementation of such interventions could also be facilitated by the policy agendas that aim to establish a community-based child welfare service system. The Ministry of Civil Affairs (2015) requires that all urban and rural communities set up a child welfare centre to support vulnerable children and their families. Evidence-based parent training programmes for families of children with DD could be delivered in those centres, to increase the quality and reach of services.

3.6.6. Implications for research

This review highlights the importance of seeking evidence from non-English databases using local languages. Future evaluations should extend timepoints of assessment and conduct long-term follow-up. The review also points to the need for research to: 1) investigate the effects of parent training programmes in reducing physical abuse in childhood for families of children with DD; 2) assess to what extent the results apply for children with a broader range of DD diagnoses; and 3) report the costs and conduct cost-effectiveness analysis. The limited service provision for families of children with DD in mainland China and financial burden among those families warrants the delivery of optimised interventions at low cost. This requires future research to further investigate the effects of individual components (examined and not examined in this review) which will also contribute to the reduction of potential harm. There is also a need to improve the scientific rigor of studies and to register trials in publicly accessible systems. The suboptimal reporting prevents readers from determining the generalisability of findings, and delays the translation of research findings into policy and practice. As such, future trial reports should use guidelines for RCT reporting, such as the Consolidated Standards of

Reporting Trials statement (Schulz et al., 2010).

a) Summary of Critical Findings

- This is the first attempt to focus on low- and middle-income countries and explore the effectiveness and critical components of parent training programmes for families of children with developmental disabilities in reducing the incidents and modifying associated factors of physical abuse in childhood.
- This review finds that such programmes reduce child emotional and behavioral problems and improve the parent-child relationship. The effects are not affected by the origin of programmes or the qualification of facilitators.
- Programmes with components to increase parental knowledge of child emotional and behavioral problems, reduce parental stress, and cultivate empathy were associated with greater success; the use of positive reinforcement in low- and middle-income countries has not shown the expected effects and might need further socio-cultural adaptations. Programmes with the following delivery features tend to have stronger effects: a longer duration, an institutional setting, efforts to build rapport, a combination of group and individual sessions, and ongoing communication.
- Research investigating the effects in reducing child abuse incidents is needed.

Summary of Implications Table

For Practice

- Behavioral and attachment-based parent training programmes should be provided to families of children with developmental disabilities, as part of a broader strategy to combat child abuse.
- The review supports the use of both homegrown and transported programmes, as well as the use of professional or non-professional facilitators.
- Such programmes should teach parents about child emotional and behavioural problems, techniques to reduce parental stress, and methods to cultivate empathy, but the use of positive reinforcements might need to be sensitive to contextual and individual characteristics. Such programmes can be delivered with more than eight sessions; in an institutional setting; rapport building efforts; a combination of group and individual sessions; and ongoing communication.

For Policy

- Such programmes can be used as part of existing policies in China that aim to provide services for more families affected by disabilities, promote positive parenting practices on a national scale, and establish a child protection system.
- The implementation of such programmes can be facilitated by policy agendas to establish a community-based child welfare service system.

For Research

- Future systematic reviews should seek evidence from non-English databases using

local languages.

- Future evaluations should conduct long-term follow-ups.
- More evaluations of such programmes should be conducted to examine the direct impact on child abuse and for a broader range of diagnoses; optimise programme components; and analyse the cost.
- There is a need to improve the methodological quality and reporting of future trials.

3.7. Moving from the Systematic Review to the Programme Evaluation

Research commonly advocates for early intensive ASD interventions that begin at an early age (Flanagan et al., 2012; National Research Council, 2001). Early intensive behavioural interventions have shown positive effects across a range of child developmental domains (Reichow et al., 2018). However, accessibility to these interventions is low, as a result of the demand for highly qualified professionals, daily involvement of caregivers for years, and high costs. Hence, short-term parent training programmes have increased in popularity, especially in low-resource settings. In fact, research shows that, due to the shortage of resources and support, caregivers of children with ASD in China have been actively seeking short-term training for themselves so that they can maximise child learning opportunities (China Association of Persons with Psychiatric Disabilities, 2015; Sichuan Normal University, 2019).

This Chapter presented the results of a systematic review of short-term caregiver trainning programmes for families of children with development disabilities in China. The review identified a subset of 11 studies focusing on ASD and the meta-analysis showed that they were effective in reducing child emotional and behavioural problems (g = -1.47, 95% CI [-2.42, -0.52]; 9 studies, 627 participants) for children with ASD. A common feature of those programmes was their brevity. For example, of the four ASD trials that reported frequency and length, one programme had 4 hours in total (YY Liu et al., 2017), two lasted for 12-16 hours (Ji et al., 2014; Z. Wu, 2016), and the last one had 24 hours with 16 hours for group sessions and 8 hours for home visits (P. Wang, 2005). However, the moderator analysis in this review suggested that programmes with more sessions (i.e., higher levels of intensity) and ongoing

communication could produce better results.

There was an absence of evaluations conducted within the context of routine services. In fact, among the 11 Chinese ASD studies identified in this systematic review, one programe was designed and tested as part of a doctoral thesis (Z. Wu, 2016), and then eight were service piloting in hospitals (Cen, 2016; P. Huang, 2018; YY Liu et al., 2017; J. Sun, 2015; Y. Sun & Li, 2015; Xiao et al., 2015; S. Zhang & Qiu, 2016; Y. Zhang, 2016); the other two studies did not provide relevant information regarding the context of provision. Last but not least, the included studies were rated at substantial risk of bias across multiple methodological aspects.

In summary, the systematic review points to the need for high quality research on the effectiveness of short-term parent training programmes that can provide more intensive support and are delivered in the context of routine service provision. To address this gap, this thesis went on to evaluate one such programme called Beijing Stars and Rain Education Institute for Autism (SREIA), using a mixed-methods approach (Chapter 2 section 2.3.1). The SREIA short-term intensive programme was initiated in 1993 and has been implemented since then to support thousands of Chinese families of children with ASD. The programme is deemed ‘short-term’ as it is delivered within 11 weeks, which is substantially shorter than traditional EIBIs that require caregiver involvement for consecutive years. It is also characterised as being ‘intensive’ because, compared to programmes that were identified in the systematic review and provided limited hours of learning, the SREIA programme offers five sessions per day with 55 sessions in total. The next two Chapters present the evaluation of the SREIA programme, with Chapter 4 focusing on the quantitative findings and Chapter 5 reporting the qualitative results.

CHAPTER 4. PAPER 2 Controlled Trial of a Short-Term Intensive Parent Training Programme Delivered within the Context of Routine Services for Families of Children with Autism Spectrum Disorder in China: Difference-in-Differences with Propensity Score Weighting

A version of this paper has been submitted to *Journal of Child Psychology and Psychiatry.*

Abbreviated title: Real-World Evaluation of a Parent Training for Autism in China

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4.1. Abstract

Background

Recent systematic reviews found limited rigorous research conducted to date of the effectiveness of parent training programmes in reducing behavioural problems for children with Autism in low- and middle-income countries. The present study is aimed at evaluating the effectiveness of a short-term intensive parent training programme in routine services in China.

Methods

A quasi-experiment was conducted by engaging the local implementing organisation and using a waitlist control group . Data were collected at baseline and immediately after the completion of the programme. The primary outcome was child behavioural problems measured using the Child Behaviour Checklist Externalising scale. Between-group comparisons used a difference-in-differences design with propensity score weighting to reduce sources of bias. A process evaluation was undertaken in parallel to assess participant involvement, programme acceptability, and delivery. Ethics were approved by the University of Oxford and Beijing Normal University. The protocol was registered in ClinicalTrials.gov (NCT04257331).

Results

The final sample size was 111 (treatment:63;comparison:48). Results suggest that the programme was effective in reducing child externalising behaviours (*b*=-2·71,95%CI[-5·23,-0·18];*d*=-2.80), compared to the waitlist control group. It also had a positive effect in increasing parental knowledge of Autism and child development, reducing parental mental health symptoms, and reducing over-reactive parenting. Exploratory analysis of implementation aspects indicated that baseline parental mental health was associated with participant engagement, and that satisfaction and engagement levels were potentially linked

to the treatment effects.

Conclusion

Findings suggest that short-term intensive parent training programmes could be used to complement brief parent support and as an alternative to traditional cost-prohibitive services that are intensively delivered for consecutive years in low-resource contexts. The results also highlighted the possibility of programme implementation by trained non-specialists to increase access to services.

Keywords

Autism, Parent Training, Difference-in-Differences, Propensity Score, Real-World Evaluation

4.2. Background and Objectives

Autism Spectrum Disorder (ASD) is a developmental disorder characterised by impairments in reciprocal social-communicative interaction, and by restricted and repetitive behaviours or interests. Although the national prevalence of ASD is yet to be estimated in China, a large regional study in 2019 revealed a local rate of around 1%, similar to the global estimate (X. Sun et al., 2019).

Children with ASD experience more co-occurring behavioural problems than their typically developing cohorts (Simonoff et al., 2008a), which create further limitations in children's daily activities and impose more challenges to parenting (Richard P. Hastings & Brown, 2002). Short-term parent training is widely used to support families of children with ASD. Such programmes have been increasingly advocated as a cost-effective alternative to more conventional intensive interventions delivered for consecutive years (such as the Early Intensive Behavioural Intervention), as a result of the increasing number of diagnoses of ASD, limited local service provision, and substantial economic cost of the ASD-associated consequences at both family- and state-levels.

Five systematic reviews have been conducted to assess the evidence-base for parent training programmes for ASD (Z. Fang et al., 2020; Nevill et al., 2018; Oono et al., 2013; Postorino et al., 2017; Strauss, Mancini, SPC Group, et al., 2013). The results showed that they can reduce child emotional and behavioural problems (Z. Fang et al., 2020; Postorino et al., 2017), decrease ASD symptoms (Nevill et al., 2018; Oono et al., 2013), promote child development (Nevill et al., 2018; Strauss, Mancini, SPC Group, et al., 2013), and improve parent-child interaction (Z. Fang et al., 2020; Oono et al., 2013). However, most studies were conducted in high-income countries, showing an unrepresentative geographic distribution of evidence. A recent review employing comprehensive searches in the Chinese language and local databases, focusing on programmes delivered in China, highlighted an absence of rigorous

evaluations of programmes being delivered in real-world settings, and a common characteristic being brevity, despite the fact that families of children with ASD in low- and middle-income countries (LMICs) often experience accumulated adversities and need substantial support (Z. Fang et al., 2020).

This paper reports an evaluation of a short-term intensive parent training programme that has been supporting thousands of Chinese families of children with ASD aged three to six years since 1993. The programme is delivered by a long-established local NGO, known as Beijing Stars and Rain Education Institute for Autism (SREIA). Despite its long history and wide coverage, the programme lacked evidence of effectiveness. This report adheres to the STROBE guidelines for observational studies, with additional items concerning the interventional aspects drawn from the CONSORT guidelines for reporting randomised controlled trials (Appendix I.2) (Schulz et al., 2010; Von Elm et al., 2007). Results of the evaluation can be used to inform service provision in other LMICs where caregivers of children with ASD face similar challenges.

4.3. Methods

4.3.1. Study design and participants

We conducted a real-world quasi-experimental study to assess the effectiveness of the SREIA programme in reducing child externalising behaviours within the context of routine service provision. Participants were drawn from a permanent SREIA waiting list. Enrolment to the programme was on a first-come, first-serve basis. Families attending between September 2020 and November 2020 comprised the treatment group. Those who signed up for the delivery between November 2020 and January 2021 comprised the waitlist control group. Due to COVID-19, some families on the waiting list decided not to attend the programme and were thus also allocated into the control group. Outcomes were measured at baseline and immediate

post-intervention. A concurrent process evaluation was also conducted to investigate programme acceptability, participant involvement, and implementation.

Recruitment of parent-child dyads was based on the standard criteria used by the SREIA programme, including a) children between three to six years of age diagnosed with or meeting the diagnostic criteria for ASD according to DSM-V, and b) primary caregivers undertaking the responsibility for the daily childcare for at least five days a week. Recruitment was conducted by the implementing organisation inviting caregivers on the waiting list to the study. Verbal informed consent was collected by trained research staff. Each family had one parent-child dyad participating in the programme. Financial reimbursements (CNY180≈GBP20) were provided to participants who completed data collection at both time points. Eight programme practitioners were also recruited to the study. Ethical approval was granted by the University of Oxford (R67619/RE001) and Beijing Normal University (SSDPP-HSC2020001). (Details about ethical considerations are presented in Chapter 2 section 2.7.)

4.3.2. Intervention

The SREIA parent training programme has a long history of providing services to families of children with ASD in China. It is grounded in applied behaviour analysis, social learning theory, operant conditioning, developmental theories, and cognitive behaviour theory. It is aimed at reducing child behaviour problems and promoting child development by increasing parental knowledge, improving parenting skills, promoting parental mental health, and creating social support. The programme offers a wide range of techniques delivered five days a week for 11 weeks (Table 7). Fourteen large didactic presentations on the core themes are offered across the 11 weeks and attended by all participating caregivers, with childcare provided by volunteers when there is no COVID-19 pandemic or restrictions on mass gatherings. Tailored training and practice opportunities are then arranged in smaller groups comprising ten parent-

child dyads to improve the use of skills. The programme is primarily delivered in-person, while the fourteen presentations were also streamed online to reduce mass gathering during COVID-19. Individual pre-consultations are offered with the aim of enabling programme practitioners to better understand family strengths and concerns. An individualised treatment plan is created and followed for each dyad, covering targeted child behaviours, caregiver areas for improvement, and other priorities identified by caregivers. Materials and handouts are provided. Practitioners are from various backgrounds (without healthcare-related education) but all trained and certified by the implementing organisation. To promote participant engagement and learning, the programme integrated a variety of delivery techniques and substantial opportunities for practice (Table 7).

The programme has two delivery formats, which are implemented concurrently and share the same programme content, with the purpose of exploring ways to reduce cost while improving outcomes. While both versions divide participants to several groups based on children's ASD symptoms, Version A has four groups of dyads who attend didactic sessions together in a larger group but practice sessions separately, whereas Version B has three caregiver groups and delivers all sessions separately for each group. Participants are offered the option of selecting either version when signing up for the waiting list. (Detailed programme description and logic model are presented in Chapter 2 section 2.4.1.)

Table 7 SREIA programme topics and delivery techniques

Topics	Delivery Techniques
Knowledge of ASD and child development	Individual consultation
Child behavioural problems and ABA techniques, including reinforcement (praise & rewards), prompts, fading, shaping, and chaining	Didactic presentation
Instruction giving	Practitioner observation
Ignore	Practitioner modelling new techniques
Redirect	Cases and stories
Parent-child communication and interaction	Practice in sessions and in-vivo feedback
Emotional labelling	Role play

Fine and gross motor skills	Homework and feedback
Child cognitive development	Videorecording and feedback
TEACCH – "Structured TEACCHing"	Group discussion on skills and experiences
Communicate with family members	Group problem solving
Parental self-regulation	Physical activity
Parental attitude and expectation	Reinforcement and active listening by practitioners
Skill maintenance and generalisation	Online group communication
Make a plan for the future	Informal peer support group
	Printed and online materials
	Childcare

4.3.3. Power calculation

The minimal detectable standardised mean difference from two-sample, two-tailed t-test was -0.57 on the primary outcome measure. This was based on a final sample size of 111 with a significance level of 0.05 and statistical power of 0.80. (Sample size calculation can be found in Chapter 2 section 2.4.2.)

4.3.4. Outcomes and measures

The primary outcome *Child behavioural problems* was assessed using the *Externalising* scale of the Child Behaviour Checklist (CBCL) for Ages 1.5-5 (25 items) (Achenbach & Rescorla, 2001a) as the majority of children were under six and similar levels of internal consistency of CBCL 1.5-5 was shown in children with ASD aged five and those aged six (Basten et al., 2014). The scale has demonstrated good cross-cultural factorial validity with children with ASD (Jianghong Liu et al., 2011).

Impact on several secondary outcomes was examined. *ASD symptoms* was assessed using the Chinese version of the Autism Treatment Evaluation Checklist (Rimland & Edelson, 1999). *Parenting style* was measured using the Over-Reactivity subscale of the Arnold-O'Leary Parenting Scale (D. S. Arnold, O'leary, et al., 1993) and the Supporting Positive Behaviour subscale of the Parenting Young Children Scale (McEachern et al., 2012). *Parental mental*

health was assessed using the Chinese version of the Depression Anxiety Stress Scale (Lovibond & Lovibond, 1995). *Family function* was assessed using the Chinese version of the Family APGAR scale (Smilkstein et al., 1982). All scales have been validated in China, except the Over-Reactivity subscale, which has been validated in families with high risks for child behavioural problems in the U.S. *Parental knowledge* was measured using a questionnaire designed for the SREIA evaluation to assess parental understanding of ASD and child behaviours. For questionnaires that do not have a Chinese version, the translation followed the WHO guideline of the Process of Translation and Adaptation of Instruments (World Health Organization, 2020).

Programme acceptability was assessed only at post-intervention using a satisfaction questionnaire tailored to the SREIA programme and Chinese context (Incredible Years, 2020). The level of *participant involvement* was captured by calculating rates of *attendance*, *engagement*, and *programme dropout*. The *attendance and engagement rates* were recorded using an attendance and engagement registry, reported by practitioners each day; *programme dropout rate* was calculated based on families who missed at least ten days. *Implementation* was measured through *fidelity* and *quality of delivery*: *fidelity* score comprised the ratio of delivered components to prescribed components, calculated using checklists filled out by practitioners each week, and q*uality of delivery* was assessed by research staff observing sessions and filling out a quality of delivery survey. The programme process was also investigated using qualitative in-depth interviews and focus group discussions, the results of which will be reported separately. (More details about measures are presented in Chapter 2 section 2.5.)

4.3.5. Data collection and analysis

Trained researchers administered the parent questionnaires online and by phone. All data

collectors had a master's degree in social work and were trained in a range of relevant topics. Caregivers were requested to keep their allocation condition private from outcome data collectors and the data collectors were asked whether they knew to which group the participant belonged after each interview. The process evaluation data, including satisfaction survey, were collected by a separate group of research staff. No violation of blinding was detected.

Data analyses were conducted in R and followed the principles of intent-to-treat by including all participant recruited at baseline. Baseline group differences were explored using two independent samples t-tests and chi-square tests. To reduce selection bias and improve baseline balance for the between-group comparison, the treatment effects were estimated using a difference-in-differences (DiD) design with propensity score weighting (PSW) (Stuart et al., 2014) (design: Chapter 2 section 2.3.1; analysis: Chapter 2 section 2.6.4.1). Propensity scores were calculated using logistic regression. The key covariates were selected based on the relevant literature and included the baseline outcome measures and child gender (Appendix B.1). The treatment and control groups were weighted using the overlap weighting scheme to avoid extreme weights and ad hoc trimming (Li & Thomas, 2019). Group balance was checked using absolute standardised mean difference, with a rule of thumb that the absolute standardised mean difference should be controlled under 0.1 (Rubin, 2001). Weighted DiD models were fitted, with accounting for the key covariates, to further adjust for unobserved variables and secular time trends (Wing et al., 2018). Dependency of outcomes for participants within each version and each caregiver group were checked using intra-cluster correlation coefficients and, when necessary, accounted for in linear mixed models with caregiver group or delivery version being treated as the random effect. Exploratory analyses were also conducted by replacing the binary treatment variable with a three-level variable in the regression models to assess the differences in treatment effects between the two versions of delivery. Robustness checks were conducted using DiD with inverse probability weighting and kernel matching (Austin & Stuart,

2015; Caliendo & Kopeinig, 2008) (Chapter 2 section 2.6.4.2). The ignorability assumption of propensity score weighting and parallel trend assumption of DiD were checked by examining the effect of group assignment on the baseline primary outcome measure and treating financial health (a placebo outcome associated with child externalising behaviours (Slopen et al., 2010) but not affected by group assignment) as the outcome variable in the weighted DiD (Imbens, 2004; Wing et al., 2018) (Chapter 2 section 2.6.4.3).

Multivariate models were created to examine potential factors associated with participant involvement, with accounting for confounders drawn from existing evidence, including quality of delivery, baseline child externalising problems, parental mental health, ASD symptoms, parental education, adult age, adult gender, and family income (Appendix B.2). The possible associations between implementation factors and the treatment effect were investigated by first using univariate models and then adjusting for the key covariates. The missing data comprised less than 5% of the entire dataset and were compensated using REML (Hartung, Knapp, & Sinha, 2008). No data were missing in variables that were included in the DiD models. Residuals in all regression models were checked for normality and outliers.

4.4. Results

Figure 18 shows the flow of participants through the study. The final sample involved 63 caregiver-child dyads in the treatment group—37 in Version A and 26 in Version B—and 48 in the control group.

Figure 18 Participant flow chart

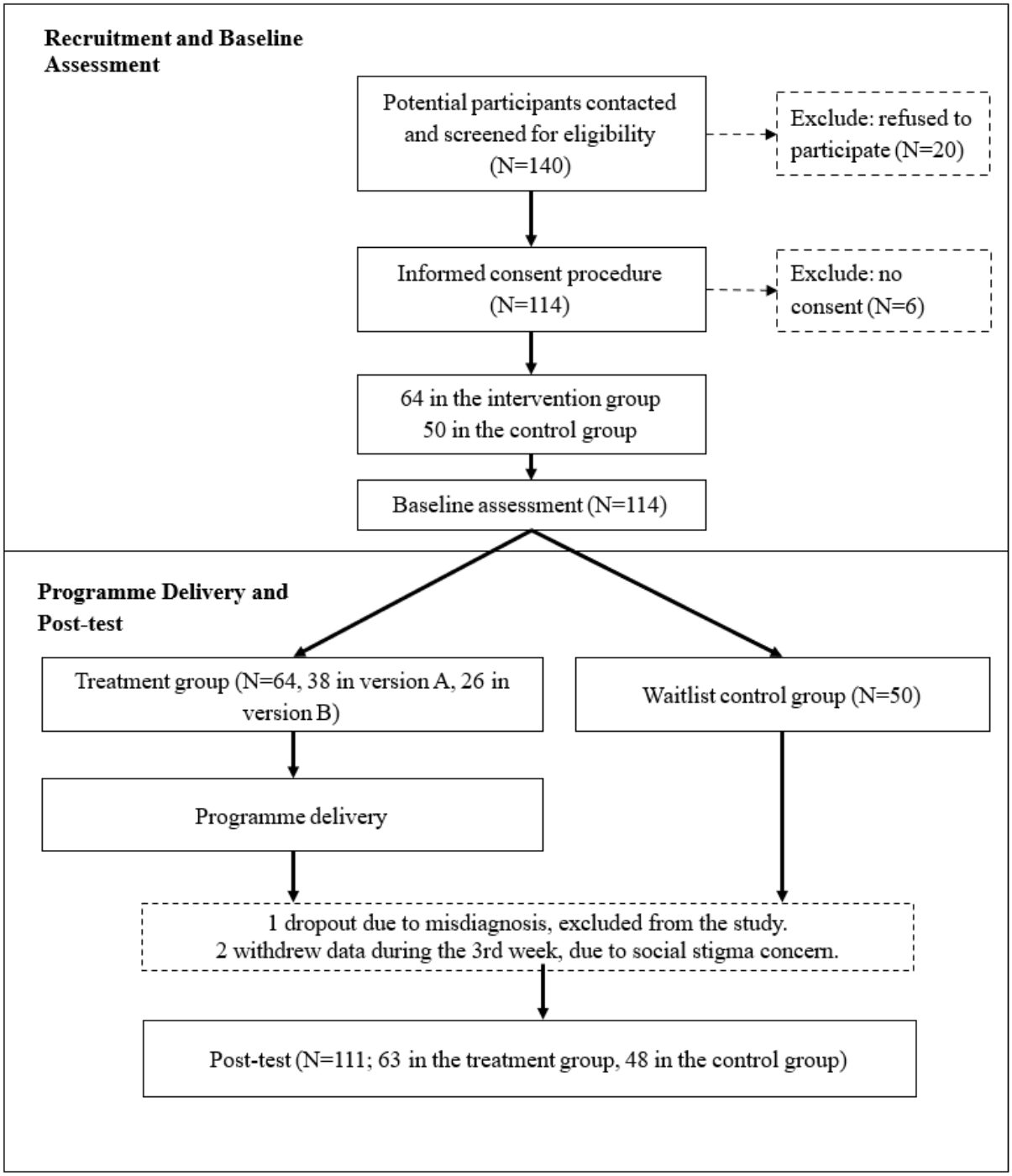


Table 8 summarises the demographic characteristics of the participants. More than 80% of the children involved in this thesis were male, in line with the fact that ASD is about four times more common in boys than girls (Maenner et al., 2020). The mean age was 4.70 (SD = 1.12). The proportion of children from ethnic minority groups (7.21%, n=8) was roughly in accordance with that reported in the Sixth National Population Census of China (8.49%) (National Bureau of Statistics of China, 2011). Participating caregivers were predominantly

female (92.79%, n=103) aged 34.75 (SD =5.8) on average. More than half were unemployed (63.06%, n=70) and attended high school or less (55.77%, n=65). About one third had an annual income below the national average salary. Half of the families (50.45%, n=56) had two or more children and slightly more have an urban household registration (54.81%, n=64). While the t-tests and chi-square tests detected no significant group difference in demographic characteristics and outcome measure at baseline, several key covariates demonstrated substantial absolute standardised mean differences. The overlap weighting successfully reduced absolute standardised mean differences across all covariates and achieved excellent group balance (Table 9).

Table 8 Demographic characteristics

Demographic Characteristics	**Control (N=48)**	**Treatment (N=63)**	**Total (N=111)**	p value
Child Gender, Female	7 (14·58%)	11 (17·46%)	18 (16·22%)	0·684
Child Age, Mean (SD)	4·57 (1·21)	4·80 (1·04)	4·70 (1·12)	0·279
Ethnicity, Minorities	3 (6·25%)	5 (7·94%)	8 (7·21%)	0·734
Previous Services, Individual Therapy	24 (50·00%)	40 (63·49%)	64 (57·66%)	0·374
Medical History, Yes	20 (41·67%)	33 (53·23%)	53 (48·18%)	0·229
Medication History, Yes	36 (75·00%)	45 (72·58%)	81 (73·64%)	0·775
Comorbidity, Yes	29 (60·42%)	39 (62·90%)	68 (61·82%)	0·790
Adult Gender, Female	42 (87·50%)	61 (96·83%)	103 (92·79%)	0·060
Adult Age, Mean (SD)	34·71 (5·18)	34·79 (6·28)	34·75 (5·80)	0·942
Adult Education, High school or less	26 (52·17%)	39 (58·62%)	65 (55·77%)	0·511
Annual Income, Below the national average salary	11 (22·92%)	21 (33·33%)	32 (28·83%)	0·230
Work Status, Unemployed	27 (56·25%)	43 (68·25%)	70 (63·06%)	0·194
Spouse Work Status, Unemployed	4 (8·33%)	6 (9·52%)	10 (9·01%)	0·828
Household Registration/Hukou, Rural	22 (47·83%)	25 (43·10%)	47 (45·19%)	0·631
Number of Children, Two or more	26 (54·17%)	30 (47·62%)	56 (50·45%)	0·494
Note: significant level p<0·05				

Table 9 Absolute standardised mean differences (ASMD)

Key Covariates	Pre-Weighting ASMD	Post-Weighting ASMD
Baseline Child Externalising Behaviours	-0.21291	-2.19E-13
Baseline Caregiver Mental Health	-0.03578	-2.43E-14
Baseline Parental Over-Reactivity	-0.15566	-1.03E-13
Baseline Positive Parenting	0.331887	2.76E-13
Baseline ASD Symptoms	-0.03055	-4.95E-14
Baseline Parental Knowledge	-0.04685	-5.89E-14
Baseline Family Function	0.142515	2.28E-13
Child Gender	0.077777	7.38E-14

4.4.1. Estimation of treatment effects

The estimations of DiDs are summarised in Table 10. Analyses found intervention effects for reduced child externalising problems (*b*=-2.71,95%CI[-5.23,-0.18];*d*=-2.80), compared to the comparison group. The results of robustness checks were in line with the estimation and did not detect violation of underlying assumptions (Chapter 2 section 2.6.4.2 and section 2.6.4.3).

In terms of secondary outcomes, analyses found intervention effects for increased parental knowledge of ASD and child development (*b*=2.08,95%CI[2.07,2.17];*d*=2.91), improved parental mental health (*b*=-5.96,95%CI[-11.74,-0.17];*d*=-2.89), and reduced over-reactive parenting (*b*=-0.63,95%CI[-0.98,-0.27];*d*=-5.02) in comparison to controls. No intervention effects were detected for ASD symptoms (*b*=-1.53,95%CI[-6.44,3.38];*d*=-0.86), family function (*b*=-0.08,95%CI[-0.88,0.71];*d*=-0.28), or positive parenting practices (*b*=0.16,95%CI[-1.89,2.21];*d*=0.22).

The exploratory analysis on version difference indicated that, compared to the comparison group, Version B was effective in reducing externalising problems (*b*=-3.77,95%CI[-6.26,-1.28];*d*=-4.26) and improving parental mental health (*b*=-12.52,95%CI[-19.87,-5.18];*d*=-4.79), whereas Version A did not differ from the control group (externalising problems: *b*=-2.08,95%CI[-4.56,0.41],*d*=-2.35; mental health: *b*=-1.02,95%CI[-8.35,6.31],*d*=-

0.39). Both versions showed an increase in parental knowledge (VA: *b*=1.49, 95%CI[0.28,2.69], *d*=3.47; VB: *b*=3.03,95%CI[1.82,4.24],*d*=7.05) and a reduction in parental over-reactivity (VA: *b*=-0.72,95%CI[-1.15,-0.28],*d*=-4.68; VB: *b*=-0.44,95%CI[-0.88,-0.01],*d*=-2.86). However, due to the small subgroup sample sizes, the analyses were underpowered.

Table 10 Difference-in-differences model estimates

Outcome Measures	**Difference-in-Differences (Treatment versus Control) *β* [95% CI]**	**Cohen's d**	**Difference-in-Differences (Version A versus Control) *β* [95% CI]**	**Cohen's d**	**Difference-in-Differences (Version B versus Control) *β* [95% CI]**	**Cohen's d**
Primary outcome:						
Child Externalising Behaviour (CBCL)	**-2.71* [-5.23,-0.18]**	**-2.80**	-2.08 [-4.56,0.41]	-2.35	**-3.77** [-6.26,-1.28]**	**-4.26**
Secondary outcomes:						
ASD Symptoms (ATEC)	-1.53 [-6.44,3.38]	-0.86	-0.82 [-7.13,5.49]	-0.36	-3.40 [-9.72,2.93]	-1.51
Parental Knowledge	**2.08* [2.07,2.17]**	**2.91**	**1.49* [0.28,2.69]**	**3.47**	**3.03*** [1.82,4.24]**	**7.05**
Parental Mental Health (DASS)	**-5.96* [-11.74,-0.17]**	**-2.89**	-1.02 [-8.35,6.31]	-0.39	**-12.52** [-19.87,-5.18]**	**-4.79**
Family Function (APGAR)	-0.08 [-0.88,0.71]	-0.28	-0.34 [-1.35,0.66]	-0.95	0.24 [-0.77,1.24]	0.67
Positive Parenting (PARYC)	0.16 [-1.89,2.21]	0.22	1.16 [-1.30,3.62]	1.32	-0.61 [-3.08,1.85]	-0.70
Parental Over-Reactivity (PS)	**-0.63*** [-0.98,-0.27]**	**-5.02**	**-0.72** [-1.15,-0.28]**	**-4.68**	**-0.44* [-0.88,-0.01]**	**-2.86**

4.4.2. Implementation evaluation

Table 11 shows that the level of participant involvement was high, with most caregivers attending 98% of the time and the average engagement score being 5.58 (SD=0.32). The main reasons for absence were child illness and family issues. On average, 95% of pre-specified topics and activities were implemented across the seven caregiver groups based on the fidelity

checklists, with a mean quality of delivery score of 51.86 (SD=1.13). The overall satisfaction achieved 78.19 (SD=6.94).

Table 11 Process measures, mean (SD)

	Total (N=63)	**Version A (N=37)**	**Version B (N=26)**
Engagement Score (maximum 6)	5.58(0.32)	5.65(0.32)	5.48(0.31)
Attendance Rate (maximum 1)	0.98(0.03)	0.99(0.03)	0.98(0.03)
Satisfaction Score (maximum 84)	78.19(6.94)	77.49(7.65)	79.19(5.80)
Quality of Delivery (maximum 72)	51.86(1.13)	51.76(0.25)	52.01(1.74)
Fidelity Rate (maximum 1)	0.95(0.04)	0.98(0.01)	0.91(0.04)

The multivariate models showed that more parental mental health problems at baseline were related to lower engagement levels (*b*=-0.003,95%CI[-0.006,-0.001]) but not attendance rate. No other factors examined were significantly associated with participant involvement (Table 12).

Table 12 Multivariate models: Factors associated with participant engagement and attendance

	Model 1: Engagement	**Model 2: Attendance**
Baseline child behaviour	0.002 [-0.006,0.009]	0.001 [-0.000,0.002]
Baseline parental mental health	**-0.003* [-0.006,-0.001]**	0.000 [-0.001,0.000]
Baseline ASD symptoms	-0.003 [-0.006,0.000]	0.000 [-0.001,0.000]
Quality of delivery	-0.107 [-0.246,0.032]	-0.002 [-0.009,0.004]
Adult education	-0.029 [-0.142,0.085]	-0.003 [-0.021,0.015]
Annual income	0.044 [-0.080,0.165]	0.008 [-0.011,0.027]
Adult age	-0.012 [-0.024,0.000]	-0.001 [-0.003,0.001]
Adult gender	0.321 [-0.080,0.712]	0.013 [-0.048,0.074]

*p<0.05; **p<0.01; ***p<0.001

Further analysis found that higher attendance rates were linked to fewer externalising

problems (*b*=-66.60,95%CI[-125.30,-7.80]). While this relationship was not present following accounting for key covariates, higher satisfaction and engagement levels were both associated with better treatment effects (satisfaction:*b*=-0.24,95%CI[-0.44,-0.03]; engagement:*b*=-6.81,95%CI[-12.19,-1.44]) (Table 13).

Table 13 Relationships between implementation factors and child externalising behaviours post intervention

			Univariate Models		
Variable	Model 1	Model 2	Model 3	Model 4	Model 5
Quality of delivery	0.25 [-1.20,1.70]				
Satisfaction		-0.20 [-0.44,0.03]			
Engagement score			-1.79 [-6.90,3.30]		
Attendance rate				**-66.60* [-125.30,-7.80]**	
Fidelity rate					22.3 [-18.00,62.00]
			Multivariate Models		
Variable	Model 1	Model 2	Model 3	Model 4	Model 5
Quality of delivery	0.03 [-1.29,1.36]				
Satisfaction		**-0.24* [-0.44,-0.03]**			
Engagement score			**-6.81* [-12.19,-1.44]**		
Attendance rate				-43.78 [-98.35,10.79]	
Fidelity rate					15.88 [-18.43,50.18]
Baseline child behaviour	**-0.51*** [-0.72,-0.30]**	**-0.55*** [-0.75,-0.34]**	**-0.50*** [-0.70,-0.30]**	**-0.47*** [-0.68,-0.27]**	**-0.50*** [-0.71,-0.29]**
Baseline ASD symptoms	0.01 [-0.08,0.11]	0.02 [-0.07,0.11]	-0.02 [-0.12,0.07]	0.01 [-0.08,0.10]	0.01 [-0.08,0.10]
Baseline parental mental health	0.02 [-0.06,0.10]	0.01 -0.07,0.09]	-0.02 [-0.10,0.06]	0.00 [-0.07,0.08]	0.02 [-0.06,0.10]
Baseline parental overreactivity	0.38 [-0.88,1.65]	0.46 [-0.75,1.67]	1.02 [-0.28,2.31]	0.54 [-0.71,1.79]	0.36 [-0.90,1.61]

Baseline positive parenting	0.11 [-0.18,0.39]	0.06 [-0.21,0.33]	0.15 [-0.12,0.42]	0.11 [-0.16,0.39]	0.11 [-0.16,0.39]
Baseline parental knowledge	0.18 [-.31,0.66]	0.08 [-0.38,0.55]	0.20 [-0.26,0.65]	0.14 [-0.33,0.61]	0.16 [-0.32,0.64]
Baseline family function	-0.18 [-0.73,0.37]	-0.12 [-0.64,0.04]	-0.34 [-0.87,0.19]	-0.24 [-0.77,0.30]	-0.18 [-0.72,0.36]
Child gender	0.73 [-3.23,4.69]	1.05 [-2.60,4.71]	-0.66 [-4.44,3.12]	0.26 [-3.52,4.05]	0.94 [-2.88,4.75]

*p<0.05; **p<0.01; ***p<0.001

4.5. Discussion and Conclusion

To our knowledge, this study is the first to evaluate a short-term intensive parent training programme with a long history of supporting families of children with ASD in China, by working closely with the local implementing organisation. The evaluation was conducted in routine service contexts with substantial effort to reduce sources of bias using a difference-in-differences design with propensity score weighting. Findings of this study may inform service provision in other LMICs where there is also a severe lack of resources for families of children with ASD.

4.5.1. Programme effects

The results showed that the programme successfully reduced child externalising behaviours, a change that equates to a Cohen's d of -2.80, which is larger than the findings of the two previous systematic reviews, including the one focusing on China (Z. Fang et al., 2020; Postorino et al., 2017). This may be because the programme provided substantial opportunities for participants to observe practitioner modelling, practice in sessions, and receive in vivo feedback. The large effects also suggested that short-term intensive parent training programmes may complement brief caregiver support to further promote child behavioural adjustment and be a promising alternative to intensive prolonged therapies led by professionals in LMICs.

Analyses of secondary outcomes indicated that the programme was also effective in improving parental mental health, which differs from the results of a previous review showing no group difference for caregivers of children with ASD aged 17-72 months in reducing parental stress (Oono et al., 2013). It also led to a reduction in over-reactive parenting. This might be because caregivers experienced an inclusive environment for the first time, which empowered and guided them towards greater acceptance of their children and themselves. Also, the improved parental self-efficacy and their perceived progress in child's development, might have created a sense of hope and control.

We found no effects in terms of reducing ASD symptoms, which is inconsistent with data from two previous systematic reviews (Nevill et al., 2018; Oono et al., 2013). A potential reason may be the absence of any long-term follow-up period and the fact that it takes time for the techniques to become established (van Aar et al., 2017). The lack of effect on parenting practices could be attributed to the services and information previously obtained by the participants, which predominantly emphasised the use of positive reinforcements. No group differences were detected for family functioning. To reduce participant burden and increase the overall quality of data, a short scale was used to assess family function, leading to a trade-off with regard to scale sensitivity. Further, conflicts might occur when non-participating family members did not understand the diagnosis or new parenting techniques.

The exploration of version differences indicated that smaller group size was more effective in reducing child externalising behaviours and improving parental mental health, possibly as a result of the more individualised feedback and reduced practitioner workload. However, the results should be interpreted with caution due to the small subgroup samples.

4.5.2. Implementation evaluation

Although previous evidence shows that parenting interventions face challenges in

participant engagement (Axford et al., 2012), this programme was delivered with a high attendance and engagement rate, in spite of its high intensity of five days a week over 11 consecutive weeks. The reasons for this may be three-fold. First, the substantial service gap and prohibitive cost of prolonged treatments might have led to a degree of urgency in terms of participant needs for parent training and social support. Second, the participants may have been highly motivated because the period from two to six years of age was considered by them to be the most 'critical' and the only chance for intervention, especially given the absence of local services for older children with ASD. Third, a variety of delivery techniques were used to promote involvement, such as ongoing and flexible communication, reinforcement by practitioners, and peer support. In terms of quality of delivery, the programme was rated as medium, which might be due to the heavy workload and lack of organisational support for practitioners.

The exploratory analyses to examine factors affecting participant involvement showed that a lower engagement rate was related to more baseline mental health symptoms, which is consistent with findings from previous research (T. Carr et al., 2016a). While the literature tends to suggest that families from disadvantaged backgrounds may have lower attendance and engagement rates (Chacko et al., 2016), the current study found no such relationship, possibly reflecting the dearth of services and the need for support across socio-economic status in LIMC contexts.

The analyses showed that a higher level of programme satisfaction and engagement appeared to be associated with improved child behavioural adjustment, whereas the quality of delivery, attendance rate, and fidelity score made little difference. However, the results should be interpreted with caution, as the estimation of dose effect was limited by the small number of parent groups and the similarly high attendance and fidelity rates across groups. Future research can further explore the relationships between dosage and outcomes using methods such as

complier average causal effect.

4.5.3. Strengths and limitations

This study has several limitations. First, as a real-world evaluation of a programme that is embedded within routine services, it was not possible to conduct randomisation, which could have resulted in unmeasured sources of confounders. Also, some families withdrew due to COVID-19, potentially increasing the risk of bias. Second, it was not possible to conduct multiple assessments prior to the programme to test the underlying parallel trends assumption of DiD due to COVID-19, again pointing to the risk of unobserved confounders. To mitigate the impact of bias, key covariates identified from the literature were included. The robustness checks also showed that unobserved factors were time-invariant and did not affect the estimation of outcomes (Wing et al., 2018). Third, although this study involved more participants than other existing evaluations in China (Z. Fang et al., 2020), the sample size was still small, limiting the power and precision to identify treatment effects. Fourth, the outcome measures relied on parent-report data, which may be subject to response bias. Efforts were, however, made to reduce this source of bias, by using measurement tools with adequate reliability and blinding data collectors to group allocation. Fifth, the study had limited male caregivers, undermining the generalisability of the results. Last, the data collection time point was immediately post-intervention. Longer follow-up periods may be necessary to examine what proportion of techniques become firmly established and the extent to which the effects are maintained over time.

Despite the limitations, the study has a number of strengths. First, it is one of the first real-world evaluations of a parent training programme for children with ASD conducted in a routine service context, thereby being more likely to provide valuable information about the range of participants in clinical practice. Local stakeholders being actively engaged in all stages

of the research also ensured that the research was locally relevant and increased the possibility of evidence uptake by community advocates and policymakers. Moreover, while many ASD treatments in LMICs are homogeneous, delivered to families with either high or low socio-economic status, this programme was attended by participants from various backgrounds (e.g., 55% without a college degree and 45% with a rural household registration), which implies that the programme may be well applicable to a wide range of families. Second, previous reviews of parent training for ASD commonly highlight the inadequate reporting of their implementation and the potential impact of this. The concurrent process evaluation within this study provided important information with regard to programme implementation while also allowing us to integrate the process data with outcome assessment to examine the associations between treatment effects and implementation variability (Oakley et al., 2006). Third, the DiD method was combined with propensity score weighting to compensate for the lack of randomisation in real-world settings and remove secular trend effects.

4.5.4. Implication and conclusion

The findings of this study support the use of short-term intensive and practice-based parent training programmes for families of young children with ASD in LMICs to promote child behavioural adjustment and reduce wider health disparities. Although treatment models for ASD can entail a variety of techniques and formats, researchers commonly advocate for intensive interventions that begin at an early age (National Research Council, 2001). Early intensive behavioural interventions have been found to be effective in promoting child development (Reichow et al., 2018), but can often be inaccessible due to the high cost and requirement for qualified professionals and the demand for caregiver daily involvement for consecutive years. As such, short-term parent training and parent-directed treatments have been developed as an alternative for families of young children with ASD (Strauss, Mancini, SPC

Group, et al., 2013). The high participant commitment and satisfaction in the current study possibly reflects the substantial need for such programmes in areas where there is a severe lack of services. Programme providers were from various disciplines and trained by the implementing agency, thereby demonstrating the possibility of having non-specialists deliver the programmes following training. Furthermore, as caregivers often play a key role as the first advocate and support for children with ASD, such parent training programmes would not only increase access to services, but also enable caregivers of children with ASD in LMICs to be empowered, and collaborative partnerships between families and the wider ASD community to become established.

Although LMIC contexts pose greater challenges to the well-being and development of families of children with ASD, there is limited evidence for caregiver support in these conditions. The promising results in this study encourage more research in LMICs to build the evidence base of family supports for ASD outside Western countries, with the ultimate goal of eliminating disparities in population health. Research with larger sample sizes should be conducted to evaluate parent training programmes for ASD in LMICs and further examine the treatment effects of programmes that are led by trained non-specialists. Future studies should also investigate the moderators and mediators of such programmes in order to better identify what works, for whom, under which circumstances. They should also document costs and cost-effectiveness to ensure the best use of limited funds. Observational measures and extended follow-up periods are recommended to reduce the source of bias and assess the long-term impact of such programmes.

4.6. Data Sharing

Anonymised individual participant data will be available upon request from researchers who provide a methodologically sound proposal. Other documents that will be available include the study protocol, statistical analysis plan, information sheet and informed consent forms, and

analytic code. The data will be available immediately and ending three years following publication. To gain access, requestors will need to sign a data sharing agreement.

4.7. Community Involvement

The implementation organisation took part in the planning of the overall research project, by contributing to the development of the research design, research questions, and evaluation tools. The recruitment of participants and implementation of the programme were undertaken by the organisation using its existing resources. The organisation has been actively involved in the interpretation of results and taking the lead in conveying the research findings to a wider ASD community in China.

4.8. Acknowledgement

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4.10. Key points and Relevance

What's Known:

- Little research has been conducted to investigate the effectiveness of parent training programmes in reducing behavioural problems for children with Autism in low- and middle-income countries, where most people with Autism reside.

What's New:

- This real-world study evaluated the effectiveness of a short-term intensive parent training programme that was delivered by a long-established NGO as part of routine services in China.

What's Relevant:

- Short-term intensive parent training programmes could be used to complement brief parent support and as an alternative to traditional cost-prohibitive services that are intensively delivered for consecutive years.
- In low-resource contexts, such programmes may help address the substantial unmet needs of young children with Autism for treatments.

CHAPTER 5. PAPER 3 A Virtuous Circle: Stakeholder Perspectives of a Short-Term Intensive Parent Training Programme Delivered within the Context of Routine Services for Autism Spectrum Disorder in China

The manuscript will be shortened for submission.

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5.1. Abstract

Although the evidence with regard to parent training programmes for families of children with Autism has continued to grow, little is known currently about the experiences and perceptions of key stakeholders, especially in low- and middle-income countries. This qualitative study was part of a larger real-world evaluation of a short-term intensive parent training programme in routine services delivered to caregivers of children with Autism aged three to six in China. It aimed to provide insights into programme acceptability, reasons for participant involvement, and factors related to programme implementation. Fourteen parents participated in the in-depth interviews, and two focus group discussions were conducted with eight practitioners (n=4 in each group). Data were analysed using a combination of data-driven and theory-driven approaches. Findings point to the needs for substantial practice and feedback; group support; individualised coaching; more Autism-related knowledge, resources, and activities for children and extended family members; and organisational support to practitioners. Further research is suggested to address the recommendations and assess their effectiveness empirically.

5.1.1. Lay Abstract

While much knowledge about Autism derives from high-income countries, most people diagnosed with Autism reside in low- and middle-income countries, where little is documented in terms of local interventions. This is also true for parent training programmes for families of children with Autism. An evaluation was conducted to understand the effects of a short-term

intensive parent training programme delivered in routine services for families of children with Autism in China. This study reported results from the in-depth interviews with 14 participating caregivers and group discussions with eight group leaders. The interviews and discussions were aimed at learning 1) to what extent the programme components were deemed acceptable, 2) what affected caregivers' attendance and engagement in the programme, and 3) what affected group leaders' delivery of the programme. Findings suggested that future parent training programmes provide adequate opportunities for caregivers to practice and receive feedback; group support; coaching experience tailored to individual challenges; more Autism-related knowledge, resources, and activities for children and extended family members; and organisational support to group leaders. This study highlights the value of qualitative research and points to the need for more empirical studies to address the recommendations, so that research findings can be better utilised to promote practices.

Keywords: Autism, children, parenting, parent training, qualitative

5.2. Introduction

5.2.1. Background

A large regional study recently conducted in China showed a prevalence rate for Autism Spectrum Disorder (ASD) of 1%, which is in line with the estimate for Western countries and equates to approximately 3.1 million children based on the Seventh National Population Census of China (National Bureau of Statistics of China, 2021; X. Sun et al., 2019). Research indicates that families of children with ASD in low- and middle-income countries (LMICs) tend to face more accumulated adversities than those in high-income countries (HICs), including problems such as resource constraints and social marginalisation (S. P. Walker et al., 2011). China's large population and high GINI coefficient suggest that the overall impact of ASD may be bigger than usual. Children with ASD are more likely to experience co-occurring externalising behaviours than typically developing cohorts or cohorts with other developmental disabilities, such as Intellectual Disability and Cerebral Palsy (Iizuka et al., 2010; C. R. Johnson et al., 2007; O. Murphy et al., 2009; Totsika et al., 2011). These behavioural challenges are linked to increased parenting stress and have an impact in terms of child development (Hayes & Watson, 2013). Early interventions have been advocated to optimise child outcomes in ASD (Courchesne et al., 2011; Sandbank et al., 2020). Early behavioural treatment models for young children with ASD, such as Early Intensive Behavioural Interventions (Lovaas, 1987) and Early Start Denver Model (Dawson et al., 2010), have shown promising effects on improving behaviours, cognitive performance, and language skills (Reichow et al., 2018; Warren et al., 2011). However, the feasibility of such interventions may be undermined by the requirement

for caregiver daily involvement over several consecutive years. Moreover, the common shortage of specialist providers and infrastructure in low-resource settings limits access to intensive specialist care (Morris et al., 2011). For instance, a study involving 57 local service agencies for children with disabilities across half of the provinces in China showed that only ten percent of them were specialised in ASD, and half enrolled no more than 50 families per year (Sichuan Normal University, 2019; X. Sun, Allison, Auyeung, et al., 2013). As such, involving primary caregivers in providing therapeutic support through relatively shorter parent training and education has been identified to be an important strategy to address this significant unmet need (Nevill et al., 2018; C. Wong et al., 2015; Zwaigenbaum et al., 2015).

As a result of the diversity in terms of the difficulties experienced by families of children with ASD, components of parent training programmes differ, ranging from information sharing to teaching primary caregivers parenting techniques and involving them as the change agent for child outcomes (Bearss et al., 2015b). Despite this heterogeneity, a number of systematic reviews have been conducted to evaluate the effectiveness of such programmes in terms of reducing child behavioural problems (Z. Fang et al., 2020; Postorino et al., 2017), improving parent-child interactions (Oono et al., 2013); reducing ASD symptoms (Nevill et al., 2018; Oono et al., 2013); and promoting child social, communicational, cognitive, and adaptive living skills (Nevill et al., 2018; Strauss, Mancini, & Fava, 2013). One of these reviews that also focused on programmes in China, found no significant group differences between transported and homegrown programmes or between programmes with and without clinically qualified deliverers in terms of reducing child behavioural problems, thereby supporting the use of parent

training across cultures and resource settings (Z. Fang et al., 2020).

While the growing evidence-base for parent training programmes for children with ASD is promising, much less is known about the views of key stakeholders with regard to the acceptability and feasibility of such programmes, especially in routine service settings. Qualitative research can identify parent training components that are meaningful to beneficiaries and that have the potential to maintain participant engagement (Butler et al., 2020; Holtrop et al., 2014; Kane et al., 2007). For example, two systematic reviews that qualitatively synthesised parental experiences of parenting programmes for families of typically developing children, discovered the mechanisms by which caregivers transitioned from a feeling of powerlessness to a sense of control through learning positive parenting and self-regulation techniques, and also identified factors that might have promoted or inhibited the process of change (Butler et al., 2020; Kane et al., 2007). However, there are few qualitative studies focused on ASD, especially in LMICs. One study of a parent-implemented naturalistic developmental behavioural intervention for children with ASD in the U.S., explored parents' reflections on children's reactions to intervention techniques and identified potential mechanisms of change that were absent in the original logic model, thereby pointing to the importance of using contextualised measures of treatment responses (Frost et al., 2021). Another study interviewed parents and psychologists in a Group Stepping Stones Triple P programme for Irish families of children with a wider range of disabilities, showing that the programme was perceived to improve parental self-regulation, behavioural management skills, and family relations, but it was also found to be limited due to time constraints and considered

as being insufficient in terms of meeting the complex needs of high risk families (Ruane, Carr, & Moffat, 2019). Only one qualitative study was identified to be conducted in a LMIC, which found a series of facilitators (e.g., knowledge and supervision) and barriers (e.g., programme complexity and logistical challenges) related to the implementation and sustainability of parent coaching for young children with ASD in South Africa, from the perspectives of caregivers and service providers (Makombe et al., 2019).

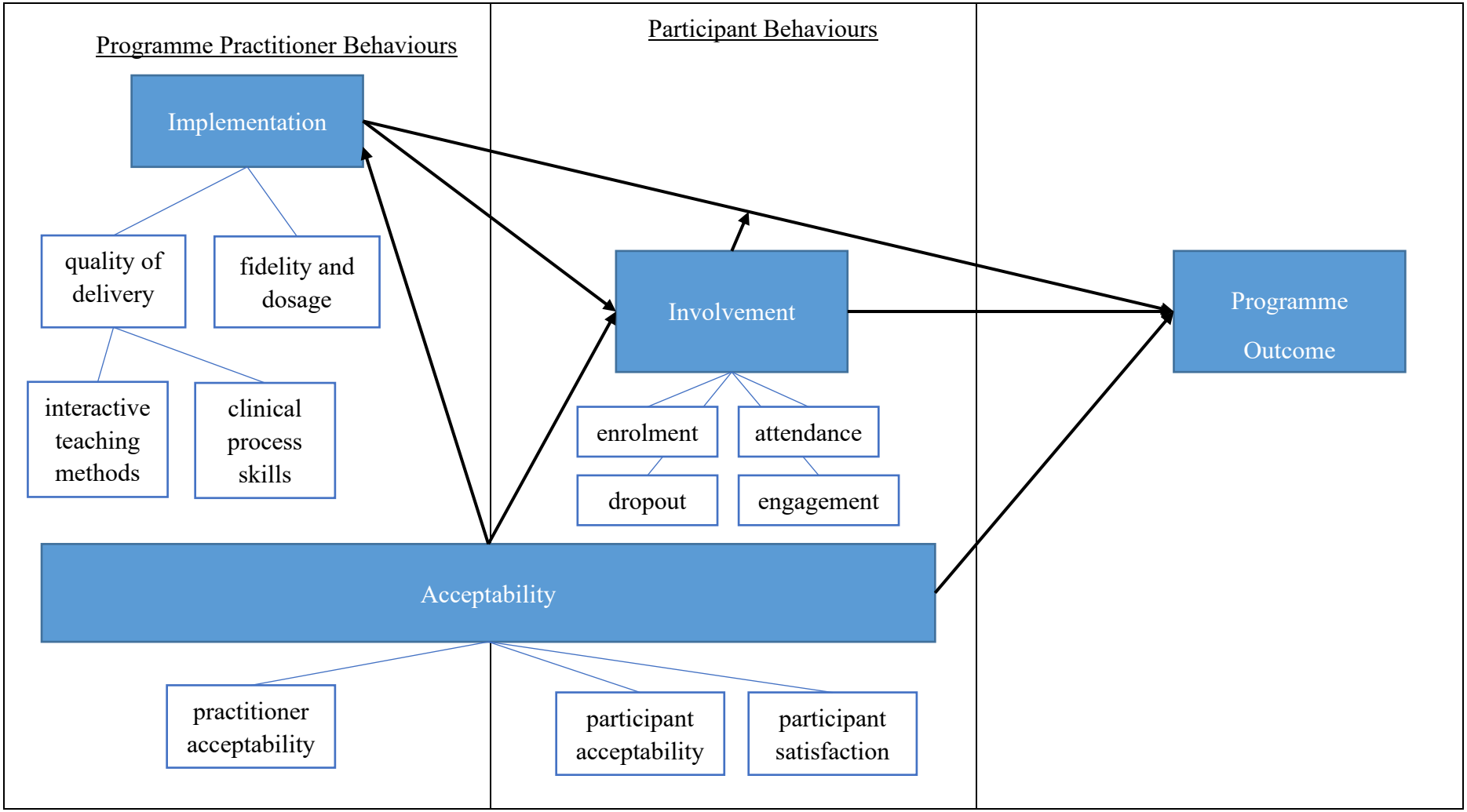
The above knowledge gap regarding stakeholder views reduces the potential to develop an in-depth understanding about parent training programmes or to recognise cross-cultural variations in ASD-related challenges, thereby delaying the integration of evidence-based ASD practices across settings. The paucity of such knowledge in China also reduces the ability of local services to address the substantial unmet needs. The current study aims to address this gap by investigating the experiences and perceptions of key stakeholders with regard to a short-term intensive parent training programme, named SREIA (Stars and Rain Education Institute for Autism), which has two decades history of supporting thousands of families of young children with ASD in China.

5.2.2. Theoretical constructs

Implementation science is aimed at promoting the translation of research findings into real-world practice (Durlak & DuPre, 2008), which is key to the increase of global access to evidence-based ASD treatments (Franz & Dawson, 2019). This study explored three constructs regarding the SREIA programme implementation process: participant involvement, programme delivery, and programme acceptability. Participant involvement consists of four dimensions—

enrolment, attendance, engagement, and dropout—and refers to the extent to which the programme maintains participants' interest and attention (Dane & Schneider, 1998). Programme delivery comprises fidelity, dose, and quality of delivery (Dane & Schneider, 1998; Dusenbury et al., 2003). Programme acceptability is to the extent to which participants consider the programme content and delivery methods as being acceptable and satisfactory (Proctor et al., 2011). A theoretical model summarising the relationships of the constructs and programme outcomes is presented in Figure 19. The three aspects of implementation have been identified as being critical to the effectiveness of parent training programmes in the general and ASD populations (Allinder & Oats, 1997; Baydar et al., 2003; T. Carr et al., 2016b; Durlak & DuPre, 2008; Furlong et al., 2012; Holtrop et al., 2014; Kazdin, 2000; Makombe et al., 2019; Nix et al., 2009). Developing an in-depth understanding of the three constructs is as such a key step to improve programme feasibility and outcomes. (More details about the theoretical constructs can be found in Chapter 2 section 2.5.4.1.)

Figure 19 Theoretical model of programme implementation, adapted from Berkel, Mauricio, Schoenfelder, & Sandler, 2011



5.3. Research Question

This qualitative study was aimed at answering the following overarching research question: What are stakeholders experiences of participating in and delivering the SREIA programme within a routine service context? The question was investigated with specific reference to the extent to which the programme content and delivery methods were deemed to be acceptable; and the extent and nature of the facilitators of and barriers to participant involvement and programme implementation.

5.4. Methods

5.4.1. Study design

This qualitative study was embedded within a larger quasi-experimental evaluation (*N* = 111) of the SREIA parent training programme (Chapter 3 Paper 2). The quasi-experiment was carried out to evaluate the effects of the programme delivered in Beijing from September to November 2020, using a difference-in-differences design with propensity score weighting (registered in ClinicalTrials.gov CT04257331). A mixed-methods approach was used, with the qualitative component nested within the quantitative design. In-depth interviews and focus group discussions (FGDs) were conducted sequentially after the completion of the programme to provide insights into the intervention process and outcomes (Creswell et al., 2011) (Chapter 2 section 2.3.1). Ethical approval was provided by the University of Oxford, UK (R67619/RE001) and the Beijing Normal University, China (SSDPP-HSC2020001).

5.4.2. Programme

The SREIA short-term intensive parent training programme has been delivered since 1993, by a long-established NGO to thousands of Chinese families of children with ASD aged three to six years. It is based on applied behaviour analysis (Cooper et al., 2007), social learning theory (Bandura, 1971), operant conditioning (Skinner, 1950), developmental (Schreibman et al., 2015), and cognitive behaviour theory (Beck & Weishaar, 1989). It is aimed at reducing child behaviour problems and promoting child development by increasing parental knowledge, improving parenting skills, changing parental attitudes, promoting parental mental health, and creating social support. A range of techniques are delivered using a variety of methods (Table 14) in an intensive format, involving five days a week for 11 consecutive weeks. Individual pre-consultations are offered with the aim of enabling programme practitioners to better understand family strengths and concerns. An individualised treatment plan is created for each parent-child dyad, covering targeted child behaviours, caregiver areas for improvement, and other priorities identified by caregivers. Fourteen two-hour didactic presentations on the core themes are offered across the 11 weeks, followed by additional training and in vivo practice in small groups of ten dyads to enhance the understanding and use of skills. The programme is primarily delivered in person, with the 14 didactic presentations also streamed online to avoid mass gathering during COVID-19. The programme has two versions of delivery, which are implemented concurrently and share the same programme content, with the purpose of exploring ways to reduce cost while improving outcomes. Parent groups in Version A attend didactic sessions together in a larger group but practice sessions separately, whereas in Version

B parents have all sessions delivered separately for each group. (Detailed programme description and logic model are presented in Chapter 2 section 2.4.1.)

Table 14 SREIA programme topics and delivery techniques

Topics	Delivery Techniques
Knowledge of ASD and child development	Individual consultation
Child behavioural problems and ABA techniques, including reinforcement (praise & rewards), prompts, fading, shaping, and chaining	Didactic presentation
Instruction giving	Practitioner observation
Ignore	Practitioner modelling new techniques
Redirect	Cases and stories
Parent-child communication and interaction	Practice in sessions and in-vivo feedback
Emotional labelling	Role play
Fine and gross motor skills	Homework and feedback
Child cognitive development	Videorecording and feedback
TEACCH – "Structured TEACCHing"	Group discussion on skills and experiences
Communicate with family members	Group problem solving
Parental self-regulation	Physical activity
Parental attitude and expectation	Reinforcement and active listening by practitioners
Skill maintenance and generalisation	Online group communication
Make a plan for the future	Informal peer support group
	Printed and online materials
	Childcare

5.4.3. Participants

All programme practitioners were invited and consented to participate in the FGDs. They included females aged 26 to 42 years from diverse backgrounds (without healthcare-related education). All practitioners had been trained and certified by the implementation agency to deliver the programme.

Potential caregiver participants for the in-depth individual interviews were identified based on their overall attendance and engagement rated by the programme practitioners. The practitioners recorded caregiver attendance using an attendance register and judged their daily

engagement according to three broad criteria: sustained attention, interaction, and completion of homework activities (Chapter 2 section 2.5.4.2). Three caregivers with different levels of engagement were identified in each parent group. Recruitment was conducted with the help of practitioners and stopped when data saturation was reached. Oral informed consent was obtained from all participants. Confidentiality was maintained unless the participant indicated that they would conduct self-injurious behaviours, or there were any concerns about possible child abuse, for which appropriate action would be taken in adherence with the Child Protection Protocol (Appendix H.7) including informing the relevant authority.

A total of 14 caregivers participated in the in-depth interviews. Participant characteristics are summarised in Table 15. The average age of caregivers was 34 (SD 5.94). All were mothers, except one grandmother. Four (28.6%) had a university degree or higher, six (42.9%) had an associate degree, and two (14.3%) attended high school. One caregiver was from an ethnic minority group. Nine participating caregivers (71.4%) were not working, whereas the majority (92.9%) of their spouses were employed. More than half (57.1%) had an annual family income below the national average and were registered as a rural resident. Their children aged 4.76 (0.98) years on average, with eleven (78.6%) being male. All children, except one, attended individual therapy (78.6%) or day care (21.4%) prior to this programme.

Table 15 Participant Characteristics

Participant Characteristics	**Sample N=14**	
Caregiver Age, M(SD)	34 (5.94) years	
Caregiver Education	University or higher	28.6% (4)
	Associate degree	42.9% (6)
	High school	14.3% (2)
Relationship with the Child	Mother	92.9% (13)

	Grandmother	7.1% (1)
Ethnicity	Han	92.9% (13)
Work Status	Working	28.6% (4)
Spouse Work Status	Working	92.9% (13)
Family Income	<60k	57.2% (8)
Household Registration	Rural	57.1% (8)
Child Age, M(SD)	4.76 (0.98) years	
Child Gender	Male	78.6% (11)
Previous Services	Day care	21.4% (3)
	Individual therapy	78.6% (11)
	No service attended	7.1% (1)

5.4.4. Data collection and analysis

The caregivers were interviewed individually for a maximum of 1.5 hours. Two FGDs, lasting for approximately 2 hours, were conducted with four practitioners in each group. Semi-structured interview schedules were designed around the three theoretical concepts to guide the interviews and FGDs, covering the following topics: 1) acceptability of programme delivery and content (caregivers and practitioners), 2) understanding and use of skills (caregivers), 3) perceived changes (caregivers and practitioners), 4) facilitators and barriers of programme delivery (practitioners) and participant involvement (caregivers), and 5) areas to improve (caregivers and practitioners). Each topic was started with broad open-ended questions followed by probes to evoke detailed responses. Questions also evolved over the course of the study to adapt the interview approach based on participants' responses (Judith Green & Thorogood, 2014). The FGDs were facilitated by the first author, and the caregiver interviews were conducted by the first author and an interviewer with a master's degree in social work, who were also trained on a range of topics including research ethics, child protection protocol,

safety protocol, and interview techniques.

The analytic approach was underpinned by a contextualist framework, which involved combining the traditionally data-driven approach with a theory-driven approach (Braun & Clarke, 2006). As such, coding of the data was guided by a coding framework, while also allowed themes to emerge from the data, so as to capture the full range of responses (Braun et al., 2019; Brooks et al., 2015). This hybrid approach has demonstrated rigor in previous research (Fereday & Muir-Cochrane, 2006).

The data analysis integrated the development of a coding framework into the six phases of thematic analysis described by Braun and Clarke (2006). It involved the following six steps. First, several coding domains were outlined based on the theoretical concepts (programme acceptability, participant involvement, and programme implementation) and research questions (facilitators and barriers) (Boyatzis, 1998). In addition to these coding domains, a topic pertaining to the experience of having a child with ASD in China emerged. Second, the transcripts were read and re-read to create a list of coding ideas. Third, initial codes were generated from a subset of data and organised in terms of the coding domains. Fourth, preliminary themes were created to develop an initial coding framework. Fifth, the coding framework was applied and constantly modified throughout the coding process. Last, themes were refined and reported. (More details about qualitative data analysis are in Chapter 2 section 2.6.5)

5.4.5. Community involvement

The implementing organisation took part in the planning of the overall research project,

by contributing to the development of the research design, research questions, evaluation tools, and the interview guides. The recruitment of participants and implementation of the programme were undertaken by the organisation using their existing resources. The organisation has been actively involved in conveying the research findings to a wider ASD community in China.

5.5. Results

A summary of the themes and subthemes under each domain is presented in Figure 20 and discussed in the following sections. The identifiers of caregiver quotes start with C and those of practitioners start with FGD.

Figure 20 Domains and themes

Experience of Living with ASD Prior to the Programme

- Lack of knowledge
- Negative experiences of services
- Poor mental health
- Reliance on family support

Programme Acceptability

a) Programme content
- All helpful and necessary
- ASD knowledge most helpful
- Behavioural management, visual support, and daily routines are the most likely to be used

b) Delivery methods
- Modelling, practice, and feedback
- A combination of group and individualised experience
- Dedicated practitioners
- Activities for children

Perceived Changes

a) Caregivers
- Improved caregiver mental wellbeing
- Increased caregiver self-efficacy

b) Children
- Better emotional and behavioural adjustment
- Improvement in functional areas

c) Parent-child relationships
- More frequent parent-child interactions
- More parent-child affection

d) Other family members
- Absence of changes in grandparents
- Positive changes in partners

Areas for Improvement

a) Programme content
- Additional resources for children
- Brief training targeting other family members
- Information sharing
- Formal mental health support
- Instructions on parent-child interaction

b) Delivery methods
- Practitioner modelling, practice in session, and in vivo comments
- Individualised support
- Programme goals
- Extended support
- Better setup of learning space

c) Support to practitioners
- Capacity building
- Reduced workload
- Mental health support

Programme Delivery

a) Facilitators
- Caregiver-practitioner cooperation
- Caregivers peer support
- Practitioner peer support among

b) Barriers
- Caregivers' denial of ASD-related deficits
- Problems with the programme
- Insufficient organisational resources

Participant Involvement

a) Facilitators
- Social support
- Intrinsic motivation

b) Barriers
- Obstacles within the family
- Problems in programme design and logistics
- Caregiver negative emotions and beliefs

5.5.1. Having a child with ASD in China prior to the programme

Several themes emerged during the caregiver interviews and focused on the overall experience of having a child with ASD prior to participation in the programme, including 1) *lack of knowledge*, 2) *negative experiences of services*, 3) *poor mental health*, and 4) *reliance on family*.

Most caregivers reported that they had never heard of ASD before their child had been diagnosed and remained largely ignorant of the disorder even after the diagnosis. Their source of information was limited to other caregivers of children with ASD and self-directed learning through the Internet and books. A few caregivers also referred to receiving limited information from the doctors who made the diagnosis:

> *"I didn't know much about Autism, or she would need life-long interventions. I thought we just needed some treatments and that was it." (CH2, 5.5-year-old boy) "I read books and look for information online…The doctor gave us some leaflets and told us about some programmes, but there was no more information from him or the hospital." (CL3, 3-year-old girl)*

Their overall experience of services prior to the programme was negative and featured inadequate access to services, due to the shortage of personnel and service provision across the country:

> *"In my city, there is only one ASD service agency…I can tell they (local service providers) don't have much experience. But you can't say that you don't want this or that practitioner. You have to give them a chance to learn, right? There are already very few practitioners available. If I am too picky, then my child will receive even less treatment." (CH7, 3-year-old boy) "Those services are in the cities. It takes two-hour's drive to get there." (CL1, 4-year-old boy) "The moment I saw the diagnosis, I know I have to go to big cities for intervention." (CL5, 3-year-old boy & CH8, 5-year-old boy)*

There was deemed to be a lack of treatment benefit:

> *"I tried some treatments in that hospital for two months. My child cried every day." (CH7, 3-year-old boy) "We've been receiving interventions since my child received the*

diagnosis at two and half years old, but I feel that those interventions did not give me any advice or help." (CH1, 5-year-old girl) "…for about three months, he did not show any progress….after going home, we tried another agency, but there was no change either." (CH5, 4-year-old boy)

The caregivers reported that there had been little conversation with practitioners and the intervention process remained vague:

"Perhaps their (service providers') focus is not communicating with or teaching parents. The agencies are so packed. Maybe they really do not have time to speak to us or explain to us any intervention details." (CH6, 4-year-old boy) "Many individual therapies do not allow parents to sit in. I don't even know if what they taught my child was right or wrong." (CH6, 4-year-old boy)

The services were perceived as being costly, especially given that there is a lack of state benefits or financial support:

"The reimbursement (from social welfare) increased a little, but the cost of services gets even higher." (CH9, 5-year-old boy) "Children won't receive reimbursement when they reach six years old." (CL5, 3-year-old boy) "I think they (service agencies) are for profit, not for my child or parents." (CH1, 5-year-old girl)

The dearth of local services that were accessible, affordable, and trustworthy might account for caregivers wanting to attend a training programme to learn a wide range of techniques, as some participating mothers described:

"Usually, those service agencies are for profit, and the skills of those providers are…It's really hard to say. So I'd rather teach my child on my own."(CL1, 4-year-old boy) "Since he was two years old, I've tried so many different things. I thought I could rely on others and things would meet my expectation. But I've realised that I should only count on myself." (CH3, 5-year-old boy)

Due to the lack of guidance, caregivers of children with ASD commonly referred to a sense of feeling lost and experiencing mental health problems, especially in terms of responding to the diagnosis or looking for treatment:

"I was so lost. I took so many detours. I was not sure what would work for my child. I tried whatever I heard…I didn't know what to do with him." (CL2, 4-year-old boy) "Since the diagnosis, I've been feeling depressed." (CH4, 3-year-old girl)

Their coping strategies prior to participation in the programme also involved reliance

on family support:

> *"My husband and I, we share the load." (CH4, 3-year-old girl) "It (the diagnosis) is always a family issue. we never think it has something to do with the state or the society." (CH6, 4-year-old boy)*

5.5.2. Perceived changes

The caregivers and practitioners described numerous ways in which the programme had produced changes in themselves, their child, parent-child relationships, and other family members.

5.5.2.1. Caregivers

Caregivers were viewed as having *improved mental wellbeing* and *increased parental self-efficacy* after participating in the programme.

a) Improved caregiver mental wellbeing

Improved mental health was an especially salient theme from the caregiver interviews and practitioner focus group discussions. For instance:

> *"I feel less confused or anxious. Although I may not be able to offer him much help, I know that I am not doing him harm, I am not treating him in the wrong way." (CL1, 4-year-old boy) "Their emotional states are much better than when they first came." (FGD1)*

Parents identified several ways in which caregiver mental health was believed to have been improved. First, some parents appeared to feel a greater ability to regulate their emotions, as a result of the emotion regulation techniques that had been learned:

> *"Sometimes when I am about to have an outburst, I tell myself to stop and calm down and walk away." (CH6, 4-year-old boy)*

The caregivers also described receiving substantial emotional support from peers and practitioners. For instance, the optimistic and supportive atmosphere in parent groups was

perceived to have provided an experience of social inclusion and belongingness, and the practitioners were perceived to be empathetic and responsive to caregiver concerns:

> *"The optimistic environment here is really good. We are equal and no one looks down upon others. We learn and support each other, we are full of hope, and we have someone to talk to if there are any problems." (CH5, 4-year-old boy) "Sometimes I couldn't sleep, and I messaged her (practitioner), I did not even expect her reply because it was so late, but she responded instantly…Having them around makes me feel supported…and maybe also less unsure about the future." (CH6, 4-year-old boy)*

Third, seeing progress in their children also appeared to have created a sense of achievement and hope:

> *"I felt so stressed because he wasn't able to learn anything. Now it's better." (CH6, 4-year-old boy) "Now I don't think he will cause us much trouble. As long as I can teach him to take care of himself…I am confident in achieving this." (CH3, 5-year-old boy)*

Another theme that emerged in terms of parental mental health, was their increased acceptance of their child's diagnosis:

> *"I didn't tell my neighbour. I haven't even told my parents. I couldn't accept that my son has Autism. I was afraid that we would be discriminated. Now I feel much more peaceful. Last week my neighbour asked me where we went, and I told her. I feel so relaxed after I did that. I think, as long as we communicate, it will be ok. I plan to tell my parents. I think, if I give them enough information, they will be able to understand. We are all very stressed." (CH3, 5-year-old boy) "Now I understand he (her child) is just a person, who is different from others. And he actually faces more challenges than I do." (CH5, 4-year-old boy)*

b) <u>Increased caregiver self-efficacy</u>

Caregivers described more positive parenting practices and less physical or verbal aggression towards children:

> *"I know how to parent him, and I now have enough strength to face his behavioural challenges. Our interactions have changed, too. I used to yell at him, saying you cannot do this or that, just trying to stop him. But now I know it's better to guide him." (CH9, 5-year-old boy)*

In addition, the caregivers highlighted they were better able to make decisions about

which other services to use after gaining more knowledge about ASD:

> *"After the programme, I know what treatments are more appropriate for my child. For example, I thought that hands-on coaching was the most helpful for my son, but now I know that some children with Autism do not like to be touched, and my son is one of them." (CH6, 4-year-old boy)*

The positive changes perceived by caregivers may have created a virtuous circle in which the occurrence of one led to that of another, which further promoted a continuous process of improvement. These interactions were also well described by one of the practitioners:

> *"I've been thinking that the core is centred around getting to know your child, know his deficit, and the signals he tries to give you through his behaviours…based on the signals, you apply the skills. During the process, you will know even more about your child, and see all the challenges he has been struggling with, then you know that you should control your own emotions and help him…You will have more strength and confidence, which in turn improves your emotions…With better emotions, you will also communicate with your family in a better way…then there is a better environment at home for your child to develop…" (FGD2)*

5.5.2.2. Children

Perceived changes in children involved 1) *better emotional and behavioural adjustment* and 2) *improvement in other functional areas*.

Many caregivers noted more compliance, less emotional and behavioural problems, and more adaptive living skills in their children. These improvements were perceived to be the result of more positive parenting practices (such as visualised routine, instruction giving, and positive reinforcement) and the improvement in child communication skills (such as their use of more expressive language, a picture exchange communication system, and feelings and emotions cards):

> *"I praise him more and yell less, so he was more willing to listen to me…It has become easier to teach him, like brushing teeth, putting on clothes…" (CH1, 5-year-old girl) "He cannot speak. He used to cry a lot and I did not why. Now he can show me the cards and let me know what's bothering him. As long as I keep trying, there will be*

improvements." (CL2, 4-year-old boy)

However, two caregivers felt that there had been no changes in terms of child emotional or behavioural problems. One reason they provided was that it was difficult for parents to be consistent in their application of the principles:

> *"I think it's our own problem. The practitioners taught the skills very well, but some child behaviours need soothing. We prefer to soothe the child, so it is difficult for us to carry on the techniques." (CL1, 4-year-old boy)*

A second caregiver who reported no changes in emotional and behavioural challenges expressed disagreement with the advice given by practitioners, due to their different judgements about the intentions of child behaviours:

> *"Unlike other parents, I never messaged her (the practitioner) or asked any questions. She once said to me, the tantrum was to avoid things, but I don't think so…She needs to learn more about my child…I'm not sure what I should do next." (CL5, 3-year-old boy)*

There were different accounts of changes in child socialisation. One caregiver reported her child being more socialised because they actively mingled with other families during and after the sessions, while another caregiver mentioned the lack of structured activities within the programme for her child to interact and develop social skills.

5.5.2.3. Parent-child relationships

More frequent parent-child interactions and *parent-child affection* were commonly referred to by the caregivers. More positive parenting practices and less physical or verbal aggression were considered as contributing to the increased parent-child intimacy:

> *"He used to be afraid of me because I spanked him. Now I no longer use physical punishment…I think he now enjoys being with me." (CL1, 4-year-old boy) "I don't yell at him now, and I've decided not to do that in the future. If he doesn't listen, I will help him respond to my instructions…Maybe he now feels more relaxed being with me, so sometimes he even comes to hug me." (CH3, 5-year-old boy)*

Techniques such as arranging time to play together was also perceived to have increased the interaction with children:

> *"We did not interact much. I was busy taking care of her, taking her to different services…I've learned that interaction is also important, so every day after dinner, I block some time to play with her." (CH4, 3-year-old girl)*

5.5.2.4. Wider family members

A few caregivers who often shared information with their partner described some *positive changes in partners*, such as less stress and more collaboration in parenting:

> *"The other day I texted him 'Thank You'. He was surprised and said it's all worth it…Although he didn't say, I think he has noticed my confidence and became more relaxed himself." (CH3, 5-year-old boy) "Her dad now knows how to stick to the principles, too." (CH4, 3-year-old girl)*

Despite attempts to share their learning with elderly relatives, there was generally perceived to have been a *lack of change in the elderly*:

> *"I've tried to explain, Autism and the techniques, to his grandparents, but I don't see any changes. Well, you can't really expect changes in the elders. Some concepts, like Autism, are just too difficult for them to understand. In their opinion, if a child does not communicate, it's only because he doesn't want to. No other excuse." (CH8, 5-year-old boy)*

One caregiver, however, described how her mother-in-law sometimes attended the sessions and spoke to other caregivers, which enabled the mother-in-law to better understand the diagnosis and adjust her expectations.

5.5.3. Programme acceptability

5.5.3.1. Programme content

All aspects of the programme were perceived to be helpful by both parents and

practitioners, with many of the techniques being seen as interrelated:

> "*They're all helpful. You cannot say one is more important than another, because they're all connected, especially the ABA techniques.* " *(CL2, 4-year-old boy) "I am really not able to identify one that is not essential. They all help cope with daily challenges." (FGD2)*

The session that focused on *Knowledge about ASD* at the beginning of the programme was nevertheless perceived to be central to enable an understanding of the diagnosis and its implications, thereby promoting the acceptability of techniques taught at later stages:

> *"[the knowledge of ASD] is like the central nervous system, without which you won't be able to receive other information or coordinate any activity." (FGD1) "Those who skipped the session always don't accept their children and are more skeptical about whatever we say." (FGD2)"Before that, I thought ASD was just a disease and could be cured by interventions. Now I know it may be a life-long condition. That is why learning these skills is so important for us." (CH5, 4-year-old boy)*

Skills reported by the caregivers as the most likely to be used included *behaviour management techniques*, *visual supports*, and *daily structure and routine*, which were consistent with the perceived changes in children, such as fewer emotional and behavioural problems and improved communicational skills.

5.5.3.2. Delivery methods

A number of delivery methods were perceived to have been important in establishing new skills in caregivers, including *modelling*, *practice*, and *feedback*, as well as a combination of *group experience* and *individualised support* to promote social inclusion and address diverse concerns.

a) <u>Modelling, practice, and feedback</u>

The caregivers and practitioners both highlighted the importance of practitioner

modelling, which was perceived to have involved a demonstration of the application of skills, build trust, and promote caregiver understanding of their child:

> *"Their modelling helped me see abilities that I had never seen in my child before. As a parent, I knew he could do A and B, but not C, so I never tried C. Now they tried C on my child and…I think they have magic powers." (CH6, 4-year-old boy) "…it made me see how it was like for my child to interact with other people." (CL5, 3-year-old boy)*
>
> *"It was our modelling of techniques that made them really understood how those skills could be used…That was also how we gained trust, because they would only believe us when they saw us successfully applying the skills to their child. " (FGD2)*

In-session practice and in vivo feedback were also identified as being central to their learning, as they were perceived to have scaffolded caregivers' engagement with targeted skills:

> *"When we practice, we expose problems so that the practitioners can correct us." (CH6, 4-year-old boy) "Watching other parents use the skills also helped me see my own problems." (CL2, 4-year-old boy)*
>
> *"That was when we gave them hands-on coaching, because they will have to do it on their own after going home." (FGD2)*

b) <u>A combination of group and individual learning</u>

The caregivers explained that the parent groups and the residential community where the programme was located, offered them a positive and inclusive environment, which nurtured their greater acceptance of their children and themselves:

> *"The neighbourhood is nice and inclusive. They know Autism and understand us. I feel comfortable being there." (CH4, 3-year-old girl) "I enjoyed it because we (the caregiver group) were like a family. We made progress together. We learned from each other about how we should treat our child and ourselves." (CH1, 5-year-old girl)*

Ongoing and flexible communication was also referenced by both groups of participants. The constant close communication between practitioners and caregivers was described as being like one-to-one coaching:

> *"No matter it was during or after sessions, once we saw them, we would speak to them. Sometimes we even scheduled individual conversations if we spotted significant issues." (FGD2)*
>
> *"I think the flexible communication was like on-one-on coaching. They coached me*

on things that my child needed most." (CH9, 5-year-old boy) "Whenever I asked my practitioner a question, she would respond in detail. Every time if thought I could not make it, I would message her, and she would rebuild my confidence." (CH6, 4-year-old boy)

Further, the flexibility within the programme was described by the practitioners as being core to implementation success, in that the programme had not only specific goals to maintain focus, but also sufficient space to accommodate change and meet identified needs:

"We must cover all the topics…but when it comes to the content in each session, I think it is flexible. We adjust the content according to the families. Different groups can have different focus." (FGD2)

Homework activities were also perceived as an opportunity to raise concerns and obtain individualised advice:

"In the sessions, they (practitioners) don't have much time for everyone. You can write down your questions or whatever you want to say (in the homework). No matter if it is about the skills or your daily challenges, they will respond."(CH3, 5-year-old boy)

c) Other themes

Other aspects of the delivery that were described as being helpful by the caregivers, included *dedicated practitioners* and *activities for children.* The practitioners were perceived knowledgeable, responsive to caregivers' concerns, and treating participants equally:

"They are very professional. Some of them are young, but still very skilful." (CH8, 5-year-old boy) "(We communicated), at any time, about any issues. They (practitioners) even say that if we come across anything difficult after the programme, we can get in touch with them." (CH6, 4-year-old boy) "If there isn't enough time during sessions, they will find another time to talk about problems you want to solve." (CH2, 5-year-old boy) "They treat us equally. They accurately find out each family's needs and create a plan for us to follow and supervise us." (CH9, 5-year-old boy)

Activities for children freed caregivers from childcare:

"I like it (child activity). That is when I felt most relaxed. I take care of him 24/7. Only when they were doing activities, I can catch a breath." (CH7, 3-year-old boy)

5.5.4. Facilitators and barriers to participant involvement

Information regarding the facilitators of and barriers to participant involvement was primarily collected from in-depth individual interviews with the caregivers.

5.5.4.1. Facilitators

Facilitators of participant involvement included: 1) *social support*, 2) *intrinsic motivation*, and 3) *appropriate delivery methods*.

a) Social support

The caregivers emphasised social support as a major facilitator of their involvement, especially with regard to programme enrolment. Support from a variety of sources—spouse, extended family, relatives, peers, and employers—made it possible to sign up for the programme:

> *"His (her child's) grandparents don't understand the situation (the diagnosis), but they always respect my decisions and support in their ways. They got my back." (CH2, 5-year-old boy) "After COVID, I spoke to my boss again and he said that, for the sake of my child, I should sign up as soon as possible and there should be no further delay." (CH8, 5-year-old boy) "I am in an online support group for ASD families. Some of those parents had this programme before and I can see their changes. They told me about their experiences here and cleared up my doubts, so I decided to come." (CH7, 3-year-old boy)*

Social support also promoted participant engagement. For example, caregivers perceived peer support to have enhanced the learning experience by collective problem-solving. They also considered familial support as necessary to help them to maintain consistency of practice at home:

> *"We (participants) support each other. For example, when I practice, if they see a problem, they will point it out and we discuss." (CL2, 4-year-old boy) "They, including other parents, they consoled me when I was down…then I found the strength to try again."*

(CH1, 5-year-old girl)

"I will definitely need my family to be consistent with me. If I tell my child not to do something, but his grandma or father allows him to do it, he will be confused too. We adults need to reach an agreement."(CH3, 5-year-old boy)

b) Intrinsic motivations

In terms of intrinsic motivations, the caregivers overwhelmingly talked about a sense of urgency, as they were aware of the importance of early intervention and the role of caregivers in influencing their child's development:

"The golden period of ASD treatments is before 6 years old, so I must make sure everything, my time and energy and money, is well spent before he turns 6. I should not waste his time." (CH6, 4-year-old boy) "He (her child) spends one hour per day in the agency but 23 hours with me…I cannot rely on agencies forever. I need to learn so he can return to the family and to the society." (CH3, 5-year-old boy)

Children's progress was commonly identified as the major reason for continuing to attend the sessions, as it was described as motivating their learning and use of skills:

"His progress reinforces me. I am now better able to offer support to my child if I learn the skills well." (CH1, 5-year-old girl & CL2, 4-year-old boy) "My child is my motivation. Everything is for him. If I found it effective, I will keep using it. That's why we came here." (CL5, 3-year-old boy) "I say our motivation is even stronger than those intern practitioners. We learn for our children." (CH7, 3-year-old boy)

5.5.4.2. Barriers

Participant involvement was perceived to have been inhibited by 1) *obstacles within the family*, 2) *problems with the programme design and logistics*, and 3) *caregiver negative beliefs and emotions*.

a) Obstacles within the family

Lack of family support was one of the barriers to attendance described by caregivers who described that grandparents were not exposed to any programme content and did not

understand the diagnosis or new skills, thus limiting wider support from within the family:

> *"They still do not accept it. My husband said that, we (her and her son) can go and get services, but he will never admit the disability." (CH7, 3-year-old boy) "For example, I told them (grandparents) that if he does not respond to your instructions, you don't have to repeat because that won't work. All you need to do is to help him complete the task. But I don't think they understood. I don't see them following my advice." (CH8, 5-year-old boy) "I'm not sure about my mother-in-law…Sometimes I say we must stick to a principle, but when I am not present, she will just let it go." (CL3, 3-year-old girl)*

Further, a common reason for being absent from sessions was family issues, such as child illness:

> *"Usually, it was because my child was ill or something happened at home. Otherwise, I wouldn't want to miss anything. (CL2, 4-year-old boy)"*

b) Problems with the programme design and logistics

Caregivers expressed dissatisfaction with the prolonged waiting time to begin the programme. Due to the limited service capacity, the programme recruits less than 300 families per year, resulting in a long waiting list of participants. The social distancing requirements related to the COVID-19 pandemic had exacerbated the situation:

> *"I heard that I had to wait, so I didn't sign up at first." (CH5, 4-year-old boy) "I was on the list and then the pandemic hit the country. Overall, we waited for one year and a half." (CL5, 3-year-old boy)*

Despite the intensity of the programme, caregivers felt that it was not long enough to support their engagement in targeted skills, thereby pointing to the need for more opportunities to practice and receive feedback, and also for the ability to address their lack of confidence*:*

> *"Less than three months...We had no chance to be supervised on many of those skills…We can only learn a big picture. We will need to keep practicing and refer to the notes for more details." (CH9, 5-year-old boy) "I've heard it and understood it, but I still don't think I can do it well." (CH2, 5-year-old boy)*

Their child being present in the session was reported by caregivers to be distracting, which is consistent with the favourable rating given to having activities for children:

"Ten little children with ASD in one room…Even if my kid does not misbehave, other kids will misbehave. It's normal, but very distracting." (CL2, 4-year-old boy) "I was about to take some notes and he started to yell." (CH7, 3-year-old boy)

Online delivery was identified as another barrier by caregivers who were less able to maintain their focus online and whose learning was often disrupted by technological failure. The lack of diversity in homework activities also contributed to some caregivers skipping home exercises, even though homework activities were also perceived to provide opportunities to obtain tailored advice:

"They (the homework activities) are the same every week, so I skipped some." (CH3, 5-year-old boy)

c) Caregiver negative emotions and beliefs

Another common barrier to participant engagement that was referred to by both groups of stakeholders was caregiver negative emotions, which were often perceived to have been caused by child non-compliance and the lack of family support:

"When he (her child) does not listen to me, I become worried again. I'm not sure if I can do this. I feel down and don't want to do the practice." (CH2, 5-year-old boy) "Overall, it's mainly their mental state that determines if they can develop solid skills…Although we practitioners need to guide them towards better mental state, their family environment plays a more decisive part in it. " (FGD2)

Disagreement about the skills, as previously described, also made some caregivers resistant to the introduction of strategies that challenged their pre-existing knowledge of the diagnosis or effective practices, thereby reducing their willingness to apply the strategies being taught:

"I have different opinions. For example, I used to make a plan for my child, and I gave her rewards when she completed the tasks. But she had a lot of emotional problems. My practitioner then suggested me to stop making the plan. I don't think this would work. If there is no plan, how would she even listen to me?" (CL5, 3-year-old boy)

"They (previous service providers) said making the child speak was the most

important thing…So I skipped some sessions that I thought not related to language skills. I did not realise until now that there can be so many ways for us to communicate. I missed a lot (of techniques introduced during the first several weeks) and I need to catch up." (CL1, 4-year-old boy)

5.5.5. Programme Implementation

The practitioner FGDs provided information on the facilitators of and barriers to the delivery of programme.

5.5.5.1. Facilitators of programme delivery

Programme delivery was described to be facilitated by 1) *caregiver-practitioner cooperation*, 2) *caregiver peer support*, and 3) *practitioner peer support*.

Caregiver-practitioner cooperation was perceived by practitioners to improve the programme delivery and be promoted by caregiver trust:

"It took less time for us to build trust this time...Perhaps it's because the COVID quarantine made them realise what they need to learn, or they've seen others who attended this programme before and made progress. Shared goals were established right away and I found it easy to communicate with them…As long as they agreed that it was important for their child, they would cooperate." (FGD2) "I told them to practice no less than five times at home…and they did!" (FGD1)

Peer support among caregivers was also perceived to be as important in terms of implementation because it increased participants' responsiveness during sessions:

"There is a feeling of solidarity among them…I don't need to do much to coordinate. They influence each other and help each other." (FGD1)

At the practitioner-level, *peer support among practitioners* involving the discussion of difficult cases and sharing of stress-reduction strategies, was perceived to have improved the quality of delivery:

"We are in the same office, and we have lunch together, so we can discuss difficult cases…We also complain to each other…It's a way of self-healing." (FGD1)

5.5.5.2. Barriers to programme delivery

The major obstacles to programme delivery that were identified by practitioners were 1) *caregivers' lack of acceptance of their children*, 2) *problems with the programme*, and 3) *insufficient organisational resources*.

a) Caregivers' denial of ASD-related deficits

A lack of knowledge with regard to the diagnosis was viewed to result in denial of the ASD-related deficits, which was in turn perceived to make it difficult to convince caregivers of the relevance of the skills during the delivery of the programme:

> *"Sometimes they don't accept the deficits. Even if the child couldn't speak, she wouldn't use pictures (to communicate), because otherwise she was admitting that her child was different. Other people would also notice his difference… It's hard to deliver unless they accept the diagnosis." (FGD2)*

b) Problems with the programme

In terms of programme design, the practitioners highlighted the dilemmas of having children present in the sessions. As with the caregiver reports, the practitioners noted the distractions caused by children being present within the session, but also stressed that their presence allowed for substantial opportunities to practice new skills:

> *"If children are cooperative, the sessions will be more efficient. But child is child, you cannot ask him to sit still for too long…It is difficult to balance." (FGD1)*

The practitioners further discussed the difficulties of having to cover a wide range of topics. Thus, even though all the content was perceived as being helpful and necessary, having too many topics within one programme was also felt to be overwhelming and challenging:

> *"We want to give them more, but then it becomes very demanding." (FGD1)*

c) Insufficient organisational resources

At an organisational level, the heavy workload and lack of organisational support were highlighted as significant barriers to programme delivery. The shortage of personnel was perceived to have resulted in an intense workload and high levels of practitioner stress. Practitioners also described an absence of formal supervision and mental health support. This may explain in part why practitioners identified peer support among practitioners as essential for the programme delivery:

> *"There were too many families…I think 20 families is the most I can take." (FGD2) "Sometimes I just want to stop thinking, but I don't have time for this…We often say to our colleagues that we don't want to speak after sessions." (FGD1) "We only had two coaches and they have their own work to do…We have to ask for supervision, or we discuss with each other." (FGD2)*

5.5.6. Areas for improvement

The caregivers and practitioners identified several areas in need of improvement in terms of the programme content and delivery methods, as well as supports to practitioners.

5.5.6.1. Programme content

Given that children being present in the session was one of the major barriers to participant involvement, it is possibly not surprising that the caregivers predominantly asked for *additional resources for children*, such as structured child activities and childcare, when their child is not involved in modelling and practice, so that caregivers can focus on learning without being distracted by child behaviours and childcare duties, and that child social skills may also be promoted:

> *"Otherwise, my focus is always on my child not the practitioner." (CH4, 3-year-old*

girl) "There needs to be something for children to play, to interact." (CH3, 5-year-old boy)

Considering the importance of family support in the use of skills, the caregivers highlighted the need for *brief training targeting other family members* to reduce resistance with the family and maximise child opportunities to learn:

> *"Other family members also need to learn, but they won't listen to us. They'll listen better if it's someone with more experience. Then we can be on the same page." (CH7, 3-year-old boy) "There can be a separate training for them, or you invite them to sit in some of our sessions. They don't need to learn so much as we do, but it should at least cover what ASD means, what positive parenting is, how ABA techniques are applied, and how they can support us at home" (CL2, 4-year-old boy)*

In addition, the participants suggested the need for: *more sharing of information* on ASD treatments, such as other evidence-based interventions and interventions for older children:

> *"I wish there was some information about adolescence, just to give us an idea what to expect." (CH9, 5-year-old boy)*

They also emphasised the need for *formal mental health support*, such as counselling and referral:

> *"Families like us need it (mental health support). We are really stressful…The child is little now, but when he grows up…I don't even want to think about it." (CL1, 4-year-old boy)*

They also wanted *more instructions about parent-child interaction* - as apart from principles of parent-child interaction - such as information on what games are available and detailed instructions on how the games can be played are equally necessary:

> *"Parent-child relationship is the foundation…We noticed that many caregivers did not know how to play, although they really wanted to interact with the child, they did not know where to start...We need to work on that." (FGD2).*

5.5.6.2. Delivery methods

In terms of delivery methods, caregivers identified the needs for more *practitioner*

modelling, *practice in session*, and *in vivo comments* to enhance skills. More *individualised support* was also perceived to be required to address individual concerns. Moreover, given the comprehensiveness of the programme topics, *clarification of the goals* of the overall programme and each component was perceived as being necessary to promote participant engagement:

> *"I'm not sure what the purpose of observation and individual counselling is." (LHL) "We need to keep clarifying the goals…Although there are a lot of topics, they are all connected to their ultimate goals and they need to be aware of that… Otherwise, we may put too much pressure on them." (FGD1)*

Caregivers also identified a need for the *support to be extended* after the completion of the programme to facilitate the use of skills at home and keep up a positive attitude:

> *"Can they give us some guidance when we have challenges using those skills at home? I will need to get in touch with them if there are problems that I cannot solve on my own." (CH4, 3-year-old girl) "Can someone collect our questions and provide feedback? Just some brief guidance will be very helpful." (CH7, 3-year-old boy) "But when the programme ends and we stay back at home, we have to again face all the challenges we had before. It is hard to make sure we still have the strength to do all these (new skills) or even to stay in a good emotional state." (CH5, 4-year-old boy)*

Caregivers also highlighted the need for a *better setup of learning space*, including arranging for an offline venue to better demonstrate skills, and improving the quality of online sessions.

5.5.6.3. Support for practitioners

The practitioners provided two suggestions in terms of improving programme delivery. First, they suggested improving the *practitioner capacity building* process through the use of a standardised training system, offering more self-learning opportunities, and providing formal supervision on a regular basis:

> *"We old practitioners have plenty of experience and we should think about how we*

can pass it to the new practitioners in a way that is systematic, standardised, and flexible…The training should cover programme content, delivery methods, and teaching skills." (FGD2) "Maybe compared to other organisations, we have more supervision and learning opportunities. However, it's still not enough, considering our needs." (FGD2)

Second, they shared their desire for *reduced workload* and *mental health support* to reduce stress and prevent vicarious trauma. *Incentives* were also identified as potentially increasing motivation:

"We need support not just for delivering the programme, but also for our mental health. Sometimes I feel like an actor, giving the best of ourselves to the parents. But after the sessions, what's left for our family is negative emotions…There is so much that we want to change, but the reality is that we must learn to give up…We need some emotional coaching." (FGD2) "It will be helpful if more financial benefits can be provided." (FGD1)

5.6. Discussion

As the evidence in relation to ASD treatments has evolved, an understanding of the intervention experiences of stakeholders has become equally important. This is especially true in LMICs, where most children with ASD reside but little is documented in terms of local interventions and how they are provided. To the best of our knowledge, this study is one of the few to rigorously investigate the experience of participating in and delivering a short-term intensive parent training programme for families of children with ASD in a LMIC. The findings of this study provide valuable information about the acceptability and feasibility of ASD treatments and can be used to inform the implementation and evaluation of parent training programmes in other LIMCs where families face similar ASD-related challenges.

5.6.1. Summary and implications of the findings

The results indicate that caregivers and practitioners highly valued the comprehensiveness of the programme, describing all topics as being helpful and necessary.

This may reflect the general lack of ASD information and local services more widely (Clark et al., 2019; McCabe, 2007). Indeed, many parents described the programme as being the major source of information for them and wanted the opportunity to participate in future programmes to secure more resources and support. Two previous studies on parenting interventions for families of children with ASD in the U.S. and Australia also showed that parents often valued additional information, such as the ASD technique using social stories and more advice on the seeking and selection of services (Dababnah & Parish, 2016; K. Whittingham et al., 2006). However, practitioners were concerned that the comprehensive cover of the programme could potentially compromise the quality of the delivery, suggesting the need to help caregivers maintain focus by encouraging them to closely relate the programme contents to their personal goals, so that caregivers can concentrate on identifying strategies that are most helpful in terms of their own needs.

Results also highlight the importance of learning ASD knowledge as a key programme component, which enabled caregivers to better understand and accept both the diagnosis and their children's behaviours, thereby paving the way for learning ASD-related parenting techniques. This finding converges with quantitative results from the evaluation, which showed that the programme significantly increased parental knowledge of ASD (Chapter 4 section 4.4.1). The practitioners also suggested that the teaching of knowledge about ASD improved caregivers' understanding of the relevance of the skills, which promoted engagement in later sessions. This is consistent with previous research on the Incredible Years parenting programme tailored for children with ASD, showing that introducing ASD terms helped

establish a ‘common ground’ (Dababnah & Parish, 2016). Moreover, as parents in China typically receive inadequate guidance on the selection of appropriate treatments for their children (McCabe, 2012), learning about ASD and getting to know their child better may support their future decision-making. In accordance with other research that found high caregiver rating of content on behavioural management, visual support, and structured routines (Holtrop et al., 2014; Lachman et al., 2016; Mejia et al., 2016), caregivers in this study also identified these techniques as the most likely to be used. These techniques are in line with the perceived changes in child emotional and behavioural adjustment and child communicational skills, as well as the quantitative programme assessments which showed a significant reduction of child externalising problems (Chapter 4 section 4.4.1). At the same time, respondents identified the need for more sessions on teaching parent-child interaction to go beyond the theoretical principles and increase caregivers’ skills in initiating and maintaining interactive play.

As a central aspect of their learning and engagement, participants emphasised the importance of practitioner modelling, the opportunity for in-session practice, and feedback. This corresponds with previous studies that also identified the role of modelling as a core programme component (Dababnah & Parish, 2016; Lachman et al., 2016) Nonetheless, caregivers asked for additional coaching, indicating a general lack of confidence in using all of the taught techniques, which might be one of the drawbacks of delivering many topics within a limited timeframe. Participants also highlighted the value of combining group experience with individualised support during and after the programme. Having a child with ASD was

characterised by participants as leading to social marginalisation, and programmes of this kind were perceived to provide an inclusive environment for caregivers to normalise their experience and expand their social support networks (Mytton et al., 2014; Wheatley et al., 2003). Practitioners further identified group support as a facilitator of programme delivery, as it was perceived to enhance caregiver learning through the sharing of resources and problem-solving strategies. The importance of individualised support was evident in themes about programme flexibility and ongoing communication sustained beyond the duration of programme. Previous qualitative systematic reviews identified a consensus across providers, researchers, and parents that such programmes should be tailored to account for individual ability and cultural differences (Butler et al., 2020; Durlak & DuPre, 2008; Mytton et al., 2014). However, this presents a challenge to programme delivery, especially given the lack of resources and the absence of research on the key intervention components in LMICs.

Past research has indicated that a collaborative and therapeutic relationship established by knowledgeable and non-judgmental group leaders contributes to programme success (Dababnah & Parish, 2014; Holtrop et al., 2014; Lachman et al., 2016; Mytton et al., 2014). Caregivers in this study also highlighted the dedication of practitioners, who were perceived to be conversant, responsive, and unprejudiced, as playing a critical part in their overall positive experience of the programme. Further, multiple caregivers in this programme described how practitioners improved their mental health, suggesting that, in low-resource settings, practitioners do not only teach skills, but provide the type of support that can lead to wider changes in parental functioning.

Having children participating in the sessions was, however, experienced in a number of ways. Although it was identified as a core component in a review on general parent training programmes (Kaminski et al., 2008), it may be more challenging to implement effectively when delivered to parents of children with ASD. While children being present in sessions offered substantial opportunities in terms of in vivo practice and feedback, it was also regarded as one of the major barriers to engagement and delivery. Therefore, caregivers commonly requested more playful and structured activities for children when they are not involved in modelling and practice. Childcare needs in parent training programmes for ASD may also differ from programmes designed for the general population. Unlike caregivers of typically developing children who need regular childcare services to promote attendance (Mytton et al., 2014), due to the core deficits of ASD, caregivers of children with ASD may expect more structured activities arranged in childcare services to promote child development. For example, parents in a study conducted to evaluate a parent training programme for children with ASD in the U.S. also requested such activities to be included in the programme in order to engage children in social interactions (Dababnah & Parish, 2016). Moreover, findings from a systematic review of parent training programmes delivered in China to parents of children with a wider range of developmental disabilities, found that components directly targeting child social skills have the potential to further reduce child externalising and international problems (Z. Fang et al., 2020).

With regard to facilitators of participant involvement, findings suggest that caregivers predominantly considered child progress as their major motive to participate and learn. This is consistent with the quantitative assessment of the programme process which found a connection

between higher levels of engagement and improved child behavioural adjustment (Chapter 4 section 4.4.2). Similarly, a qualitative study in South Africa found that perceived improvement in child development contributed to participant buy-in and might increase the likelihood of behavioural changes in caregivers of children with ASD (Makombe et al., 2019).

A qualitative systematic review of parent training programmes for children without disabilities indicated that poor familial support can undermine participant attendance and engagement (Mytton et al., 2014); another qualitative review on general parent training programmes found that wider family support facilitates attempts to apply new skills (Butler et al., 2020). Caregivers in this study also highlighted the impact of support from family members on the level of engagement, describing that the lack of support inhibited them from signing up for the programme, engaging in the targeted skills, and maintaining consistent parenting practices. This may explain the recurrent suggestion to provide brief training sessions for other family members, alongside the need to enable other family members to be aware of, and to use, the new skills being taught.

Raising a child with ASD is stressful irrespective of geographical location, but the severe lack of information and resources (Clark et al., 2019; McCabe, 2007) and the long-held negative attitude towards disabilities in China (Fong & Hung, 2002; M. Huang & Zhou, 2016) may have created additional sources of pressure for the caregivers in the current study. Although caregivers commonly reported mental health concerns prior to joining the programme, they experienced a substantial improvement in mental wellbeing upon completion, which concurs with the quantitative assessments of programme effects, showing that the intervention

had a significant impact on reducing mental health symptoms (Chapter 4 section 4.4.1). Despite research suggesting that parental mental health can influence treatment adherence (T. Carr & Lord, 2016; Hackworth et al., 2018), only a few caregivers explicitly linked their improved mental health status with the course. One potential reason is that many caregivers of children with developmental and behavioural problems focus less on their own problems, as was shown in the study of Incredible Years for pre-schoolers with ASD, where parents reported that there was little time to attend to their own self-care needs (Dababnah & Parish, 2016). However, receiving more formal mental health support was among the most important post-programme needs for caregivers in this study, which may be related to their concerns about the potential fade-out of programme effects in both child and parental domains (van Aar et al., 2017).

Disagreement about the skills being taught was perceived as another barrier to participant involvement. The finding is in line with previous research showing the negative impact of a mismatch between programme philosophy and parental expectations (Lachman et al., 2016; Mytton et al., 2014), pointing to the importance of clarifying the programme goals at an early stage of intervention. Online delivery was considered by caregivers as less helpful, because of technological failures and the difficulty in maintaining focus. Nonetheless, online delivery of evidence-based intervention has become a global trend driven by the efforts to promoting equal access to healthcare services and accelerated by the COVID-19 pandemic. This highlights the need to address technical challenges, especially in LMICs where there is a lack of infrastructure, and to explore ways to promote participant engagement in digital intervention initiatives.

In terms of programme implementation, practitioner peer support can promote long-term skill development (K. Turner & Sanders, 2006) and the sustainability of ASD early interventions in other low-resource contexts (Makombe et al., 2019). Practitioners in this programme recognised the benefits of seeking advice and wider support from peers. However, the lack of organisational resources may have led to their overdependence on peer support. Capacity building has been consistently shown by the literature as a key ingredient to implementation success, especially in terms of the delivery of complex interventions (Butler et al., 2020; Mytton et al., 2014). Therefore, it is of particular importance that implementing organisations provide adequate and ongoing supervision and training, especially given that the use of less qualified programme providers has been increasingly advocated to close service gaps in LMIC contexts (McCabe, 2012; Tomlinson et al., 2018). Other aspects of organisational support related to the need for a reduction in their workload and the improvement of practitioner mental health. Despite their dedication, practitioners in this study expressed that their quality of work was limited by intensive workload and stress. Although the stress may be alleviated by, for instance, organisational mental health support and rest breaks, fundamental solutions to reduce workload are needed at a state-level. National support has been suggested to address the problems in human resources, including investment in ASD-related professional training and incentivisation of service provision (K. Turner & Sanders, 2006; Yamey, 2012).

5.6.2. Limitations and strengths

The study has several limitations. First, there was a lack of male caregivers in the interviews, which impeded the investigation of their experiences and perceptions. Second, the

data were collected retrospectively, which might have introduced recall bias. Third, despite efforts to promoting generalisability, the research focused solely on one programme in China, and the results should as such be treated with caution. Fourth, the interviews and FGDs were conducted in Chinese. The report of findings involved translation between distinct cultures, which could have resulted in more bias (van Nes et al., 2010). To improve the validity, the data analysis was conducted in Chinese, involving two bilingual co-authors, who were born and raised in China. The English report was prepared by one bilingual co-author in discussion with the other, and further checked by co-authors who are native English speakers.

There are also a number of strengths of this study. First, this study was conducted within a routine service setting and involved participants who were more representative of a real-world population, thereby improving the generalisability of findings. Second, a number of steps were taken to improve the quality and trustworthiness of this research: the data was collected from both caregivers and facilitators to increase the diversity of perspectives; all interviews were conducted privately with research staff reassuring participants about confidentiality; conversations were audio-recorded and transcribed verbatim to capture all points made by the participants; and transcribed data were sent to participants for verification and additional inputs before data analysis was begun (Birt et al., 2016). To further improve credibility, the data analysis was conducted by another researcher checking 50% of the initial coding categories, participating in the development of the coding framework, and reviewing all codes and themes before they were finalised (Lincoln & Guba, 1986). The software ATLAS.ti was used to record the coding process and maintain dependability of the research (Liamputtong, 2013).

Furthermore, a reflexive approach was taken in order to address the possible influence of researchers' backgrounds and knowledge (Braun et al., 2019; Kuper et al., 2008). For instance, a theoretical framework was used to guide the research, and rapport was built with participants prior to the interviews and focus group discussions to reduce power differences and encourage disclosure.

5.6.3. Conclusion and implications

This study provides important insights on key stakeholder perceptions about a short-term intensive parent training programme for parents of children with ASD in a LMIC. A number of suggestions are provided for future parent training programmes for families of children with ASD. In terms of programme design, adequate opportunities for caregivers to practice and receive feedback, as well as a mixture of group and individualised support, are central to creating an overall positive and empowering experience. It is also recommended that support be extended beyond the duration of the programme to maintain programme effects. ASD knowledge and programme goals should be introduced at an early stage to increase the likelihood of collaborative relationships between practitioners and caregivers. More instructions on parent-child interaction may also promote parent-child relationships and parental engagement of targeted skills at home. Structured activities can be arranged separately for children, except when parents need to practice skills directly with children with the support of a practitioner. Resources should be shared to help caregivers navigate the service system and improve mental health. Other family members may also need to be briefly involved to strengthen family support. In addition, helping caregivers identify progress in children may

promote participant engagement. To improve the quality of programme delivery, more organisational resources—including adequate and ongoing supervision and training, and mental health support—should be provided to practitioners. Support at a national level is needed to address the human resource challenges. Lastly, creative solutions are needed to overcome technical barriers and to engage participants via online platforms. More research should be conducted to address these recommendations and assess their effectiveness using experimental designs, such as micro-trials (Howe et al., 2010) and factorial experiments (Collins et al., 2014).

5.7. Declaration of Interest

There is no conflict of interests.

5.8. Role of Funding Source

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CHAPTER 6. OVERALL DISCUSSION

6.1 Overview

The overall objective of this DPhil thesis was to investigate the effectiveness and the implementation of a parent training programme that was delivered to caregivers of children with Autism Spectrum Disorder (ASD) in China. This thesis used a mixed-methods approach to address the following research aims, resulting in three stand-alone papers:

1) Summarising the empirical evidence on the effectiveness of parent training programmes for caregivers of children with a broad range of developmental disabilities in promoting child behavioural and emotional adjustment and associated outcomes in mainland China (*DPhil Paper 1,* published in *Trauma, Violence, & Abuse*);
2) Assessing the effectiveness and implementation process of a short-term intensive parent training programme delivered in the context of routine service provision for caregivers of young children with ASD in China (*DPhil Paper 2, in submission*);
3) Understanding the experience and perceptions of caregivers and practitioners in terms of programme acceptability, participant engagement, and programme delivery in the short-term intensive parent training programme (*DPhil Paper 3, in submission*).

For this DPhil thesis, I first conducted a broad systematic review and meta-regression to synthesise the effectiveness of parent training programmes in reducing child behavioural and emotional problems and associated outcomes. The review involved a search of both English and Chinese databases and included a wider range of developmental disabilities (*Chapter 3 Paper 1*). A subset of studies focusing on ASD showed that parent training programmes for

caregivers of children with ASD in China may be effective in reducing child emotional and behavioural problems and improving the parent-child relationship. In the subgroup analyses, I found the following moderators of the effects on child emotional and behavioural problems: knowledge of child emotional and behavioural problems, skills to improve parental mental health, techniques to promote child empathy, and positive reinforcement, as well as longer duration, a combination of group and individual sessions, rapport building, ongoing communication, and delivery venue in hospitals or service agencies. Programmes identified in this review were generally brief, despite the fact that parent training programmes for ASD in China can be often delivered with a greater intensity (Clark et al., 2019; McCabe, 2012), which is similar to Western countries where there is also substantial heterogeneity in terms of programme length and session duration (Schultz et al., 2011). Moreover, there is an absence of evaluations of programmes delivered in the context of routine service provision.

I went on to evaluate a short-term intensive parent training programme with a long history of supporting caregivers of young children with ASD in China, using a mixed-methods design. Programme treatment effects were estimated with a difference-in-differences model with propensity score weighting to diminish selection and confounding bias. Results showed that the programme significantly reduced child externalising behaviours, increased parental knowledge, improved parental mental health, and decreased over-reactive parenting practices. The process evaluation conducted alongside the outcome assessment showed high levels of participant involvement, satisfaction, and implementation fidelity. Exploratory analyses suggested that poor baseline parental mental health was linked to lower programme engagement, and that

satisfaction and engagement rates were potentially linked to the treatment effects (*Chapter 4 Paper 2*). Qualitative data were collected sequentially from parents and practitioners to provide insights into the quantitative results and were analysed using a combination of data-driven and theory-driven approaches. Findings highlighted the need for substantial practice and feedback; a mixture of group experience and individualised coaching; structured activities for children and resources for family members; and organisational support for practitioners (*Chapter 5 Paper 3*).

In the following section, I synthesise findings from the thesis by integrating the quantitative and qualitative results from the three papers. The penultimate section discusses the limitations of the thesis and implications for future practice, policy, and research. This chapter ends with a summary of the dissemination activities conducted and planned thus far to promote research impact, as well as a plan for long-term follow-up assessments.

6.2 Overarching Findings

A unique advantage of mixed-methods research is the potential for synthesis and integration of quantitative and qualitative information to harness strengths that offset the weakness of each method (Creswell & Clark, 2018). While quantitative data provides a general understanding of programme effectiveness, qualitative information offers a detailed observation of the process. Taken together, the overarching findings from this thesis are centred around the following five topics: 1) delivery of short-term intensive parent training programmes for families of children with ASD; 2) provision of sustainable support, characterised by ongoing communication and a combination of group and individualised experience; 3) targeting and

assessing parental mental health; 4) building trusting practitioner-caregiver relationships and practitioner capacity; and 5) conducting real-world mixed-methods evaluations using robust designs to fill the evidence gap in low-resource settings.

6.2.1 Delivering short-term intensive parent training programmes for families of children with ASD

The systematic review (Chapter 3 Paper 1) identified 31 unique parent training programmes delivered for Chinese caregivers of children with developmental disabilities, of which 11 involved families of children with ASD. The meta-regression showed that the programmes for ASD had a larger effect (g = -1.47, 95% CI [-2.42, -0.52]; 9 studies, 627 participants) in reducing child emotional and behavioural problems than had been identified to date in existing reviews (Postorino et al., 2017; Skotarczak & Lee, 2015; Tellegen & Sanders, 2014), potentially due to the severe lack of other more routine services and thus more room for improvement. Of the trials that provided information about programme intensity, most had no more than ten sessions over less than six months. Despite the short duration, they commonly tried to cover a wide range of topics, such as child functional development, behaviour management techniques, parent-child interaction, parental self-regulation, massage, nutrition, and familial communication—resulting in brevity of each topic and limited support.

For decades, parent training has been used to modify the interaction patterns between caregivers and their typically developing children (Brookman-Frazee et al., 2006). However, the core deficits in children with ASD necessitate parent training with a more intensive and specified focus for this population. Specifically, the transactional intervention model proposed

by Karst and van Hecke (2012) suggests that ASD deficits are linked to difficulties in a number of child, parent, and family domains; and that impacts of the diagnosis on those domains can reciprocally affect the development of children with ASD. In accordance with the transactional intervention model, a widely cited systematic review found that parent training programmes for ASD are characterised by their comprehensiveness, multiple targeted outcome domains, and flexible structures, reflecting the complexity of working with families of children with ASD (Schultz et al., 2011).

The qualitative findings in Paper 3 showed that, because of the absence of services, educational opportunities, and government financial support, Chinese parents are often the primary instructor and advocator for their child with ASD. Furthermore, this reflects the findings of a study conducted more than ten years ago (McCabe, 2007), showing an extremely slow development of ASD service provision in China. A large survey involving more than 3800 Chinese families of children with ASD found that 85% of those caregivers emphasised the need for systematic and intensive parent training (Guo et al., 2014). The first parent training in China was provided by the SREIA NGO, which was the local collaborator of this DPhil project. The SREIA programme started in 1993 initially focusing on Applied Behaviour Analysis (ABA) and Discrete Trial Teaching. The programme has been expanded over the years to address multiple challenges and obstacles faced by families of children with ASD. The ongoing rise in ASD diagnosis and the increasing demand for parent training in China resulted in a growing number of organisations modelling their practice after the SREIA programme, with which they established the Heart Alliance, a National Autism Intervention Association in China (Clark et

al., 2019).

To build on existing evidence of parent training programmes in China, Paper 2 examined the effectiveness of the SREIA programme in the context of routine delivery. Corresponding to the moderator analysis in Paper 1, which found that programme with more sessions tend to have stronger treatment effects, Paper 2 showed that the short-term intensive parent training had a large effect in reducing child externalising problems (b = -2.71, 95%CI [-5.23, -0.18]), with an effect size equating to a Cohen's d of -2.80 and being substantially larger than the pooled effects of the brief programmes identified in Paper 1 (Chapter 3 section 3.5.5). It also had high rates of participant involvement and satisfaction, thereby supporting the delivery of short-term intensive parent training programmes in Chinese contexts.

The systematic review (Paper 1) and the evaluation (Paper 2) both found a considerably larger effect size in parent training programmes for children with ASD than other existing studies, which synthesised trials conducted primarily in high-income countries and yielded effect sizes ranging from SMD=-0.39 to -0.59 (Postorino et al., 2017; Skotarczak & Lee, 2015; Tellegen & Sanders, 2013). The reasons can be three-fold. First, the data collection relied on caregiver report, which might have been biased due to social desirability (Fisher, 1993). Participants might have been trying to please the researchers and the practitioners by providing more 'acceptable' answers. They might also have viewed the interviews as tests and believed that 'poor' performance would jeopardise their receipt of future services, although they were repeatedly reassured that all information was anonymised and confidential. The social desirability bias might have also been increased by the presence of data collectors. In spite of

this, we decided to administer the questionnaires by data collectors reading out the questions rather than having participants read on their own, because we anticipated a great diversity in the education levels and there was a need to reduce error variances in the measures and increase statistical power, especially given the small sample size (Zimmerman & Williams, 1986). Second, the wider evidence shows that parent training programs typically have a greater impact for families living in low-resource settings and who have an urgent need to address child behavior problems (Gardner et al., 2015; Leijten et al., 2013). As was discussed at the beginning of this section, the Chinese context is characterised by a severe lack of ASD-related resources, and caregivers were in desperate need of evidence-based techniques with which to tackle some of the problems being experienced by their children, which could have increased the effect sizes. Third, children with ASD demonstrate more behavior problems than children without ASD or with other developmental disabilities (Totsika et al., 2011), and the wider research suggests that programs targeting families of children with existing behavior problems have stronger effects than universal or selective programs (Leijten et al., 2019). While the severity of the problems in children involved in this study may also be reflected by caregivers' determination to participate in the program amidst all the challenges caused by COVID19, this might also have introduced a potential selection bias, in terms of making the sample less representative, which will be further discussed in section 6.3.3.

Paper 3 provided a more in-depth understanding of these results through in-depth interviews and focus group discussions with key stakeholders, which identified a number of key aspects in terms of the delivery of the programme, including: the importance of teaching

knowledge of ASD and child developmental at an early stage; sharing extra ASD-related information; providing hands-on coaching; offering structured activities for children; and setting clear and targeted goals with caregivers.

Opportunities to learn about ASD was identified among this group of parents as being among the top parental support needs (Hartley & Schultz, 2015). Consistent with previous research in China (McCabe, 2007), caregivers who took part in the in-depth interviews described in Paper 3 commonly referred to the lack of information and knowledge about the diagnosis prior to the programme, which may have resulted in an increased capacity for change. This was also reflected in the results of Paper 2, which found that parental knowledge about ASD and its implications was significantly increased in both versions of delivery upon the completion of programme. Attribution theory posits that one's assignment of the causes of behaviours influences one's reaction to the person exhibiting the behaviours (Weiner, 1993). Providing support to the attribution model, practitioners in the focus group discussions perceived that an improved understanding about child conditions increased the use of positive parenting practices, by changing parental attitudes and promoting parental acceptance. This is also consistent with findings in Paper 1 which suggested that teaching knowledge about child behaviours can potentially enhance treatment effects.

Moreover, as McCabe (2012) described, while profit-driven ASD treatments with little evidence to support their use rapidly increased in China like 'bamboo shoots after the spring rain (*yuhou chunsun*),' parents in general received little advice on how to select an intervention to address the problems they were facing. They chose those with 'hardware' that looked the

'most advanced' and blamed themselves for not doing enough if they had not tried everything of which they were cognizant. As such, delivering ASD-related knowledge and promoting parental understanding about their child's needs was believed to be of particular importance in terms of guiding future decision-making (Paper 3 section 5.5.2.1b). This also speaks to the need to receive extra ASD-related information, especially because the lack of a reliable information source and a sense of "not knowing where to go" were repeatedly referenced by the caregivers in Paper 3. Indeed, sharing extra resources, such as information about other treatments and social stories, is often regarded by caregivers of children with ASD as being an essential component in training programmes also in developed countries (Dababnah & Parish, 2016; K. Whittingham et al., 2006).

Paper 3 showed that practitioner modelling and in-session practice were perceived by both caregivers and practitioners to play a key role in promoting participant engagement and improving parental self-efficacy. Other parent training programmes with high levels of intensity, such as the GIFT programme in the U.S. (Anan et al., 2008), similarly highlight the benefits of hands-on application and in-vivo practice of techniques to increase the parent's understanding of the skills and their ability to apply them at home. In addition, Paper 1 provided some evidence that improving child social skills was a key component in parent training programmes aiming to reduce behavioural problems. While this component was absent in the SREIA programme; caregivers in Paper 3 believed that adding structured activities for children to develop social skills could have augmented the child and parental outcomes. Indeed, some quantitative studies show that improved child social abilities are associated with less disruptive

behaviours (Carter Leno et al., 2019; J. L. Matson et al., 2010; G. H. Murphy et al., 2005) and better parental mental health (Pastor-Cerezuela et al., 2016). At the same time, the interviewees in Paper 3 highlighted a potential logistical challenge when including children in sessions. They suggested that while the presence of the child provides opportunities for caregivers to practice, it may become a source of distraction when there is no in vivo application of skills. Providing structured activities for children could have enabled caregivers to be more engaged in didactic teaching sessions, thereby promoting treatment effects. Although arranging separate activities for children can be beneficial, this has cost implications and may reduce the scalability of programmes. Nonetheless, having children present in sessions is a common and valuable delivery method in parent training programmes for ASD. The review by Schultz, Schmidt, and Stichter (2011) found that four fifths of existing parent training programmes for ASD were delivered with children present, irrespective of the programme intensity. As such, it is important to strike a balance between having sessions attended by parent-child dyads and offering structured activities for children when they are not involved in in vivo modelling and practice.

The desires of caregivers and practitioners to learn or provide more information and techniques may compromise the quality of interventions (McCabe, 2012). Due to a lack of services and educational resources, caregivers of children with ASD in China often become the child's primary teacher (Clark et al., 2019). This is difficult for caregivers. Expecting them to acquire a large number of techniques within a short period of time may further exacerbate already high levels of stress. Similarly, delivering multiple topics over an intensive period may increase pressure on practitioners, which was perceived to negatively affect their mental health

and undermine the quality of services (Paper 3). On the other hand, caregivers commonly described their sense of urgency to provide treatments for their child while the child was still young, as well as a feeling of anxiety when they thought they were not doing enough. Practitioners were also committed to better equipping caregivers for future challenges. Covering a variety of topics was thus reassuring for both groups of stakeholders. To avoid overwhelming caregivers while satisfying their needs for more techniques, the practitioners proposed to repeatedly remind caregivers of how the programme objectives may relate to their personal goals, so that caregivers can focus on identifying strategies that are most helpful for their contexts. Stress reduction for practitioners is another important aspect, which will be discussed later in section 6.2.4.

6.2.2 Providing sustainable support characterised by ongoing communication and a combination of group, individualised, and family support

The findings from the three DPhil papers highlighted key factors that are important to the development of sustainable support for caregivers, including the need to combine peer support, individualised mentoring, and familial collaboration; and the need for the support to be extended beyond the duration of the programme.

Although a previous review of parent training programmes for caregivers of ASD found that less than 20% of existing interventions use both group and individual sessions (Schultz et al., 2011), findings from Paper 1 and Paper 3 of this thesis point to the advantages of offering a mixture of group and individualised support in a Chinese context. Meta-regressions in Paper 1 suggest that programmes combining group and one-on-one delivery were more likely to have

better treatment effects for Chinese families of children with developmental disabilities in general, compared to those using solely individual sessions or group sessions. This finding is consistent with the results of a previous meta-analysis of parent training programmes for developmental disabilities in HICs, which showed that the treatment effect was statistically significant only when there was a mixture of group and individual sessions (Skotarczak & Lee, 2015).

Paper 3 further illustrated potential advantages for mixed delivery by identifying the different benefits of group and individualised support, respectively. The group experience for caregivers of children with disabilities was valuable in terms of improving parental mental health and their efficacy in coping with disability-related parenting challenges (Bray et al., 2017). Such parent-to-parent support, formal or informal, has been considered especially important in China, where children with ASD are often turned away from schools and seldom supported by social welfare services (Guo et al., 2014; M. Lu et al., 2015; McCabe, 2008). Paper 3 also found that caregivers felt that the support from peers provided encouragement and nurtured their acceptance, a finding that is consistent with McCabe (2008). Caregivers in this study further described that the parent groups provided an inclusive environment, where they experienced being treated equally and empowered, which may have reduced negative feelings arising from social stigma and self-blaming (Mak & Kwok, 2010). This again supports the attribution model of Mak and Kwok (2010), which posits a link between support from friends and better parental psychological wellbeing in parents of children with ASD. Existing research shows that peer support can also promote parental self-efficacy; being with other caregivers

who have similar experiences allows them to learn from each other (McCabe, 2008) and deal with daily stressors (Dunn et al., 2001). Caregivers in this study viewed peer support as being helpful in enhancing the learning process because they were able to discuss problem-solving strategies and identify areas in need of improvement. Practitioners in this programme also believed that the parent-to-parent support facilitated caregiver learning as the supportive peer relationships contributed to their engagement in sessions. Future evaluation studies may be conducted to assess peer support as a mechanism of change in parental self-efficacy.

Ecocultural theory, built upon the ecological theory and family systems theory, has been widely used to examine the relationships between the development of children with developmental disabilities and their family (Bernheimer et al., 1990; Weisner, 2002). It postulates that family practices are shaped by cultural and familial characteristics, and then in turn affect the developmental status of children with disabilities. Informed by ecocultural theory, treatments for children with developmental disabilities may benefit from being contextually accommodated into the daily routines of the family so that they can be maintained over time (Brookman-Frazee, 2004). Following this idea, as well as due to the complex nature of ASD, the majority of parent training programmes for ASD use a one-to-one format to individualise the treatment (Schultz et al., 2011). The benefits of this are corroborated by the findings of this thesis. Paper 1 found potential harm associated with not tailoring positive reinforcement techniques to the child's characteristics and contexts. The quantitative exploratory investigation of version differences in Paper 2 also suggested that the version with a smaller group size—where there was greater chance to provide targeted support—had a larger effect in reducing

child externalising behaviours than the alternative version with larger parent groups (b = -3.77, 95%CI [-6.26, -1.28]; d = -4.26, section 4.4.1). Paper 3 further unravels the mechanisms of change, suggesting that the inbuilt programme flexibility and caregiver-practitioner communication allowed practitioners to tailor the advice and address individualised difficulties in each family. The personalised mentoring was perceived to enable caregivers to develop their own problem-solving strategies, thereby creating a sense of controllability over daily challenges and increasing the possibility of the consistent application of skills (Brookman-Frazee, 2004; Mak & Kwok, 2010).

Moreover, overall findings from the thesis suggest that there is a need for both types of support to be sustained beyond the duration of the programme. A previous systematic review including trials conducted in HICs showed that parenting programmes for parents of children with developmental disabilities that had more sessions, sometimes produced stronger effects in terms of reducing child externalising and internalising problems (Tellegen & Sanders, 2013). Likewise, the meta-regression analyses in Paper 1 found that ongoing communication between programme deliverers and participants tended to produce better child outcomes, whereas shorter programmes appeared to aggravate child problems. A recent systematic review showed evidence of sleeper effects in some parenting programmes aimed at reducing disruptive behaviours in typically developing children, as caregivers need more time to better implement the skills and children may initially show resistance to new parenting practices (van Aar et al., 2017). Ongoing communication can, however, provide caregivers with opportunities to troubleshoot problems in terms of the application of learned techniques and facilitate the

materialisation of intervention effects. For instance, the caregivers in Paper 3 described how the practitioners actively responded to their queries and concerns whether during or outside the sessions, which was perceived to substantially increase their understanding and use of skills. This responsiveness and efficient communication extending beyond the duration of the main programme, may have contributed to the large treatment effects detected immediately post-intervention (b = -2.71, 95%CI [-5.23, -0.18]; d = -2.80, section 4.4.1). Programmes with fewer sessions, however, are less likely to provide sufficient time for practitioners and caregivers to build such sustainable partnerships or communicate concerns, potentially leading to caregiver frustration and causing temporary exacerbation of existing behavioural problems (Chapter 3 section 3.5.7).

It may also be necessary for the support to be extended after the completion of programme to avoid fade-out, especially when there is a general shortage of local ASD resources. Fade-out effects have been found in some trials whereby reductions in behaviour problems in children without ASD were no longer significant at follow-up assessments, compared to immediate post-intervention (Lachman et al., n.d.; van Aar et al., 2017). Paper 3 found that the caregivers who participated in the SREIA programme were similarly worried about losing their ability to apply the techniques following completion of the programme. Some respondents voiced the concern of feeling isolated after the programme, demonstrating the need for continuous peer support and practitioner follow-ups. Family members could potentially be a source of support post-programme. However, caregivers in Paper 3 also commonly identified barriers within the family, whereby other family members showed little understanding of the diagnosis or

motivation to try new techniques, thereby resulting in inconsistent parenting attitudes and practices at home (section 5.5.4.2a). This concern is validated by Paper 2 that found no treatment effect on family function (b = -0.08, 95%CI [-0.88, 0.71]; d = -0.28, section 4.4.1), which may be due to the short scale that was used, not being sensitive enough to capture pre-post differences, but also may have indicated the lack of significant changes in other family members after the programme. Hence, to create a support system that can be sustained beyond the programme, it is critical to also involve family members, for instance, by providing brief and remote sessions for partners and grandparents, as suggested by Paper 3 (section 5.5.6.1).

In sum, in low-resource settings, it can be helpful for parent training programmes to create support that is sustainable and not limited to the duration of the programme. Group experience, individualised coaching, and family support may be of equal importance in terms of promoting better outcomes in multiple domains. There may also be benefits of continuing these outside the sessions and after the completion of programme to maintain and boost treatment effects.

6.2.3 Targeting and assessing parental mental health

Mental health support stood out in this thesis as being one of the most urgent needs in caregivers (Chapter 5 section 5.5.6.1). Due to high levels of care demands and behavioural problems, ASD has historically been associated with more mental health concerns in caregivers than children with other developmental disabilities and children without disabilities (Richard P. Hastings, 2003; Lecavalier et al., 2006; McStay et al., 2014; Tomanik et al., 2004). For instance, a study using a UK representative sample (N=18,415) found that, compared to children with Intellectual Disability and those with typical developmental trajectories, emotional and

behavioural concerns were the most prevalent in children with ASD, and that the presence of ASD was significantly related to more maternal emotional disorders (Totsika et al., 2011). Studies in China has also found heightened levels of parental stress in caregivers of children with ASD (M. H. Lu et al., 2018), with the main stressors often being child behaviours exhibited in public space (M. Huang & Zhou, 2016) and the internalisation of social stigma (K. K. S. Chan & Lam, 2018). Raising a child with ASD is a stressful experience in any country, but the long-held negative attitudes towards disabilities and the strict requirements on conforming to social norms in China may have put extra pressure on these parents (Fong & Hung, 2002; M. Huang & Zhou, 2016). For example, a large survey conducted in multiple areas in China showed that, among 3867 caregivers of children with ASD, 81.5% asked for formal mental health counselling (Guo et al., 2014).

Parent training programmes targeting child behavioural problems have often been shown to reduce parental mental health concerns (Schultz et al., 2011; Tellegen & Sanders, 2013). For example, a randomised controlled trial (N=105) assessing the impact of a parent education and behaviour management intervention for preschool children with ASD found long-term effects on parental anxiety, depression, and somatic symptoms ((F = 2.97, p = .007)) (Tonge et al., 2006). This thesis also identified the potential benefit of promoting parental mental health in a Chinese context. The systematic review (Chapter 3 Paper 1) found one study assessing the treatment effect on parental adjustment for parents of children with ASD, which detected a small effect size in reducing parental stress (g = -0.34, 95% CI [-1.11, 0.42]; 1 study, 27 participants), although the study was rated at high risk of bias across several methodological

domains. The evaluation of the SREIA programme (Chapter 4 Paper 2) also found a significant group difference in terms of reducing parental stress, anxiety, and depression (*b* = -5.96, 95%CI [-11.74, -0.17]; *d* = -2.89, section 4.4.1). Notably, Version B of delivery, which had a smaller group sizes within sessions, produced an even larger effect size in parental mental health (*b* = -12.52, 95%CI [-19.87, -5.18]; *d* = -4.79, section 4.4.1) than the overall programme, potentially again pointing to the benefits of individualised mentoring, small group processes, and strong peer group cohesion. In line with the quantitative results, most caregivers in the qualitative interviews perceived that their mental state and emotional wellbeing substantially improved during the programme. This was further explained by practitioners who viewed improvements in understanding the implications of their children's diagnosis as a fundamental mechanism for improved caregiver mental health.

In addition, findings from this thesis also indicate that the association between child behaviours and parental mental health was not unidirectional. This is consistent with the transactional model, which posits that child development, including child externalising behaviours, is shaped by the ongoing reciprocal interactions between the child and the environment (Belsky, 1984; Gross et al., 2008; Sameroff, 2009; X. Zhang et al., 2008). Consistent with the theory, the research using a large UK representative sample (N=18,415) shows that parental stress is both a result and a predictor of child behavioural problems (Totsika et al., 2011) and such transactional association is similar across children with and without developmental disabilities (Neece & Green, 2014). This thesis found relevance of the transactional model in Chinese contexts. Subgroup analyses in Paper 1 showed that

programmes containing components aimed to reduce parental stress were more likely to reduce child emotional and behavioural problems. While Paper 2 did not formally investigate the covariance between parental health and child externalising behaviours, an exploration of the implementation process showed in two separate multivariate models that better mental health was associated with higher engagement rates, and that higher levels of engagement was linked to fewer externalising problems post intervention. These results suggest that reducing parental mental health symptoms may promote participant engagement, which has the potential to improve child behavioural adjustment.

Although less straightforward, findings in Paper 3 similarly demonstrated associations between improved parental mental health and child behaviours. Caregivers believed that the better mental health contributed to the use of more positive parenting practices and less violent discipline, which then increased child compliance and reduced behavioural problems. Previous quantitative research in the general population has also demonstrated that less parenting stress was linked to more positive parenting (Respler-Herman et al., 2012) and that nonviolent discipline techniques were key to the reduction of child disruptive behaviours (Leijten et al., 2019). Practitioners further viewed this as a virtuous circle with multi-dimensional benefits, describing the way in which the improvements in child behaviours and parental emotional wellbeing would be conducive to a better family environment, which would in turn promote child and parental outcomes—a finding that is also congruent with the transactional theory of child development (Sameroff, 2009).

It is noteworthy that, although the quantitative and qualitative findings all provide some

evidence of better mental health at post-intervention, caregivers in the in-depth interviews commonly highlighted the need for more formal mental health services during or after the programme (Chapter 5 section 5.5.6.1). This might be related to their poor mental health status at baseline (Chapter 5 section 5.5.1) and reflected their concern about the fade-out of programme effects after returning home. As such, integrating the development of a sustainable multi-source support system into parent training programmes for ASD may be necessary, not only because it may support better child behavioural adjustment, but also in that it may be critical for the preservation of good mental health for Chinese caregivers.

To sum up, short-term intensive parent training programmes for caregivers of children with ASD in China may be a promising approach to improving parental mental health, and better mental health may contribute to higher levels of programme engagement. More robust moderator and mediator analyses are suggested to investigate the direct relationships between parental mental health and programme effects. Sustaining programme effects in terms of children's behaviour in the long term may also be better achieved by maintaining the positive treatment effect on caregiver mental health.

6.2.4 Building trusting practitioner-caregiver relationships and practitioner capacity

Building trust is considered to be a critical element in establishing constructive partnerships between caregivers of children with disabilities and professionals (Angell et al., 2009; Soodak & Erwin, 2000). The level of trust may be influenced by openness and competence (Blue-Banning et al., 2004; Tschannen-Moran & Hoy, 2000). Paper 3 found that previous service experiences of caregivers in the SREIA programme were characterised by

unhelpful intervention processes and limited treatment benefits, which may also have contributed to reduced parental confidence in service providers. As such, restoring trust and establishing a closer and more harmonious practitioner-caregiver relationship may be an essential part of the successful delivery of parent training programmes in Chinese settings. For example, Paper 1 indicated that 1) programmes having activities to build rapport with caregivers tended to be more effective in promoting child emotional and behavioural adjustment; and 2) programmes delivered in an institutional setting, such as a hospital, also had a larger pooled effect size than those delivered in local service agencies; as was identified in previous chapters, hospital staff were often the first source of information for caregivers of children with ASD in China (Chapter 5 section 5.5.1) and people working in institutional settings (irrespective of qualification) are thought to be the most knowledgeable about the diagnosis (Chapter 3 section 3.6.2), thereby being perceived by caregivers as having authority and being trustworthy. The trust in hospital staff may also have implications for scale-up and replication of parent training programmes for ASD in China.

As with the literature in the field of special education (Blue-Banning et al., 2004; Stoner & Angell, 2006), practitioners in Paper 3 pointed out that caregivers who doubt practitioners' level of skills and knowledge would be less likely to show trust or adhere to the programme, and that a trusting relationship with caregivers could be built by demonstrating competence, especially via the in vivo modelling of strategies. For example, caregivers in the SREIA programme showed admiration for practitioners who successfully applied techniques with their child during sessions, complimenting them as having 'magic powers' (Chapter 5 section

5.5.3.2a). Despite many positive comments from caregivers, the SREIA practitioners believed that their abilities to teach skills and build trust were still inadequate because their competence was substantially limited by the lack of capacity building and the general high levels of stress. This corresponds to a finding in Paper 2—although treatment effects were large in multiple outcome domains and programme satisfaction scores were generally high, the observed quality of delivery was rated as medium on average (section 4.4.2). Future research would benefit from further exploration of the relationship between quality of delivery and practitioner-parent trust.

This thesis found promising results in terms of the use of programme providers without clinical qualifications. Paper 1 showed similar treatment effects across programmes using practitioners with and without clinical qualifications, and the backgrounds of SREIA practitioners were also diverse, with none of them having healthcare-related degrees (Chapter 2 section 2.4.3.2). However, the use of less qualified staff further necessitates adequate training and supervision. Triple P programmes reported that high quality training increased practitioner skills and confidence, and has been one of the major facilitators of programme implementation and take-up (Shapiro et al., 2012). Also, training is considered to minimise programme drift (K. Turner & Sanders, 2006). The SREIA practitioners suggest that the training be standardised to ensure that the learning and subsequent deliver experience is the same for new practitioners. Moreover, to increase and maintain the quality of delivery, the training needs to be comprehensive, covering three main domains (Chapter 5 section 5.5.6.3): programme content (such as knowledge about ABA techniques), methods of delivering the content (such as modelling positive reinforcement), and general skills to conduct effective group sessions (such

as communication skills, collaborative relationship building, reflective listening, empathy, and problem-solving) (Tomlinson et al., 2018).

Findings from this study also emphasises the importance of post-training capacity building, including peer support and formal supervision. Parent group leaders in Incredible Years programmes receive regular peer review sessions to share successful experiences and obtain support in finding alternative strategies for difficult cases (Webster-Stratton & Taylor, 1998). Videotapes of sessions are also reviewed in the peer meetings to facilitate reflection and discussion. Such sessions are perceived by practitioners to maintain group leader optimism for families lacking apparent success (Webster-Stratton & Taylor, 1998). In addition, Triple P established peer support networks for new practitioners to interact and prepare for accreditation, which was perceived to have a long term positive impact on preventing programme drift and continuous skill development (K. Turner & Sanders, 2006). Paper 3 also found that peer support was key to the delivery of the SREIA programme, where practitioners helped each other by offering moral encouragement and discussing difficult cases.

Ongoing supervision is another aspect of post-training capacity building. Research suggests that regular supervision promotes the use of training content and maintains programme fidelity (Durlak & DuPre, 2008). However, the provision of formal supervision is often hampered by high workload and inadequacy in supervisors tasked with providing coaching and mentoring (Bond et al., 2001; Kavanagh et al., 2003). According to the SREIA practitioners, the organisation had only two senior coaches who oversaw the delivery, trained new facilitators, and provided one-on-one consultations for all participating families. The intense workload may

have inhibited them from offering advice to practitioners as part of a formal and regular approach, which may have been one of the reasons that practitioners relied more on informal peer support and may also have contributed to reduced self-efficacy in practitioners. The SREIA practitioners highlighted the importance of arranging formal supervision sessions, which would require implementing organisations to provide the infrastructure necessary for timely coaching and mentoring (Fixsen et al., 2005). However, this remains challenging due to human and financial resource limitations.

Supervisory support has also been shown to be related to the reduction of stress of practitioners (J. A. Gibson et al., 2009). High work demands and stress were perceived as another major barrier to the delivery of the SREIA programme (Chapter 5 section 5.5.5.2c), which is consistent with previous research indicating that staff supporting families of children with disabilities are generally exposed to more workplace stress caused by a lack of organisational resources, especially inadequate personnel (Skirrow & Hatton, 2007; White et al., 2006). Practitioners in this study also described the risk of experiencing vicarious trauma due to empathising with families who had been experiencing multiple adversities. The high rates of stress can lead to low levels of job satisfaction, productivity, service quality, and retention (Maslach et al., 2001; Shanafelt et al., 2002). High level of stress also pose risks for physical and mental health (Melamed et al., 2006; Whittington & Burns, 2005). Social exchange theory proposes that staff often conduct subjective cost-benefit analysis in the workplace and that perceived organisational support encourages staff to cope with daily stressors (Eisenberger et al., 1986). This theory may explain why research has demonstrated

that supervisory support moderates the relationship between intensive workload and stress for ABA therapists for young children with ASD (J. A. Gibson et al., 2009), which constitutes another reason for providing practitioners with coaching and mentoring opportunities in parent training programmes for children with ASD.

In conclusion, trusting practitioner-caregiver partnerships are important in parent training programmes for caregivers of children with ASD in China. The development of such relationships necessitates adequate practitioner capacity building, which consists of two critical components: a) entry training and b) post-training supervisory and peer support. The capacity building process may increase practitioner competence and reduce practitioner stress, thereby having the potential to improve the quality of delivery and treatment effects.

6.2.5 Conducting real-world mixed-methods evaluations using robust designs to meet the evidence gap in low-resource settings

Evaluating ASD treatments using randomised controlled trials is widely recognised to be the gold standard for studying intervention efficacy (Tristram Smith et al., 2007). However, the randomisation process can often be impeded by practical (e.g., when the availability of end users must be considered) and ethical (e.g., delaying treatments for patients with acute needs) considerations (Blunt, 2015). Randomised trials may also apply strict recruitment criteria for participants and a rigid adherence to intervention protocols that may differ from usual clinical practice, thereby undermining external validity and generalisability of the results in terms of which practices can produce the best effects when carried out in different settings (D. Campbell & Stanley, 1963). While randomised controlled trials continue to be the ‘gold standard’ for

making causal inferences, other designs have also been used to increase the knowledge. For example, an overview of parent training programmes for caregivers of children with ASD showed that, due to the high heterogeneity among children with ASD and difficulty in finding comparable groups, over 70% of the evaluations adopted a single-subject research design (SSRD) to identify clinically relevant factors and mechanisms of change (Schultz et al., 2011).

Flay et al. (2005) suggest that effective interventions should be tested in real-world conditions to inform the application in routine practice. Real-world evaluations have the advantages of requiring less resource than randomised trials and including the full range of participants and service patterns in clinical settings (Camm & Fox, 2018). This may be of particular relevance in places where there is a scarcity of resources and substantial unmet needs (Yamey, 2012). For instance, with the rapidly increasing diagnosis of ASD, the number of ASD service agencies continues to grow in China (Clark et al., 2019). However, due to limited access to evidence that is often reported in foreign languages and little collaboration with research institutes, service provision is often perceived to be trial and error (i.e., “feeling stones to cross the river”) (McCabe, 2012), whereby evidence-based techniques may be adapted based on practitioner experiences. This suggests the need to increase their capacity to conduct rigorous evaluations and apply scientific evidence to guide practice.

This thesis shows the possibility of embedding a real-world evaluation into routine service provision by involving service providers throughout the research process, using existing resources, and adopting a robust mixed-methods research design. The following sections will discuss the partnership with the local implementing agency, the feasibility of minimising

sources of bias, and the benefits of conducting mixed-methods research.

6.1.1.1. A collaborative approach

In contrast with traditional research approaches in which researchers are in full charge of the process, community-involved research, or community participatory research, aims to establish more equitable partnerships between researchers and stakeholders, and to promote a co-learning process in which partners share their expertise and collaboratively contribute to the understanding of a phenomenon (Israel et al., 2008). The intentional engagement of stakeholders allows for a combination of knowledge and action, which increases the likelihood of translating research findings into future practice (Banks et al., 2013). The conduct of this thesis was underpinned by a recognition that the evaluation of the SREIA programme should be responsive to local needs and create mutual benefits for all partners. It also sought to implement the research using existing resources, especially given the lack of additional funding. As a result, the research process actively engaged the implementing organisation in all aspects of the research process, except data analysis, which was not possible due to the project being a DPhil thesis.

During the first stage, the roles of each partner were defined and a contract was signed (Rosenthal et al., 2014). Orientation was conducted for programme managers and practitioners and also involved the director of the organisation, which might have increased staff commitment to the research (Couzos et al., 2005). Capacity was provided by both partners: the implementing organisation provided me with substantial programme materials and invited me to sit in online sessions prior to the start of the evaluation; I conducted several brief trainings

to introduce topics such as implementation and research, evaluation process, and research designs (Couzos et al., 2005), highlighting the value of their contribution to the study, instead of just providing access to participants (Hicks et al., 2012). An open and respectful communication style was initiated by actively involving programme managers in the development of the research proposal (Wallerstein & Duran, 2010). For example, we explored the possibility of adopting of different research methods. A randomised controlled trial was initially considered, but a detailed discussion with the recruitment staff identified multiple ethical and practical that prevented this, including the fact that as a result of the high programme intensity, it was impossible to require caregivers to attend for 11 consecutive weeks without considering their own preferences, and we were not able to incentivise the attendance due to the lack of funding. In addition, the programme had a long waitlist, and it may have been unethical to further prolong the waiting time, especially given the caregivers' concern about missing the 'critical period' for early intervention. Nonetheless, we were able to reach a consensus on the importance of a comparison group and discussed the feasibility and implications of different types of control group (e.g., a control group from the SREIA waitlist or from other ASD service agencies).

At the planning stage, stakeholder buy-in was further promoted by inviting programme managers to create a programme logic model and define research questions (Riffin et al., 2016). Tools were also developed in partnerships with the organisation. For example, the tool measuring ASD knowledge was designed based on an existing questionnaire used by the organisation; the quality of delivery survey was reviewed by programme managers to increase

contextual relevance; the translation of English scales was completed by the organisation identifying caregiver volunteers (one of them being the recruitment manager who was also a mother of a child with ASD) to participate in the piloting of tools (World Health Organization, 2020). As a result of these efforts, the participating organisation may have gained a sense of autonomy and ownership, which thereby led to a high level of adherence to the research protocol during the evaluation. For example, two staff were assigned to recruit families and coordinate meetings between researchers and potential participants, resulting in a sample size larger than anticipated *(N* = 111 instead of the originally planned sample size of 100 participants). Data collection was supported by the organisation repeatedly reminding participants of the interview appointments and reimbursing research assistants, who were recruited from the social work training programme headed by the local research collaborator for this project. Participants in the qualitative interviews were also approached by the programme deliverers, who had a stronger rapport with participating caregivers.

Across all stages, an open and flexible communication style was maintained (Wallerstein & Duran, 2010). Feedback was regularly obtained from programme stakeholders to ensure that the research activities fit well with the routine service delivery (Rosenthal et al., 2014). For instance, the paper-based attendance and engagement checklist was converted into an online survey, so that practitioners were able to spend more time with caregivers when they were at the venue instead of on paperwork. To further enhance partnerships, successes were celebrated at each stage of the research process (Rosenthal et al., 2014); for example, at the end of the programme and the completion of each data collection. Moving forward, a discussion will be

held with the organisation to further interpret the research findings and assist them in deciding how the research findings can be translated into practice (Balcazar et al., 2009). They have also taken the lead in disseminating findings in Chinese ASD-communities using their social media accounts and via the Heart Alliance Association. Sustained collaboration between the organisation and the research team after the study has also been planned (Michener et al., 2012). For example, routine data will continue to be collected. An SREIA staff will be trained on data analysis, with a beginner-friendly data analysis template that has been created using Microsoft Excel®. Funding proposals for future research and policy recommendations are being incubated with the organisation director.

However, this collaborative process also had several limitations. First, it did not engage family beneficiaries in the research process—although consultations were conducted with one of the programme managers who was also a mother and primary caregiver of a child with ASD –thereby precluding the possibility of including caregiver perspectives into the research design. Also, practitioners could have been more involved during the initial stages of the study; instead, communications with practitioners during the early stage were mostly coordinated by a programme manager, which may have led to some resistance from practitioners to research activities. To establish a closer relationship with the practitioners, I actively initiated interactions as soon as they consented to my having access to them. It still took a few weeks after the baseline assessment for the practitioners to show acceptance of the research activities and to share ideas, such as proposing to investigate the relationships between parental mental health and programme engagement and outcome, although that was already covered in the

research plan. Second, the participatory approach created an extra burden for programme managers and deliverers (Riffin et al., 2016). Paper 3 showed that the practitioners had high levels of workload and stress. The closer partnership may have further increased their workload and the potential for burnout (Dodson et al., 2007).

Third, the boundaries between researcher and study participants were at times not clear to the study researchers (Horn et al., 2008). This can particularly affect the collection and analysis of qualitative data, which may be shaped by the researcher background and experience (Braun et al., 2019), although the potential for bias was reduced in this case by the use of a theory-based coding framework and a reflexive approach during the interpretation of results (Chapter 5 section 5.6.2). Fourth, the capacity building in programme and research aspects was still inadequate for both partners. For instance, I remained unaware until the start of evaluation that, as part of their routine monitoring, the Autism Treatment Evaluation Checklist (ATEC, one of the secondary outcome measures in this study) was reported also by practitioners for each child during the last week of the programme. If programme managers had been aware of the important differences between self-report and observational data in terms of the risk of bias, it might have been possible for me to collect practitioner-reported ATEC data at both time points as an alternative to parent-report data, which may have reduced reporting bias. However, requesting practitioner reports would have further increased their workload and created an extra burden.

6.1.1.2. Improving scientific rigor

Paper 2 of this thesis improved the scientific rigor of the real-world evaluation in several

ways. Trial results are often biased if only a portion of the target population join the research (Glennerster, 2017). The evaluation study achieved a high enrolment rate with the involvement of the implementing organisation and an open communication between potential participants and the research team. Over eighty percent of families that we initially identified from the programme waitlist provided consent to take part in the research. The enrolment rate was higher in the treatment group (93%) than the control group (69%), potentially because some families in the control group were uncertain about their future participation in the programme and perceived the research as irrelevant to themselves, whereas those in the treatment group had already registered in the programme and may have been concerned about the negative impact of not participating in the research, despite reassurances to the contrary; for all participants, informed consent procedures aimed to reassure potential participants that there would be no consequences should they decide not to contribute to the research and that they had the right to drop out at any stage.

To ensure the rigour of research conclusions, issues of attrition and missing data need to be addressed (Glennerster, 2017). Paper 2 involved the implementation of several steps to minimise dropouts and missing data. It maintained a flexible and open conversation with the participants. The purpose of the research was explained to all participants, who were also encouraged to contact me at any time via phone call or a messaging app for any research-related concerns. All data collection interviews were set up primarily based on participant preferences and avoiding conflicts with their daily activities. The appointments were thus scheduled as early as 7:00 in the morning to 11:30 at night within a two-week timeframe. Two personalised formal

reminders were sent to each participant by data collectors one day and one hour prior to the interview. Practitioners, who maintained good relationships with participants, advocated for the research again during the last session, thereby increasing the participant response rates. The implementing organisation also provided tracking data at baseline for me to individually reach out to families who had not responded to data collectors at the scheduled time. The interviews were conducted online and economically, using easily accessed Wi-Fi and cellphone data. Participants were reimbursed for any data or airtime costs for participating in interviews conducted online or via phone calls, as well as for the completion of data collection at both time points. All data collectors were post-graduate students in Social Work, who had been trained in counselling skills, such as attending, reflection, and clarifying, to establish rapport and increase participant adherence to the research activities (Jacob & Furgerson, 2012). Adequate data collectors were recruited to prevent overwork and stress. During the interviews, data collectors provided constant feedback to me, reporting the status of each interview and any concern. Meanwhile, the online data collection system was closely monitored to ensure that the answers were received and safely stored, and that there were no missing answers due to errors from the research team.

At the end of the evaluation, a high retention rate (97.4%) was achieved Moreover, the dataset was compiled with no missing data in outcome variables and less than 5% of missing data in the demographic data. The latter reflected the fact that the demographic information questionnaire was administered by the implementing organisation as a routine practice during the participant enrolment process. Missing data might have been reduced if the data had been

collected by the research team. However, that would have required a contact prior to participant signup on the waitlist, which was not possible in this study but could potentially be done in future collaborations. Nonetheless, the estimation of treatment effects was not affected by missing data because all outcomes and covariates in the DiD regression models had a complete set of data. Exploratory analyses of the implementation process involved demographic variables with individual missing data, and thus, compensated the missing data using the Restricted Maximum Likelihood approach (Bates et al., 2015).

Real-world observational studies may be contaminated by external events that occur during an intervention, pointing to the need to account for secular trends in the outcome variable (Abadie, 2005). This study isolated time trend effects by using a difference-in-differences design (DiD) (Dimick & Ryan, 2014). The key assumption of a parallel trend in DiD was checked by replacing the primary outcome of interest (externalising behaviours) with a placebo outcome (financial health) in the DiD model (Chapter 2 section 2.6.4.3). The results showed that group-varying differences (if any) should have been time-invariant, thereby suggesting no violation of the assumption (Wing et al., 2018). The absence of randomisation in real-world evaluations can also subject them to selection bias (Blunt, 2015). However, participants were allocated from a naturally occurring SREIA waiting list, and the assessment of baseline data using two independent samples t-tests and chi-square tests detected no significant group differences based on p-values. In spite of that, the tests were underpowered by small sample sizes, and the examination of absolute standardised mean differences of key covariates that were demonstrated by the literature to be closely associated with treatment effects, showed that

there was a high level of heterogeneity between groups (Chapter 2 section 2.6.4.1). Hence, a propensity score weighting approach was utilised to re-balance the treatment groups based on the key covariates (Li & Thomas, 2019; Stuart et al., 2014). The diagnostic check of pre- and post-weighting absolute standardised mean differences showed that the weighting method substantially reduced group differences for all covariates and created comparable groups for the estimation of intervention results (Chapter 2 section 2.6.4.1) (Rubin, 2001). In addition, a sensitivity test was conducted by applying the DiD model to the pre-treatment data, setting the baseline primary outcome as the dependent variable (Chapter 2 section 2.6.4.3). The result detected no "treatment effect", providing support to the assumption of ignorable treatment assignment (Godard-Sebillotte et al., 2019).

Detection bias occurs when there are systematic differences in the way outcomes are assessed in the treatment groups (Shea et al., 2017). Paper 2 reduced detection bias by 1) using validated measurement tools where possible and a standardised translation process when needed (World Health Organization, 2020) to minimise variations in assessments; 2) training and supervision of data collectors: all data collectors were walked through, and practiced in pairs, each questionnaire item to ensure a common understanding of the constructs; they were also involved in several discussions about potential ways to ask the most difficult questions; 3) blinding of data collectors to participant group status, by administering the satisfaction questionnaire separately and data collectors reporting their knowledge of group allocation after each interview (Blunt, 2015). However, this study was not able to blind participants to reduce performance bias as they were aware of their exposure to the programme.

Real-world evaluations should also account for spillover effects, which occur when participants in the control group are exposed to some of the programme content, leading to contamination bias (Dimick & Ryan, 2014). We did not specifically require caregivers to withhold any information from those in the control group, as we considered it to be unethical, especially given their lack of information and social support (McCabe, 2012). However, the contamination bias was reduced by conducting separate induction sessions for the two groups of participants. Nonetheless, it should be noted that, approaching the end of this programme, some caregivers were contacted online by those in the control group to learn about their experiences of participating in the programme. Although there was a lack of formal monitoring, caregivers in the control group could also have learned parenting and ABA techniques from other sources, such as online materials and other programmes. Despite those unavoidable sources of bias, this study detected no significant pre-post differences in the control group, indicating limited impact caused by potential contamination.

Reporting bias in this study was reduced by registering the study protocol with ClinicalTrials.gov and Open Science Framework prior to the start of the evaluation, which ensured that the actual quantitative and qualitative analyses were in line with the original plan (Ohtake & Childs, 2014). The only deviation from the original protocol was that an Inverse Probability of Treatment Weighting (IPTW) scheme was initially proposed as the main method to estimate propensity score weights, whereas the Overlap Weighting (OW) scheme was ultimately used to produce the final results. This was because the analysis found that IPTW created outliers and suboptimal group balance, which was more likely to reduce the internal

validity of the results. However, the IPTW method was still reported as a robustness check and showed results consistent with the OW scheme (Chapter 2 section 2.6.4.2), suggesting that no bias was caused by this change of analytic technique. Moreover, the systematic review in Paper 1 showed a pattern of inadequate reporting in Chinese studies. To further improve the quality of reporting and the transparency of this research, the protocol was developed by strictly adhering to the SPIRIT guideline (A. W. Chan et al., 2013) (Appendix I.1), the final report of quantitative results conformed to the STROBE guidelines for reporting observational studies (Von Elm et al., 2007) (Appendix I.2), and the report of qualitative results adhered to the Standards for Reporting Qualitative Research (O'Brien et al., 2014) (Appendix I.3). By following the subset of items for cross-sectional studies, this thesis found all items in STROBE well applicable because of the observational nature of this quasi-experimental study. However, STROBE lacks items about the interventional aspects. Therefore, additional components were drawn from the CONSORT guide (Schulz et al., 2010)—such as trial design, group allocation, and programme description—to inform the writeup of report (Appendix I.2). The adequate and transparent reporting will enable readers to scrutinise all aspects of this research and better judge the generalisability of findings to their settings (Schulz et al., 2010).

Last but not least, ASD treatments are often restricted to certain groups of beneficiaries, as research finds either that programmes are attended by a predominance of families with higher income levels (Kilbourne et al., 2006; Mandell et al., 2009; Tek & Landa, 2012) or that services are delivered specifically for underserved populations, such as those from lower socio-economic status, with the purpose of eliminating health care disparities (T. Carr & Lord, 2013;

Durkin et al., 2015; Roman-Urrestarazu et al., 2021). The results of this evaluation, however, had greater generalisability for the following reasons. First, the research was conducted in the context of routine service delivery by recruiting participants from the existing SREIA waiting list, thereby being more likely to provide valuable information about the range of participants in clinical practice. Second, differing from other ASD treatments, the SREIA programme was delivered to families from various backgrounds. For instance, there was a mixture of families across all economic status, with 28.83% living in poverty. Also, the participants were roughly divided into equal halves in terms of multiple demographic characteristics, including: urban (54.81%) versus rural (45.19%) household registration; having one child (49.55%) versus two or more children (50.45%) within the household; caregiver completing college (44.23%) versus high school or less (55.77%); child with (48.18%) versus without (51.82%) other medical conditions; and child previous attending (57.66%) versus not attending (42.34%) individual therapies. Moreover, the constitution of participants reflected the distribution of beneficiaries observed in real-world service delivery. For example, there were 16·22% of children being girls, which was in accordance with the 4.3:1 gender ratio in ASD diagnosis (Maenner et al., 2020), as well as 7.21% being ethnic minorities, which was generally in line with the Seventh National Population Census in China showing that ethnic minorities comprise 8.4% of the whole population (National Bureau of Statistics of China, 2021). The great diversity of participants substantially contributed to the high external validity of findings. Nonetheless, it should be noted that the generalisability was limited by the lack of male caregivers, which will be discussed later in section 6.3.3 of this Chapter.

6.1.1.3. Mixed-methods approach

Compared to randomised controlled trials that involve ideal conditions, real-world evaluations have the potential for better reflecting real life contexts (Camm & Fox, 2018). The benefits can be augmented by conducting mixed-methods evaluations to investigate the intervention process and outcomes in greater depth, which is of particular importance in areas where there is a general lack of evidence (Palinkas, 2014). This thesis used an explanatory sequential design (Creswell & Clark, 2018), with the quantitative outcome and process data collection followed by qualitative in-depth caregiver interviews and practitioner focus group discussions (Chapter 2 section 2.3.1). The advantages can be summarised in four ways, including i) providing knowledge about the circumstances that necessitate an intervention, ii) explaining the initial results, iii) identifying mechanisms of change, and iv) informing any future implementation process.

First, qualitative findings in this thesis contribute to the contextualisation of intervention effects. Paper 1 (systematic review) and Paper 2 (quantitative study) of this thesis both showed that parent training programmes for families of children with ASD in Chinese contexts tend to have a treatment effect that was larger than those reported in previous research (Postorino et al., 2017; Skotarczak & Lee, 2015; Tellegen & Sanders, 2014). Paper 3 (qualitative study) provided the context for the results, by describing the generally negative experience of having a child with ASD in China, such as the common lack of resources, ASD knowledge, and treatment benefits. This may have allowed more room for improvement and thus, larger treatment effects (section 6.2.1).

Second, while quantitative data can provide a general understanding about the associations between variables, qualitative data can explain the meaning of such associations (Creswell & Clark, 2018). For instance, the qualitative interviews with caregivers provide more detailed explanation regarding the quantitative results that showed improved parental mental wellbeing, including more acceptance, more confidence, and less anxiety. In addition, Paper 3 provides a possible explanation for the lack of treatment effect in family functioning (such as partnership and growth), describing how family members had little knowledge about the diagnosis or new techniques and as such had limited opportunities for within-family collaborations (section 6.2.2). Paper 2 identified an association between participant engagement and child externalising behaviours at post-test. This is further illustrated by Paper 3 showing that the learning and use of skills were perceived to interact with child progress to build parental confidence, which further promoted caregiver engagement and improved child outcomes. The process evaluation in Paper 2 found that there was a relatively lower level of delivery quality, compared to the large treatment effect and high satisfaction scores; Paper 3 provide further understanding of this result, revealing that, despite their dedication, the high workload and stress was identified by practitioners as reducing their quality of delivery and in addition to a lack of training and supervision to assist them with daily stressors (section 6.2.4).

Third, the mixed-methods research design provides insights into complex social phenomena and allows for the identification of potential key factors that affect the intervention outcomes in real-world settings (Creswell & Clark, 2018; Peterson et al., 2013). This thesis identifies several potential processes of change, which can be tested in formal moderator and

mediator analysis. For instance, parental mental health may have played a role in the association between participation in the programme and the reduction of child behavioural problems (section 6.2.3). Increased knowledge about ASD appears to have had an impact on treatment effects by changing parental attitude and facilitating programme delivery (section 6.2.1). Furthermore, a mixture of group and individualised experience appeared to be critical in terms of producing changes in multiple domains (section 6.2.2).

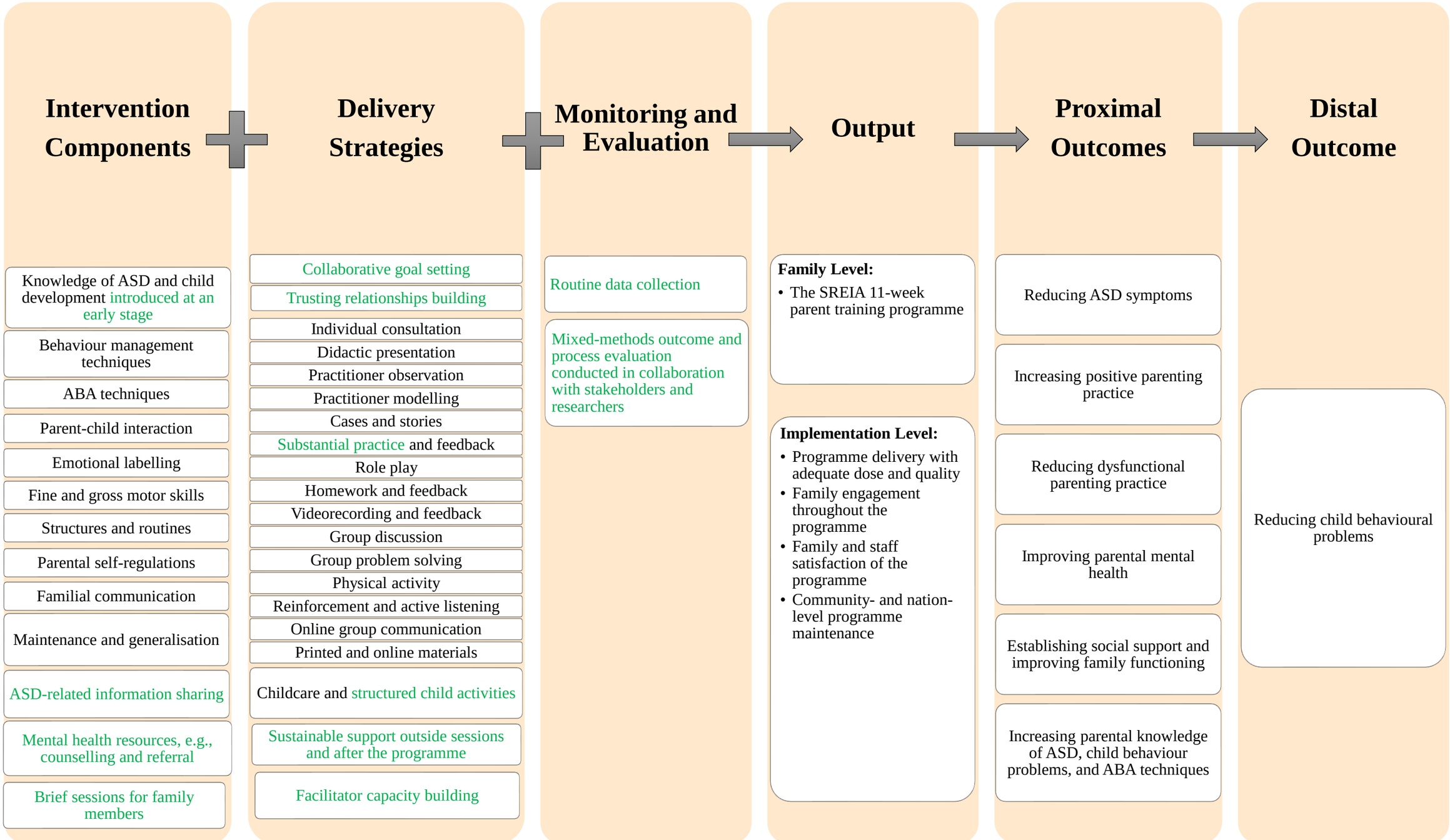
Lastly, mixed-methods approaches may contribute to the refinement of interventions for future delivery. By combining quantitative and qualitative data, this thesis has contributed to the adaptation of parent training programmes for ASD by highlighting some of the key delivery components necessary for promoting treatment effects, such as creating sustainable social support, offering structured child activities, and enhancing practitioner capacity building.

In summary, given the lack of evidence in low-resource settings, real-world evaluations are urgently needed build the evidence base. This thesis has demonstrated how such evaluations can be conducted by establishing partnerships between researchers and implementing organisations, making use of existing resources, and employing a robust mixed-methods design.

Revised logic model

The five overarching findings can be used to inform the revision of the logic model and future iterations of the programme. The revised logic model is presented in Figure 21. Changes are highlighted in green.

Figure 211 Revised SREIA logic model



6.3 Limitations

Despite the strengths mentioned in the above section, this thesis has several limitations regarding the validity of the results. This section presents these by first describing two drawbacks of the overall thesis design, then listing the limitations of the systematic review and meta-analysis (Chapter 3 Paper 1) and finally discussing sources of bias undermining the internal and external validity of the SREIA evaluation (Paper 2 and Paper 3).

6.3.1 Limitations of the overall design

First of all, the primary outcome of interest was different in the systematic review (child physical abuse, Chapter 3 Paper 1) to that of the SREIA evaluation (child behavioural problems, Chapter 4&5, Paper 2&3), potentially limiting the review's ability to inform the evaluation. The systematic review was a version of my MPhil thesis tailored for publication in the journal of *Trauma, Violence, & Abuse*. While the original MPhil thesis was designed and written up with a focus on child behavioural problems, the published paper was adjusted to highlight the implications for child abuse because of the journal scope and peer reviewer comments. However, child behavioural problems remained one of the three primary outcomes in the review (Chapter 3 section 3.4.1) and the adjustments were mainly limited to the background section, made to highlight the link between child abuse and behavioural problems. Moreover, the review identified only one study measuring child abuse using an unvalidated questionnaire, whereas the majority of studies provided data on child behavioural problems. As a result, all subsequent subgroup, moderator, and sensitivity analyses were conducted on child behaviours. As such, it

was deemed plausible to use the results of the review to inform the evaluation, and to integrate findings from the review and the evaluation in the overall discussion. In order to maintain the coherence of this thesis, a linking section (section 3.7) was added between Paper 1 and Paper 2&3 to explain this discrepancy and describe the link between them.

However, it should also be noted that, the SREIA evaluation only assessed one aspect of child behavioural problems—externalising behaviours, whereas the outcome measure in the review combined externalising behaviours with internalising behaviours. This was due to the lack of separate data reported for externalising behaviours in the review. In spite of that, the SREIA evaluation did not administer the full CBCL questionnaire to measure both externalising and internalising behaviours. This was because child externalising problems was identified as the distal outcome of the programme by the practitioners (logical model, section 2.4.1). Further, the CBCL contains 100 items and would further increase caregiver burden, which could have jeopardised the ethical soundness and accuracy of data, especially given that the other questionnaires already amounted to over 200 items. Therefore, we prioritised internal validity over the consistency with the review. To avoid misinterpretation, the overall discussion carefully distinguished the differences in outcomes of interest.

Secondly, due to time constraint, the qualitative study selected caregiver participants only based on attendance and engagement rates. We could have been able to further probe the reasons behind different treatment effects, if the treatment effect estimations were used to inform the selection of participants. Future mixed-methods evaluations may benefit from more detailed planning of this, should resources be available. In addition, the qualitative caregiver

interviews did not identify distinct patterns between caregivers with low and high rates of attendance and engagement. This may be because of the high levels of involvement in general and the small number of interviewees (n=14). Future studies may consider increasing the sample size, assessing participant involvement using standardised tools to increase sensitivity, and expediting data analysis, for example, by developing a coding template and populating the analysis once the data become available.

Third, the involvement of stakeholders in the research was insufficient. Stakeholders were limited to organisation staff, who provided basic inputs into the research design and interpretation of results. More opportunities could have been sought at every stage to deepen the power of such partnership, so that we can further improve the relevance of the research to the community and shorten the time it takes to translate the findings into practice. Implications for future participatory research are discussed in detail at the end of section 6.5.

6.3.2 Limitations of the systematic review and meta-analysis

First, as a result of the small number of included studies and participants in the systematic review (i.e., child internalising and externalising behaviours in children with four types of developmental disabilities: k=23, n=1768; child internalising and externalising behaviours in children with ASD: 9 studies, 627 participants), the meta-analytic models, especially the subgroup analyses and meta-regressions, may have been underpowered (Borenstein et al., 2011). The meta-regression models aimed to increase the power by incorporating multiple covariates (Higgins & Green, 2011). However, the suboptimal reporting of identified studies could have compromised the ability to properly adjust for covariates.

Second, there were high levels of heterogeneity in the models for child internalising and externalising behaviours (four types of developmental disabilities: $I^2 = 75.40\%$, $Q(df = 58) = 1262.86$, $p < .0001$; ASD: $I^2 = 68.01\%$, $Qe(df = 55) = 850.25$, $p < .0001$), which may have reduced the predictive values (Melsen et al., 2014). Although studies differ naturally (Higgins & Green, 2011) and I^2 can be biased by small sample sizes (Huedo-Medina et al., 2006), findings should be interpreted with caution, especially given that the sources of heterogeneity remained largely unexplained.

Third, there were insufficient details provided about the intervention content or delivery methods. For example, the programme descriptions in some reports contained no more than a couple of sentences. As for delivery components, of the 31 included studies, nine did not mention the duration and/or frequency of sessions, 25 did not report any method undertaken to control programme fidelity, 20 did not describe the delivery setting, and 14 provided no information about practitioner qualification. This lack of information in the included studies may have substantially reduced the power and undermined the validity of results. As such, the non-statistically significant results in the subgroup analyses and meta-regression might not necessarily mean that the components did not contribute to the heterogeneity or that they were genuinely not associated with the outcomes. Future studies should consider using reporting guidelines, such as CONSORT and TIDieR checklists (Hoffmann et al., 2014; Moher et al., 2010).

Related to this, the internal validity of the included studies was also of concern. Across five out of the seven domains, the risk of bias was rated high. Most randomised trials did not

conduct allocation concealment, which may have compromised the randomisation process (Blunt, 2015). The outcomes were predominantly measured using parent-report data, especially for child internalising and externalising problems, and the data collectors were not blind, with only one exception (Ji et al., 2014). In addition, the judgement of risk of bias was again inhibited by the lack of reporting, as information about critical methodological aspects remained absent in many studies, despite an effort to retrieve more details by contacting the authors via phone calls and emails.

The scope of the review was also limited by time and resource constraints. Only four English databases were searched (i.e., Medline, Embase, PsycINFO, and Cochrane). Although they were more likely to contain studies of interest, there might also be relevant trials in other databases, such as CINAHL, which provides nursing and health literature and, as this review shows, 27 of the 31 included Chinese trials were conducted in hospital settings and three were reported in nursing journals. This review covered the four largest Chinese databases and had a high level of confidence in terms of being able to identify all relevant trials published in Chinese language. However, the publication bias was reported as high, warranting a deeper exploration of local grey literature, such as from university databases.

Finally, evidence continuously evolves, and systematic reviews need to be up-to-date to inform practice and research (Higgins & Green, 2011). Searches for this review were conducted in August 2018 and the report was published two years later, compromising the extent to which they were fully up to date. Although a systematic review found that there was at least a 1.5-years gap between search date and publication date in about 10% of existing reviews (Beller et

al., 2013) and the publication process to a large extent remains out of researcher's control, such delay negatively influences end users by failing to incorporate new evidence. The Cochrane Collaboration suggests that systematic reviews be renewed every two years (Higgins & Green, 2011). Furthermore, due to the COVID-19 pandemic, remote programmes have been designed and evaluated to address the needs of families of children with ASD during quarantine. For instance, a 12-week online parent education and training programme was offered to 294 Chinese parents of children with ASD in early 2020 (McDevitt, 2021). Therefore, a new search is recommended to update the evidence and potentially compare the treatment effects of new digital programmes versus traditional in-person programmes when enough trials of online delivery have been conducted.

6.3.3 Internal validity of the SREIA evaluation

There are several potential threats to the internal validity of the SREIA evaluation. First, the lack of randomisation increased the potential risk of selection and confounding bias (Blunt, 2015). While selection bias refers to the unrepresentativeness of participants, confounding bias arises when treatment allocation is related to a factor that also influences the outcome (Porta, 2014). Families in the SREIA evaluation had the following characteristics: 1) they were generally open to positive parenting principles and applied behaviour analysis; 2) they were willing to travel and attend group sessions for eleven consecutive weeks even when COVID-19 has not completely come to an end; and 3) they consented to the study, attended both data collection interviews, and, for some caregivers, also participated in the qualitative interviews. Considering these features, the sample in this study might be over-representing families who

were highly motivated and thereby more likely to be engaged in the programme and behavioural changes, compared to the general ASD population. In addition, since the group assignment was not random, it was possible that the allocation was driven by a variable that also had a direct impact on the treatment effects, resulting in confounding (Shadish et al., 2012, 2002). The reduced enrolment rate for the control group (section 6.2.5b) might have indicated the existence of such unknown confounders. This thesis attempted to reduce both sources of bias by combining regression adjustment with propensity score (Haneuse, 2016). Regression models were built by adjusting for important confounders identified from the literature (Stuart et al., 2014), and propensity scores were estimated to show the probability of being in a treatment condition as the result of potential measured confounders (Rubin, 2001). Multiple propensity score weighting methods were also integrated into the regression models to assess the robustness of the results. However, these efforts rely on the assumption that there is no unmeasured confounding variables affecting the outcomes (Caliendo & Kopeinig, 2008). Although this assumption was validated by treating the pre-treatment outcome score as a dependent variable (Chapter 2 section 2.6.3.4), there may still be unknown factors causing potential bias (Fredriksson & Oliveira, 2019).

Second, this study did not assess the parallel trend assumption of DiD using pre-treatment periods. DiD assumes that the trends in outcomes are consistent in treatment groups. A common practice to verify this assumption is to collect data at multiple time points prior to the start of the intervention and examine the trends between those time points (Fredriksson & Oliveira, 2019). If the groups show the same pattern at pre-treatment periods, it is then more tenable to

claim that the treatment effects are due to the intervention alone, as opposed to other confounders (Wing et al., 2018). Unfortunately, the SREIA evaluation, was not able to collect pre-intervention data multiple times, partly due to funding limitations and because the COVID-19 pandemic created uncertainties with regard to families' actual participation in the programme. The programme was delayed for five months, resulting in an increasing number of caregivers withdrawing from the waitlist during this time. Consequently, it was not possible for us to finalise participants in either treatment group before the programme was officially resumed, which was three weeks prior to the first session. There was also a lack of funding for us to conduct the consent procedure, or multiple data collections at pre-treatment periods for all potential participants on the waitlist. Nonetheless, this thesis was able to confirm that group characteristics remained stable during the programme (Chapter 2 section 2.6.3.4), which means that any factors that might have affected the trends in outcomes stayed constant and their effects can thus be successfully isolated from the true treatment effects by estimating the pre-post difference in between-group differences (Godard-Sebillotte et al., 2019). Future evaluations of this kind, however, will still need to provide more solid support to the parallel trend assumption by collecting data from pre-intervention periods.

Third, the small sample size (N=111) was determined by the service capacity of the implementing organisation and the lack of research funding, which led to a reduced power to detect true effects and potentially also to an exaggeration of the estimation (Button et al., 2013). Hopkin, Hoyle, and Gottfredson (2015) suggest that, when it is not possible to increase the sample size, the statistical power can be enhanced by reducing sample variance and using

reliable measures. In this study, some effects of sample heterogeneity were diminished by estimating within-group pre-post difference (Hawkins et al., 2007) and including multiple key covariates in the regression models (Chapter 2 section 2.6.4.1) (Collins et al., 2001; Raudenbush, 1997). Although including more covariates may undermine the predictive value of regression models (Peduzzi et al., 1996), increasing evidence shows that statistical power can be substantially increased by including covariates that are closely associated with the outcome (Kahan et al., 2014; Pocock et al., 2002; E. L. Turner et al., 2012). Using reliable measurement tools is an another approach to increasing statistical power, as it can reduce error variance in the measure (Zimmerman & Williams, 1986). As such, tools that have been validated at global and local levels were prioritised in this thesis to further strengthen its power. However, to reduce participant burden, some of the tools are short, such as the APGAR measuring family function (Smilkstein et al., 1982) and the Supporting Positive Behaviour subscale of the Parenting Young Children Scale (McEachern et al., 2012), thereby limiting their sensitivity to detect treatment effects. In addition, it is worth noting that the statistical power in this study may have also been reduced by using linear mixed models, where there were only two levels of random effects (Snijders, 2014).

The small sample size further underpowered the subgroup analysis, undermining the accuracy of the results (Petticrew et al., 2012). For instance, there could have been an over-estimation of treatment effect on the primary outcome for Version B (which showed an effect size larger than the overall sample; section 4.4.1) and an under-estimation for Version A (which did not differ from the control group). To reduce bias, Petticrew et al. (2012) advise against

post-hoc data dredging. As such, this thesis pre-specified the subgroup analysis in the registered protocol. Moreover, despite the fact that the subgroup analysis was necessitated by the organisational needs for exploring more efficient ways of delivering the SREIA programme, it was also based on pre-existing theories suggesting that small caregiver group size and more individualised treatment are related to better developmental outcomes of children with disabilities (Bernheimer et al., 1990; Brookman-Frazee, 2004; Schultz et al., 2011; Weisner, 2002). With all that being said, the presentation and discussion of findings emphasised extra caution to be taken.

Fourth, consistent with most of the studies included in the systematic review, this evaluation relied on parent-report data. Parental self-report data can be biased by social desirability (R. J. Fisher, 1993), particularly if people feel ashamed to reveal personal and familial issues and if the participants perceived the lines between researchers and implementers as being blurry. There might also have been peer pressure in the programme that led caregivers to report better child outcomes. This study attempted to reduce reporting bias by reminding participants that the answers would remain confidential and anonymous and that their honest answers were of the most value. However, the reliability of data in this evaluation could have been strengthened by triangulating data sources, such as using practitioner-report (section 6.2.5a) and observational data (F. Gardner, 2000). For example, another intensive parent training programme for caregivers of children with ASD in the U.S. measured child cognitive functioning by psychologists administering a standardised test, although the authors still expressed a concern about performance bias (Anan et al., 2008). The Preschool Autism

Communication Trial evaluating a parent-mediated social communicational therapy for young children with ASD in the U.K., assessed parent-child communication by recording videos of parent-child play and measured child adaptive behaviours by teacher rating (Pickles, Le Couteur, Leadbitter, Salomone, Cole-Fletcher, Tobin, Gammer, Lowry, Vamvakas, Byford, Aldred, Slonims, McConachie, et al., 2016). Major reasons for the absence of additional data sources in this evaluation were the short timeframe; limited funding and high cost of observational measures; inadequate communication with and increased workload for practitioners; and adherence to ethics guidelines that prohibited in-person research activities during COVID-19.

Fifth, post-intervention outcomes were only assessed immediately upon the completion of the programme. A systematic review of parenting interventions for caregivers of typically developing children found some programmes having fade-out or sleeper effects (van Aar et al., 2017). Data from the in-depth interviews also showed that the caregivers were commonly concerned about their ability to continue applying the skills properly. Therefore, short-term assessments may limit our understanding of the programme effects. Long-term follow-ups are recommended to assess whether the programme can produce sustained benefits for families of children with ASD in China.

Sixth, the internal validity of associations between process outcomes and intervention outcomes may also have been reduced by some of the above-mentioned sources of bias. The analytic sample size was further reduced to the 63 participants in the treatment group. To increase the statistical power, the regression models controlled for key covariates that were

shown by the literature to be associated with child behavioural outcomes (Appendix B.1) or participant involvement in parent training programmes (Appendix B.2). The measurement of participant engagement relied on practitioner report. A consultation on criteria for the level of engagement was conducted with the practitioners to complement findings from the literature. However, the reliability of the results could have been further improved by using standardised questionnaires.

Seventh, COVID-19 may have also undermined the internal validity of results. COVID-19 disrupted the lives of the practitioners and caregivers in general, creating additional sources of stress (S. M. Brown et al., 2020; Cluver et al., 2020). The elevated stress might have had an influence on practitioner quality of delivery and caregiver baseline mental health status. Also, due to the pandemic and the prolonged waiting time it caused, some families withdrew from the SREIA programme and therefore ended up in the control group, leading to unmeasured confounding effects. Moreover, the format of programme delivery was adapted due to restrictions on mass gathering and travelling, as the implementing agency converted some didactic sessions that used to be delivered in large groups into digital format, which may have influenced the programme effects.

Finally, all research is within a stance (Creswell et al., 2011). The reflexivity of the qualitative aspect could have been improved by creating a formal reflexive journal to systematically document my day-to-day introspections, feelings of conducting and analysing the interviews, the impact of my feelings on key decisions, and regular check of biases. Also, the introspection could have been guided more by the literature, for instance, by following

Major and Savin-Baden's example (2012) to reflect on how my personal background and experiences had an influence on the purpose, source, and components of the research question.

6.3.4 External validity of the SREIA evaluation

Generalisability of the evaluation was potentially undermined by a few factors. First, quantitative data were collected with only two male caregivers in the treatment group and five in the control group. Participants in the qualitative interviews were identified based on the highest and lowest attendance and engagement rates, and thus, involved neither of the two male caregivers from the treatment group. The reason for this was possibly the demographic characteristics of participants in this study: two thirds of the female participants were full-time caregivers, whereas 90% of their spouses were employed (Chapter 4 section 4.4). This is consistent with previous surveys, indicating that the majority of primary caregivers of children with ASD in China were mothers (Guo et al., 2014; Sichuan Normal University, 2019). The gender bias in the sample can be attributed to the conventional gender values, which support the view that women's role is to support men and that wives should prioritise domestic affairs while husbands undertake productive activities (Deutsch, 2006). However, fathers are not absent in parent training programmes for ASD in China. For instance, fathers constituted around half of the sample size in two studies identified in the systematic review (Chu, Yan, & Wei, 2007: N=98; Zhou, Nie, & Chu, 2014: N=112), and one fifth of the participants in another two included programmes (Qian, Hua, & Xu, 2015: N=200; Yan, Xing, & Deng, 2012: N=60). Therefore, it could have been beneficial to increase the generalisability of the SREIA evaluation by involving more male caregivers using targeted recruitment and sampling strategies.

External validity of the findings was further limited by the fact that the data were collected from only one programme. Although many parent training programmes in China follow the SREIA model (Clark et al., 2019), the transferability of results to other programmes should be judged with caution. Also, the programme was delivered in Beijing, capital city of China. In spite of its location in suburban lower-income areas, this may have provided a better infrastructure than programmes delivered in other remote and rural areas. Moreover, as discussed in section 6.2.5 (a), although this evaluation increased the relevance of research findings to routine practice by engaging the implementing organisation at all stages of the evaluation process, it did not invite family beneficiaries to the partnerships, thereby failing to further strengthen the generalisability of findings. However, involving families in the entire research process requires substantial time and resources, and could not be accomplished without substantial funding. Moreover, the study only involved local Chinese service providers and families, thereby having limited generalisability outside of China. Nevertheless, other countries where there are similar cultural contexts and/or substantially limited resources for families of children with ASD, may benefit from this research.

Last, the evaluation was conducted during the COVID-19 pandemic. As was previously discussed, the programme delivery format was adapted to provide online sessions, and the lives of participants (both parents and practitioners) have been affected in many respects. Therefore, the findings may be less applicable to a non-pandemic context. However, COVID-19 has been creating fundamental changes to people's life and work at a global level (S. M. Brown et al., 2020; Cluver et al., 2020). The heightened parenting stress during quarantine may have

potentially increased the awareness of the need to build positive parent-child relationships and the need for parent training programmes. The pandemic may have also accelerated the digital trend of service provision (Nguyen et al., 2020). Hence, findings of the study can still be used to inform programmes delivered post-pandemic. Future research should be conducted to assess the impact of digital delivery.

6.4 Implications for Practice and Policy

This thesis supports the delivery of short-term intensive parent training programmes for caregivers of children with ASD in Chinese contexts to reduce child externalising problems. Findings suggest that programmes may need to deliver ASD knowledge at an early stage; establish common goals between caregivers and practitioners; serve as a reliable information source; provide sufficient opportunities for practice and feedback; and offer childcare and structured child activities. They should aim to provide support that can be sustained beyond the duration of programme, by maintaining continuous caregiver-practitioner communication, encouraging peer support, creating tailored experiences to empower caregivers, and enabling within-family collaborations. Alternatively, the duration of support can be extended by spreading out the programme sessions, providing the same amount of session over a longer period of time, which may also promote the generalisation of skills. Such programmes also may benefit from addressing parental mental health, as well as from reducing practitioner stress and promoting practitioner capacity building.

This thesis also has several implications for future policy. Chinese families of children with ASD experience substantial economic burdens. A survey that was conducted to investigate

the financial state of over 1300 families of children with ASD, other disabilities, and typically developing children (Ou et al., 2015), found that, compared to those with other disabilities or no disability, parents of children with ASD were much more likely to be unemployed, live in a lower-income household, and have more disability-related expenditures. The Regulation of Education of Persons with Disabilities released in 2017 suggests that support and opportunities should be created for persons of children with disabilities (including ASD) in terms of education, physical and mental health, development of their abilities, and protection of their rights to full participation as equal members of society (The State Council of the People's Republic of China, 2017). Informed by the new Regulation, local governments of several economically more developed cities, such as Hangzhou, Nanjing, and Shenzhen, has been providing an increasing amount of financial assistance to families of children with ASD aged 0-7 (W. Fang, 2018).

However, ASD treatments have yet to be included in the national healthcare system or extended to older children (Clark et al., 2019). Educational opportunities for children with ASD are still limited by the failure to provide a standard curriculum, nor are there sufficient teachers trained in ASD (Yingna Liu et al., 2016). Organisations offering ASD treatments also remain largely self-funded, of low capacity, and disproportionately limited in less developed cities and rural areas (China Association of Persons with Psychiatric Disabilities, 2015; McCabe, 2012; Ke Wang et al., 2018). This economic stress and inadequate support from services may contribute to high levels of psychological distress and low rates of life satisfaction in parents of children with ASD (M. Lu et al., 2015), who are often the main caretaker, educator, and advocate for their children (Clark et al., 2019; McCabe, 2007). Therefore, greater institutional

resources are suggested to support the implementation of parent training programmes in China to reduce parental stress, create social support systems, and increase child opportunities to learn. Moreover, financial assistance for families of children with ASD currently focuses on reimbursing auxiliary equipment and rehabilitation trainings for young children aged 0-6 (State Coucil of the People's Republic of China, 2018). However, the needs of caregivers and older children with ASD may also be considered, and financial assistance can be expanded to cover caregivers' attending parent training programmes. Such expansion may also contribute to the national policy agenda to promote family education and child development (All-China Women's Federation, 2016), by increasing the accessibility of parent training services and reaching families of children with disabilities.

The 2021-2025 Five-Year Plan of Family Education suggests the need to promote research on parent training in China (China Family Education Institute, 2021). The findings of the current study support the design of real-world evaluations to build the local evidence base and indicates that future implementation may benefit by increased funding to facilitate a closer collaboration between service providers and research institutes. With financial support to establish more equal partnerships, research activities could receive more buy-in from practitioners, and may be more likely to promote the translation of findings into future practice (Wallerstein & Duran, 2010). The provision of institutional funding could also contribute to the scientific rigor of research. For instance, the robustness of this study could have been improved in several aspects if adequate funding had been available; we would have been able to randomly allocate participants into different treatment groups by offering incentives and/or alternative

care; the sample size might have been enlarged by recruiting more participants and offering more parent groups; end users of the programmes could have been involved in the planning of research to improve the generalisability of the findings; and the parallel trends assumption could have been fully examined by conducting multiple data collections prior to the beginning of the programme implementation.

In addition to assessing effectiveness, it is recommended that policies and funding are developed to promote the further application of implementation science. According to interviews conducted with academic leaders who specialise in disseminating interventions in low-resource settings, a major barrier to scale up health-related interventions in LMICs is the lack of research that bridges the gap between intervention effectiveness and the implementation process (Yamey, 2012). This thesis involved the conduct of a parallel process evaluation with both quantitative and qualitative data collection, which provided an in-depth understanding about the implementation aspects of the programme and identify several ways to improve future delivery. Funding support may have further advanced the process evaluation by making it possible to measure participant engagement rates and practitioners' adherence to prescribed contents using observational tools. Additional in-depth interviews could have also been conducted with more caregivers stratified by demographic characteristics and treatment effects. Moreover, building the evidence base is not a one-time effort but a cyclical and iterative process of test and modification. As such, it is recommended that recurrent support is provided to interventions that show promise in increasing end user gains, so that such interventions are more likely to be sustained, institutionalised, and scaled up (K. Turner & Sanders, 2006).

Personnel has consistently been one of the top barriers to address health challenges in LMICs, where there is also the greatest need (Joint Learning Initiative, 2004). Despite an increasing number of evidence-based programmes becoming available, the uptake remains low due to inadequate staff, insufficient knowledge, and low levels of motivation (Leeman et al., 2017). According to previous research, educational programmes to train professionals in ASD-related treatments are scant in China, fundamentally inhibiting access to services (X. Sun, Allison, Auyeung, et al., 2013). Building and sustaining a strong ASD workforce requires country-level leadership that guides the collaborations between multiple sectors, such as health, education, finance, and human resource (Joint Learning Initiative, 2004). It is recommended that health and education sectors work collectively to provide systematic training, enrich post-training learning opportunities, and increase the number of qualified ASD practitioners. Human resource and finance sectors control the quality of ASD personnel, support career development, and provide adequate incentives (Mathauer & Imhoff, 2006; Tomlinson et al., 2018; Yamey, 2012). The incentives could also be a combination of financial and non-financial benefits, and provided not only to ASD service deliverers but also partners who contribute to the development and refinement of ASD treatments (K. Turner & Sanders, 2006).

It is also recommended that organisations and the wider society promote the positive professional identity of practitioners to increase the quality of their work. During the partnership with the SREIA implementing organisation, the managers commonly identified that the negative societal attitude towards people with ASD, or disabilities in general, has made disability-related work among the least desirable occupations in China and had led to low self-

and group-esteem in existing practitioners. Research indicates that training and career development are critical to promote positive professional identity (M. Johnson et al., 2012). The organisation, as such, has been providing training opportunities for practitioners nationally, and launched several awards with the Heart Alliance—National Autism Intervention Association in China, to show appreciation of their excellence and increase their sense of self-acknowledgement. However, recognition from the wider society may also be needed to sustain a positive professional identity. Political commitment to raising public awareness of ASD and advocating for a more inclusive society for people with disabilities may also be an essential part of the process of building the workforce.

Further, the development of ASD personnel in China may be expanded to involve parents of children with ASD. In the U.S., family members who provide daily care for children with intellectual and developmental disabilities can be compensated through Medicaid Home and Community Based Services Waiver (Rizzolo et al., 2013). In China, more than 90% of caregivers of children with ASD, or people with other disabilities, are family members (K. Fisher & Jing, 2008; Guo et al., 2014; Zheng et al., 2016), who constitute a large but ignored healthcare workforce. Providing them with compensation and opportunities to improve caretaking skills (e.g. through parent training programmes) may be of particular importance in addressing the lifelong care demands of children with ASD, the current shortage of services, and the financial stress in these families.

6.5 Implications for Research

This thesis points to several directions for future research. First, complex interventions

need to be evaluated by combining quantitative outcome assessments with qualitative investigation of stakeholder views and experiences (Lewin et al., 2009). Different mixed-methods designs can be used to embed qualitative data into the core trial design. For instance, quantitative and qualitative data can be collected in parallel and merged to develop a more comprehensive understanding of a phenomenon. Data can also be collected sequentially to inform the design of subsequent phases or further explain the results of the first phase (Creswell & Clark, 2018). In addition to a thematic analysis, other qualitative approaches can also be used to gain insight into how caregivers engage in parent training programmes and targeted skills. For instance, the methodology of grounded theory can be employed to discover the process of change using an iterative data collection and analysis process (Glaser & Strauss, 1967). Ethnographic research may also be conducted to explore stakeholder experience in their natural environment (Palinkas, 2014). Additionally, qualitative research could be conducted at a more distal timepoint to explore sustainment of skills and programme effects. Furthermore, such a mixed-methods approach will allow for the investigation of the relationships between implementation and programme effectiveness. For instance, associations identified in the quantitative analysis could be fully described in the in-depth interviews, and potential factors found in the qualitative information regarding the factors affecting participant involvement, and programme delivery could be tested using quantitative data.

Second, there is a need for more research on the economics of this type of programme delivery. One systematic review highlighted the lack of economic evidence on parent training programmes in the general population, finding only six studies from 12 electronic databases

(Charles et al., 2011). This is also true for parent training programmes for caregivers of children with ASD. A search of the literature found only three primary individual studies investigating the costs of such programmes. The evaluation of the GIFT parent training programme for children with ASD between 2 and 6 years old showed that the total cost of the 180-hour parent training and monthly follow-up consultations was around £5700 per year for the participating families (Anan et al., 2008). Similarly, the MEHRIT parent-mediated social-communication-based intervention for young children with ASD aged 2 to 5 found that the associated annual cost was about £2900 per child (Casenhiser et al., 2013). Another study conducted a cost analysis for a 40-week centred-based child programme that was combined with a parent group training and support component, finding that the staff cost per child was approximately £3400 (Roberts et al., 2011). All were perceived to be significantly lower than the annual cost of traditional intensive behavioural therapies delivered by professionals. Future research could also use more standardised methods to explore the economic impacts of parent training programmes for ASD, such as cost-effectiveness analysis that estimates the costs needed to gain a unit of outcome (Weinstein & Stason, 1977), cost-utility analysis that measures the disability-adjusted life-year and the quality-adjusted life-year (B. J. Cohen, 2003), and cost-benefit analysis that compares the costs and long-term benefits in monetary terms (McIntosh et al., 1999). These studies would be helpful in terms of rationalising the implementation of parent training programmes at government level, especially in low-resource areas of China.

Third, more studies may be conducted to identify the active ingredients of short-term intensive parent training programmes in Chinese contexts. There is generally a limited number

of studies investigating moderators or mediators of ASD early interventions with parental involvement. A study that tested the relationship between the core components of a parent-mediated social communication intervention named JASPER and the outcome of joint attention using hierarchical analysis and mediation analysis, found that mirrored pacing (parents imitating child play by adapting to the child's expression) had a mediating effect on promoting joint engagement (Gulsrud et al., 2016). Another study that identified key components of a parent-mediated naturalistic developmental behavioural intervention called ImPACT using a single-subject multiple-baseline design with eight young children with ASD and their mothers (Ingersoll & Wainer, 2013), found that the teaching of alternative communication methods (such as picture exchange communication system) might increase spontaneous communication. The mechanisms of change in the ImPACT project were further investigated by matching the results of a qualitative content analysis against the intervention logic model (Frost et al., 2021). This thesis's qualitative study demonstrated that the process of change could be more complex than the theoretical causal model, calling for contextualised interventional strategies to promote social communication for children with ASD. A number of other experimental designs could also be used to establish causal links between critical components and outcomes, such as micro-trials (Howe et al., 2010) and factorial experiments within the MOST framework (Collins et al., 2014). Furthermore, combination of the identification of key ingredients and the evidence on economic impacts of parent training programmes for ASD would allow for the optimalisation of interventions for distinct settings.

A more focused attention to male caregiver involvement is another direction for future

research. Although some programmes tended to have more fathers than others (Chu, Yan, & Wei, 2007: N=98; Zhou, Nie, & Chu, 2014: N=112), male caregivers are still often underrepresented in parent training programmes and early interventions in general for children with ASD. For example, a systematic review investigating the extent of male caregiver involvement in parent training programmes to improve social and communicational skills in children with ASD aged two to five, only found three studies explicitly reporting the presence of fathers (Flippin & Crais, 2011). Another review with a broader child age range and outcomes reported that only 23% of the programmes had fathers present in sessions (Schultz et al., 2011). Research shows that parents play an integral role in child development, especially in terms of social and communicational skills (Pancsofar & Vernon-Feagans, 2006). In addition, the absence of fathers in early intervention for ASD may subject mothers to the risks of isolation and familial conflicts (N. L. Johnson & Simpson, 2013), which is also one important finding of Paper 3 in this thesis. As such, a mother-centred participation model is less likely to maximise child gains. Previous studies indicate that father training programmes for ASD can increase child verbal communicational skills (Seung et al., 2006), promote father-child interactions (Elder et al., 2011), improve paternal parenting styles (Bendixen et al., 2011), and reduce maternal stress (Bendixen et al., 2011). In addition, men's contributions to housework and childcare have been increasing at a global level (Hook, 2006; Kan et al., 2011), and traditional gender values in China have been eroded in the new generations with higher levels of education and female employment (Y. Hu & Scott, 2014). Hence, more research may be conducted to investigate ways to increase male caregiver involvement in parent training programmes for

ASD and investigate its effects on child and family outcomes.

It is now recognised that trusting relationships between caregivers and practitioners can promote programme outcomes but can be affected by practitioner competence (section 6.2.4). Training and post-training capacity building are a continuous set of actions to promote practitioner skill development (Joyce & Showers, 2002). The capacity building process will be insufficient with either aspect absent. Research to date has assessed the relationship between on-site clinical supervision, therapist adherence to the treatment model, and youth-level outcomes in a multisystemic therapy to reduce youth behavioural problems and functioning (Schoenwald et al., 2004). Future studies can similarly investigate the contribution of each practitioner capacity building components, as well as their interaction effects, to the delivery and outcomes of parent training programmes for ASD. Such information could be used to advance implementation theory and inform future design of parent training programmes.

This thesis also highlights several methodological issues that warrant further consideration in future studies. Paper 1 (Chapter 3) of this thesis showed that future systematic reviews can benefit from seeking evidence from non-English databases (Shenderovich et al., 2016) and be updated to incorporate new evidence on a regular basis (Higgins & Green, 2011). Future trials can be registered, and provide details about intervention components and implementation processes, as well as important methodological issues, to enable readers to judge the validity and relevance of the findings (Hoffmann et al., 2014). The SREIA evaluation suggests that when randomisation is not possible, other observational designs can also be used to assess the effectiveness of interventions in real-world conditions. However, to improve the validity of the

results, a careful planning process needs to be carried out to examine the underlying assumptions of those designs and address each potential source of bias (Camm & Fox, 2018). Efforts may be made to increase or understand the impacts of sample size and power, such as performing a power calculation prior to the trial, collaborating with stakeholders to recruit more participants, and employing innovative statistical methods to facilitate robust analyses with small sample sizes (Bacchetti, 2013; Button et al., 2013; Etz & Arroyo, 2015). Observational measures are needed for future evaluations to enable the collection of data that is less affected by personal bias and to observe changes that take place in natural settings (F. Gardner, 2000). Further long-term follow-ups would also be helpful for understanding whether and how parent training programmes may produce long-term benefits for families and society.

Last but not least, in future SREIA studies, key stakeholder involvement should include not only practitioners, but also family beneficiaries and stakeholders in the wider community, such as ASD advocators and policymakers. They need to be invited into the advisory group at an early stage and their roles in the collaboration should be clearly defined (Michener et al., 2012). Also, more time and resources should be provided to build trust and capacity among all partners (Rosenthal et al., 2014). Power issues should be examined more closely and discussed more frankly, so as to achieve a balance where researchers are neither taking control of the project nor handing all power over to the stakeholders (Michener et al., 2012). Moreover, capacity building needs to be conducted more systematically. A capacity building plan that is comprehensive, feasible, and flexible, should be created in collaboration with all partners. Creative educational methods are also needed to promote knowledge sharing and integration

(Holkup et al., 2004). Additionally, partner understanding of each evaluation stage needs to be assessed. Opportunities for partner inputs should also be prespecified at each stage (Hicks et al., 2012).

A less rigid research proposal can be developed at the initial planning stage to allow for additional inputs from stakeholders at subsequent stages (Couzos et al., 2005; Wallerstein & Duran, 2010). All partners can work together to determine areas that can and cannot be modified. All communications and decision-making processes should be kept on record so that partners can draw lessons from past experiences. In future studies, research results may also be shared and discussed with partners sooner to allow for joint interpretation, and this needs to be done with more efforts to reduce potential bias (Rosenthal et al., 2014). A dissemination plan can be developed together with partners to actively pursue their earlier involvement in the presentation and translation of findings. Moreover, resources need to be allocated to all partners to facilitate their participation across all stages (Michener et al., 2012). Further, future evaluations of the SREIA programme should explore the impact and economic benefits of stakeholder involvement, as well as potential contextual and process facilitators and barriers to the participatory research, using a mixed-methods design. Methods and results of the investigation should be presented in a systematic manner by adhering to relevant reporting guidelines, such as the GRIPP2 checklist (Staniszewska et al., 2017).

6.6 Dissemination, Impact, and Future Plans

This DPhil project aimed to produce research findings that could be used by stakeholders to inform future practice and advocacy. Dissemination of findings from this project will include

three publications in peer-reviewed journals (one has been published and two are in the process of submission); and presentations at an upcoming conference, the SREIA implementing organisation, the Centre for Evidence Based Intervention research group in the Department of Social Policy and Intervention, and the School of Social Development and Public Policy at the Beijing Normal University. A Chinese report of the SREIA evaluation has been created and submitted to Beijing Disabled Persons' Federation to advocate for wider ASD support. Research results will also be summarised into a one-page brief using layperson language to share with participants in the SREIA programme. A series of posts have been created to convey the findings via the social media accounts (WeChat and Weibo) of the implementing organisation and the Heart Alliance to a wider ASD community in China. Data from this study can be shared upon request and with a data sharing agreement in place.

An ongoing partnership has been established with the implementing organisation and the local research institute of Beijing Normal University to conduct follow-ups and assess the long-term effects of the programme. Routine monitoring and evaluation data on several outcome domains and implementation aspects are being collected for several versions of the SREIA programme, including the full intervention evaluated in this thesis, a reduced five-week version, an online version created in response to the COVID-19 pandemic, and a follow-up consultation programme provided for caregivers who previously attended the full intervention. Proposals will also be developed jointly to seek funding for future research activities. Hopefully, such efforts will enable us to understand the treatment effects using a much larger sample and to explore the impacts of different components and delivery methods.

6.7 Conclusion

Children with ASD are more likely to experience co-occurring behavioural problems that heighten parenting stress and limit child opportunities to learn (Hayes & Watson, 2013; Totsika et al., 2011). Research shows that parent training programmes can reduce child behavioural problems (Z. Fang et al., 2020; Postorino et al., 2017), but such evidence is limited in LMICs in terms of both the number of studies conducted in routine contexts and the scientific rigor of existing evaluations. This thesis used a mixed-method approach to investigate the effectiveness and implementation process of parent training programmes for caregivers of children with ASD in China. It provides new evidence on effective parent training strategies to reduce child externalising behaviours and improving a range of associated outcomes in Chinese settings. It has implications for contexts where there is a similar lack of ASD-related services.

Paper 1 was the first systematic review of parent training programmes delivered to families of children with developmental disabilities in China and the first of its kind to draw evidence primarily from studies reported in Chinese, which have been missed in previous reviews due to language and database biases. Findings from the review and meta-analyses showed that parent training programmes are effective in reducing child internalising and externalising behaviours, as well as improving parent-child relationships, for Chinese families of children with ASD, as well as those with a wider range of developmental disabilities. It also identified several programme content and delivery methods that may influence the treatment effects. Paper 2 and Paper 3 presented the results of the SREIA evaluation, which was the first mixed-methods study conducted in a routine service setting to explore in more depth, a short-term intensive parent

training programme for caregivers of young children with ASD in China. Paper 2 utilised a difference-in-differences design with propensity score weighting in real-world service context to compensate for the inability to conduct randomisation. Findings suggested that the SREIA programme had a large effect in terms of reducing child externalising behaviours and improving three out of the six secondary outcomes. Paper 3 conducted a thematic analysis of caregiver in-depth interviews and practitioner focus group discussions using a mixture of inductive and deductive approaches. The results provided detailed explanations of the treatment effects and identified several key ingredients that should be included in any future delivery of this programme.

Overall, this DPhil thesis contributes to the literature on parent training programmes for caregivers of children with ASD in low-resource settings. Findings encourage the implementation of short-term intensive programmes to complement brief caregiver support and as an alternative to traditional intensive therapies delivered for consecutive years, especially when there is a lack of local ASD treatments and substantial unmet need. The thesis also calls for more collaborations between service providers and academic institutes to build the evidence base in LMICs, and to advocate for ASD populations outside the U.S. and Europe. Such efforts could collectively contribute to the improved access to evidence-based interventions for families of children with ASD across cultures.

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APPENDICES

Appendix A Existing Parent Training Programmes for ASD

Program Name	Topics	Dose	Format	Age	Country	Trial	Design	Outcome
a parent training intervetnion	joint attention, joint action routines, behavior management	a 3-hour session every 6 weeks for 12 months	individual	mean=22.5 months	UK	Drew 2002	RCT	child language
Autism 1-2-3	simple ABA strategies to promote child eye contact, gesture, and words	5 days a week for 2 weeks	group	17–36 months	Hong Kong	Wong 2010	RCT	child social and communication skills, CEBP; parental stress
Autism Preschool Program (APP)	knowledge of ASD, ABA techniques, interventions to encourage and enhance communication, techniques to improve social interaction and engage the child in play, processes of problem solving and program development.	5 weekly 3-hour seminars and 10 weekly 3-hour consultation sessions	group	24-72 months	Canada	Jocelyn 1998	RCT	parental knowledge, ASD symptoms, child language, family functioning
Behavioral Intervention	function and consequences of child behavior; behavior mamagement strategies; techniques to improve child communicational and daily living skills	11 core sessions with 1-1.5 hours, 2 optional sessions, 1 home visit, and 6 parent-child coaching sessions over 16 weeks	individual	3-7 years	USA	Bearss 2015	RCT	CEBP
DIR/Floortime	self-regulation and interest in the world, engagement and relating, purposeful emotional interaction, social problem solving, creating ideas, thinking logically	15 hours and 10 minutes per week for 3 months	individual	2-6 years	Thailand	Pajareya 2011; Solomon 2007	RCT	
EarlyBird/EarlyBird Plus	knowledge of ASD; ASD and communication; working with your child; visual support; preventing problems and developing daily routines; understanding and managing behavior.	8 2.5-h sessions, across 12 weeks	group + individual	< 9 years	UK; New Zealand	Dawson-Squibb 2019 (SR): Shields 2004; Anderson 2006; Murray 2011; Stevens 2013	quasi-RCT	parental knowledge and confidence; child behavior and communication skills
EIBI	EIBI techniques based on the UCLA model	5 hours per week for 3-9 months	individual	18-42 months	USA	Smith 2000	RCT	child cognitive functioning, language and communication skills, adaptive behavior
Focused Playtime Intervention (FPI)	parent-child play	12 weekly sessions with 1.5 hour per session	individual	< 6 years	USA	Siller 2012	RCT	parental behaviors, child language skills
Group Intensive Family Training (GIFT)	behavior techniques, such as reinforcement, shaping, chaining, prompting, generalization, errorless teaching, and systematic data collection, to promote prerequisite skills and behavioral changes	240 hours in total: 5 days a week with 3 hours each day for 12 consecutive weeks, and 5-hour home practice per week	group + individual	25–68 months	USA	Anan 2008	pre-post	adaptive behaviors; cognitive function
Group-Based Parent Training	understanding the function of children's behaviour, play, using praise and rewards to encourage appropriate behaviour, effective limit setting, managing parental stress, facilitating communication, using ignoring and time out, managing obsessions, intense interests, rigidity and repetitive behaviours, and sensory sensitivities	9-10 2-hour sessions	group	4-11 years	UK	Todd 2010	pre-post	child behavior, parental confidence

Program Name	Topics	Dose	Format	Age	Country	Trial	Design	Outcome
ImPACT	set up home environment to use techniques, how to play, turn-taking, prompting and reinforcement	12 1-hour weekly sessions	individual	1.5 to 8 years	USA	Stadnick 2015	quasi-RCT	child communication
Incredible Years-Autism Spectrum and Language Delays (IY-ASLD)	child-directed narrated play, pre-academic and persistence coaching, social coaching, emotion coaching, pretend play, child self-regulation skills, praise and rewards, limit setting and behavior management	12 weekly sessions	group	2-8 years	UK	McIntyre 2008; Hutchings 2016; Williams 2017	RCT; pre-post	CEBP, parent-child interaction, parental mental health
JASPER	modeling, prompting, imitating, expanding, pacing adult language to match the child's language, adjusting play routines based on the child's interests	3 sessions per week for 8 weeks, with each session lasting for 45 minutes	individual	< 9 years	USA	Kasari 2010; 2014; 2015	RCT	child social and communication skills
Milton & Ethel Harris Research Initiative (MEHRIT)	assess the individual strengths and challenges of the child from the perspective of speech and communication, sensory, cognitive and motor abilities; and teach parents about their child's strengths and challenges and devise a set of strategies appropriate for the child and the family	weekly sessions with 2 hours per session for 12 months	individual	24-59 months	Canada	Casenhiser 2011	RCT	child behavior, child language
More than Words	responding to the child's communicative attempts, following the child's lead, building and participating in joint action routines in play, enhancing interaction during caregiving routines, using books and play as contexts for communication elicitation and reward, using visual supports to help children understand expectations, supporting peer interactions, and scaffolding peer play dates.	8 group sessions and 3 individual sessions	group + individual	15-25 months	USA	Carter 2011	RCT	ASD symptom, child cognitive skills, communication skills, and adaptive behavior
Parent Education and Behavior Management (PEBM)	knowledge of ASD; child developmental stages; underlying developmental causes of CEBP; behavioral management strategies; techniques to promote prerequisite social and communicational skills; parental self-care and emotion-regulation; and social support	10 1-h individual sessions and 10 1.5-hour group sessions, across 20 weeks	group + individual	23-70 months	Australia	Tonge 2006; 2012	RCT	parental mental health; CEBP, ASD symptoms, child social and communication, adaptive living skills
Parent Education Program for Chinese Americans	understanding ASDs, special education system, teaching communication skills, teaching social and play skills, reducing challenging behavior, teaching academic skills, teaching functional skills, opportunities and outcomes for individuals with ASDs, coping strategies, and community resources	10 weekly 2-hour group sessions	group	3-11 years	USA	Chiang 2014	pre-post	parental stress, confidence, QoL
Parent Management Training	psychoeducation, comic strip conversations, social stories, management of CEBP	1 day workshop and 6 individual sessions	group + individual	6-12 years	Australia	Sofronoff 2004	quasi-RCT	CEBP, social skills
Parent–Child Interaction Therapy (PCIT)	behavior management in child-directed and parent-directed interactions	14 weekly 1-h sessions	individual	2–7 years	USA	Ginn 2015; Masse 2007; Solomon 2008	RCT; pre-post	parental mental health; CEBP, child social skills

Program Name	Topics	Dose	Format	Age	Country	Trial	Design	Outcome
Parents' Plus Program	using parental attention to change behaviour, play and special time with children, encouragement and praise, using reward systems effectively, set rules and help children keep them, use active ignoring to reduce misbehaviour, use time out and other sanctions, solution building with children	eight weekly sessions of 2 hours each	group	4-7 years	Ireland	Quinn 2007; Coughlin 2009; Hand. Raghallaigh 2013	pre-post	CEBP, parental stress, family functioning
Pivotal Response Training (PRT)	ABA-based techniques integrated with a developmental perspectives to improve child motivation and delivery in natural environment	10-12 weekly sessions, with each session lasting 50-90 minutes	group/group + individual	2-10 years	USA	Baker-Ericzen 2007; Gengoux 2015; Minjarez 2011	pre-post	child adaptive behaviors and language development; parental skills
Play and Language for Autistic Youngsters (PLAY)	identify and respond to child cues, engage the child in reciprocal exchanges, provide the child developmentally appropriate challenges, parent-child play	3-hour monthly home visit for 12 months	individual	32-71 months	USA	Solomon 2014	RCT	ASD symptoms, parent-child interaction, child development, child social functioning, parental stress
Preschool Autism Communication Trial (PACT)	increase parental sensitivity and responsiveness to child communication and reduce mistimed parental responses; skill generalization and maintenance	biweekly 2-hour sessions for 6 months and monthly booster sessions for another 6 months	individual	24-59 months	UK	Green 2010; Pickle 2016	RCT	ASD symptom, child communication, parent-child interaction
RUPP	behavior management (behavioral model and assessment, reinforcement, consequences, daily schedule, and preventive strategies), functional communication, skill generalization and maintenance, time-out, contingency contracting, crisis management	11 core, 3 optional, and 3 booster sessions with 75-90 minutes per session, across 16 weeks	individual	3-6 years	USA	Aman 2009; Arnold 2012; Bearss 2013	pre-post	CEBP
Self-Directed Learning Program (SDLP)	PRT strategies to increase child motivation to engage in social communication, behavioral management techniques	the total running time of the DVD was 1 hour 6 minutes.	individual	< 60 months	USA	Nefdt 2010	RCT	child communication skills, parental confidence
Social Communication Intervention	psychoeducation, focusing, sensitivity, modelling, consolidation, and elaboration	monthly sessions for 6 months and 2-monthly sessions for another 6 months	group + individual	29-60 months	UK	Aldred 2004	RCT	ASD symptoms, adaptive behaviors
STAR	following children's lead, modeling and expanding, environmental arrangement, prompting and reinforcement	weekly 1-hour group session for 9 weeks and 3 45-minute individual sessions	group + individual	3-4 years	USA	Ingersoll 2006	pre-post	parental knowledge and satisfaction,
Stepping Stones Triple P (SSTP)	Primary Care SSTP and Standard SSTP: child behavior problems, developmental issues, learning difficulties, disruptive behavior disorders, behavior management techniques	primary care: 80 minutes over 4 sessions standard: 10 hours over 8-10 sessions	group + individual	2-9 years	Australia	Whittingham 2007; Tellegen 2013	RCT	CEBP, parenting style
VIPP-AUTI	attachment and exploration; speaking for the child; sensitivity chain; sharing emotions	biweekly sessions lasting 1-1.5 hours over 3 months	individual	25 to 52 months	Netherlands	Poslawsky 2015	RCT	parent-child interaction, parental sensitivity and self-efficacy, child social skills

Appendix B Covariates in the DiD and Regression Models

1. Factors associated child behavioural problems

This section describes the factors that have been found to be associated with child behavioural problems (e.g. child gender, parental knowledge, parenting practices, and family function) or that have been found to modify programme effectiveness (e.g. ASD severity, initial child behavioural problems, and parent mental health status) for the purpose of informing the data analysis in Chapter 2 Section # Page # and Chapter 4 Section # Page #: building regression models to estimate the propensity scores and difference-in-differences. It is based on evidence from both interventional and observational studies, and from the general population when ASD research was absent.

i) Factors associated with behavioural problems

Research consistently shows that child behavioural problems vary between male and female children with ASD.[1] For example, a meta-analysis found that boys exhibited a significant higher level of repetitive and stereotyped behaviours than girls (Van Wijngaarden-Cremers et al., 2014). Newly conducted individual studies with large sample sizes generated comparable results. A study involving 1064 Chinese children with ASD (21% being female) (S. Wang et al., 2017), as well as a pooling study combining 28 datasets from nine European countries (N=2684, 17% being female) (Tillmann et al., 2018), indicated that repetitive and stereotyped

[1] However, there is one systematic review suggesting no gender difference for ASD-related behavioural problems, but the analytic model included only five studies with substantial heterogeneity and underrepresentation of female children with ASD (Hull et al., 2017).

behaviours were fewer in girls than boys.

More parental knowledge about child development and behavioural problems was found to be in associated with fewer challenging behaviours in a cross-sectional study of children with ASD (García-López et al., 2016) and in longitudinal and cross-sectional studies involving typically developing children (Benasich & Brooks-Gunn, 1996; Hill & Bush, 2001). In addition, existing studies suggest that parental knowledge is significantly correlated with fewer dysfunctional parenting practice in the general population (K. Y. Huang et al., 2005; Scarzello et al., 2016), which has also been shown as being linked to challenging child behaviours (M. Liu & Guo, 2010; Mckee et al., 2007; Morawska et al., 2009; Stormshak et al., 2000).

Parenting practices have been shown to be strongly associated with child behavioural problems. Three systematic reviews of parent training programmes in the general population all suggested that the use of effective parenting practices contributed to the reduction of children behavioural problems (Kaminski et al., 2008; Leijten et al., 2019; Leijten, Gardner, Melendez-Torres, et al., 2018). Observational evidence also showed that negative parenting practices are linked with more behavioural problems in typically developing children in the U.S. (Stormshak et al., 2000) and in China (M. Liu & Guo, 2010), as well as in children with ASD (Clauser et al., 2021).

Home environment and family function have been found to be associated with developmental competence in children with normal developmental trajectories and those growing up in high-risk circumstances, such as disability and poverty (Hessl et al., 2001; Totsika & Sylva, 2004). An eight-year longitudinal study (Woodman et al., 2015) and three cross-sectional studies (Herring et al., 2006b; Jellett et al., 2015; Sikora et al., 2013) all showed a strong relationship

between child behavioural problems and positive or poor family functioning for children with ASD. There is a similar pattern in the general population. Two cross-sectional studies involving typically developing children in low- and middle-income families identified dysfunctional household and chaotic home environment as a predictor of child disruptive behaviours (Coldwell et al., 2006; Hardaway et al., 2012).

ii) Factors associated with the impact of programmes on behavioural outcomes

ASD research suggests that the severity of ASD symptoms and the level of child skills moderate the impact of programmes on children's behavioural outcomes. A meta-synthesis of six systematic reviews of Early Intensive Behaviour Interventions (EIBI) for young children with ASD indicated that the relationships between initial child ability and behavioural outcomes became stronger as the level of parental involvement increased and that children with more skills at baseline tended to benefit most (Strauss, Mancini, SPC Group, et al., 2013). In addition, several cross-sectional and longitudinal studies also found that children with severe ASD symptoms were more likely to experience elevated challenging behaviours (Andersen et al., 2017; Jang et al., 2011; Lindor et al., 2019; J. L. Matson et al., 2008).

Although there is limited evidence specifically with regard to ASD, three systematic reviews, with two focusing on the Incredible Years parenting programme for typically developing children between zero to 12, found that higher initial disruptive child behaviours predicted larger effect sizes (Leijten et al., 2013, 2020; Menting et al., 2013). Studies conducted in typically developing children have also identified the impact of parental mental health on

treatment effects.[2] The systematic review conducted by Leijten et al. (2020) aggregating individual-level data from 11 trials and 1395 beneficiaries found that the Incredible Years programmes appeared to reduce child conduct problems to a greater extent when it was delivered to female caregivers who had depressive symptoms. Similarly, a randomised controlled trial assessing the Family Check-Up programme also indicated that the programme reduced more child externalising behaviours when there was a high level of maternal depression (Shaw et al., 2006). Potential reasons for this association include that caregivers with poor mental health status tended to use less positive parenting, thereby having more room for change, and that the programmes provided social support and improved parental mood, which in turn created a positive environment for child development (Leijten et al., 2020; Shaw et al., 2006).

Research suggests, however, that that there are no significant relationships between the treatment effects of parent training programmes and the following factors: *child age* (Furlong et al., 2012; Frances Gardner et al., 2019; Lundahl et al., 2006; Oono et al., 2013; Skotarczak & Lee, 2015), *child comorbidity* (Bjørnebekk et al., 2015; Leijten et al., 2020; Leijten, Raaijmakers, Wijngaards, et al., 2018; Riosa et al., 2011), *socio-economic status* (Frances Gardner et al., 2010; Jonathan Green et al., 2010; Leijten et al., 2013; Leijten, Raaijmakers, Wijngaards, et al., 2018; Oono et al., 2013; van der Put et al., 2018), *ethnicity* (Leijten,

[2] The review by Reyno and McGrath (2006) indicated that there was no significant difference in terms of programme effectiveness in reducing child externalising behaviours between female caregivers with and without depression or other psychopathological concerns. However, it should be noted that there were small numbers of trials in each analytic models (maternal psychopathology: k=3, n=247; maternal depression: k=5, n=428).

Raaijmakers, Wijngaards, et al., 2018; van Mourik et al., 2017), *number of children in the household* (Reyno & McGrath, 2006), and *caregiver age* (Frances Gardner et al., 2010; Reyno & McGrath, 2006).

2. Factors associated with participant involvement

This section summarises the evidence with regard to the specific factors associated with participant involvement in parent training programmes, with the purpose of informing the data analysis in this DPhil study (Chapter 4 Section # Page #: building regression models to investigate participant characteristics related to participant involvement). The literature review again included research conducted in the ASD and the general population. Participant involvement is a process element of parent training programmes, comprising three main components: enrolment, attendance, and engagement (Gopalan et al., 2010; Karver et al., 2005). The following factors have been found to be associated with caregiver involvement: child behavioural problems, ASD severity, parental mental health, caregiver gender, caregiver age, caregiver education, socio-economic status, and practitioner efficacy.

This review of the literature identified only three studies investigating the implementation aspects of parent training programmes for the ASD population, two of which indicated a significant correlation between participant involvement and ASD severity, although with contrasting results. One study assessing the DIR/Floortime intervention for children with ASD showed that caregivers of children with higher levels of ASD severity were more likely to be engaged in sessions and in-home practice (Praphatthanakunwong et al., 2018), whereas another study suggested that caregivers with children of lower non-verbal intelligence had higher levels

of engagement in a parent-mediated ASD intervention for low-income families (T. Carr et al., 2016b). However, Carr et al. (2016) had a larger sample size and measured engagement in a more systematic approach using a standardised questionnaire administered to caregivers each week, therefore having higher internal validity than Praphatthanakunwong et al. (2018).

Carr et al. (2016) also found that engagement was inversely related to distress in caregivers of children with ASD, which was consistent with another study of a parent-mediated ASD intervention called ImPACT, which found a partial correlation between parental depression at baseline and programme completion (Ingersoll & Berger, 2015). Parental mental health has also been found to be associated with participant involvement in the general population. For instance, two large trials showed that stress had an impact on enrolment, attendance, and engagement rates (Hackworth et al., 2018; Rostad et al., 2018). Nix et al. (2009) also found that parental stress was significantly correlated with engagement, although not with attendance. Moreover, Carr et al. (2016) indicated that higher education and skilled occupation predicted more attendance but not engagement for families of children with ASD, which is consistent with research involving children without the diagnosis. (Corso et al., 2010).

Evidence regarding a number of other factors has also been found for the wider population of parents. There are mixed findings in terms of the impact of child behavioural problems on caregiver involvement in programmes delivered to families of children without ASD. While some studies showed that more severe child behavioural problems could lead to lower levels of caregiver attendance (August et al., 2003; Kazdin et al., 1997; Morawska & Sanders, 2006; Prinz & Miller, 1994), others have found that caregivers who reported greater initial child

behavioural challenges were also more likely to be involved (Baker et al., 2011; Dumas et al., 2007; Garvey et al., 2006; Heinrichs et al., 2005; Reid et al., 2004).[3]

A small number of studies also found linkages between participant involvement and parent gender and age. In the national evaluation of a community-based family strengthening programme for hard-to-reach beneficiaries in Australia, Cortis, Katz, and Patulny (2009) found that male caregivers were much less likely than female caregivers to enrol in or attend training sessions. This pattern is in fact present in most studies of parent training programmes for children with (Flippin & Crais, 2011; Schultz et al., 2011) and without ASD (Panter-Brick et al., 2014). In terms of parent age, Hackworth et al. (2018) and Corso et al (2010) both showed that younger parents of typically developing children had lower rates of enrolment and attendance in training programmes.

Research suggests that economically disadvantaged families have lower levels of attendance. Two systematic reviews found that programmes with more impoverished participants had significantly higher rates of attrition (Chacko et al., 2016; Reyno & McGrath, 2006). Similarly, a more recent trial involving families of typically developing infants and toddlers identified an inverse correlation between receiving government benefits and caregiver attendance (Hackworth et al., 2018). This literature review identified no such evidence generated from the ASD population, which was potentially due to the general lack of access to ASD services in families of lower socio-economic status (T. Carr & Lord, 2013; Kilbourne et al., 2006; Mandell

[3] A meta-analysis included eight studies and found no association between child behaviour and attendance, which can be likely due to the mixture of prevention and treatment programmes in the analysis (Reyno & McGrath, 2006).

et al., 2009; Tek & Landa, 2012).

Practitioner efficacy (such as teaching skills, experiences, and knowledge about programme content) has also been found to be positively associated with caregiver involvement in parenting programmes for non-ASD populations. For example, a narrative review indicated that participant involved could be promoted by practitioner abilities to apply motivational interviewing techniques; conduct engagement sessions to discuss programme benefits and family expectations; establish a collaborative partnership with caregivers; and tailor programme delivery to address individualised family needs (Ingoldsby, 2010). Two recent studies also showed that practitioners who were better at supporting and collaborating with caregivers tended to promote participant attendance and engagement (Hackworth et al., 2018; Ingoldsby et al., 2013).

Appendix C Search Terms, Excluded Studies, and Ethical Clearance in Chapter 3 Paper 1 Systematic Review

1. Search terms and records

1. China National Knowledge Infrastructure (CNKI, 1949 to August 7th, 2018)
(SU%干预+治疗+矫正+教育+培训+育儿+团体辅导+训练+正面管教) AND (SU%家长+父母+祖父母+亲子+子女+儿童+青少年+青春期+少儿+幼儿+未成年) AND (SU%亲子关系+代际关系+代际冲突+亲子冲突+沟通+家庭功能+家庭生活+父母行为+知识+育儿方法+素质提升+教养技能+养育方式+效能+心理健康+压力+态度+理念+满意度+行为问题+攻击性行为+依附+亲密+儿童虐待+儿童忽视+肢体惩罚+暴力+体罚+打骂+儿童发展+学校表现+健康) AND (SU%特殊需要儿童+特殊儿童+发展障碍+发育缺陷+智障+智能发展迟缓+弱智+智力缺陷+精神发育不全+认知障碍+脑性瘫痪+脑瘫+ASD+自闭症+孤独症+autism+pdd+阿斯伯格+阿兹伯格+亚斯伯格+asperger+星儿+ADHD+多动症+注意缺陷多动障碍+天使人症候群+安格曼症候群+胎儿酒精综合症+听直觉处理障碍+听力损失+听觉障碍+唐氏综合症+'21-三体综合征'+先天愚型+脆性X染色体综合征+脆X综合征+获得性癫痫性失语+学习障碍+学习困难症+学习缺陷+读写障碍+读写困难+失读症+难语症+阅读障碍+诵读障碍+失算症+书写障碍+书写困难+沟通障碍+言语障碍+克果纳杰氏症+肌营养不良+视力受损+视力残疾+神经系统疾病+代谢+甲减+甲状腺功能减退+苯丙酮尿症+普拉德威利综合症+低肌张力+性腺发育低下+肥胖综合征+普达威利综合症+癫痫+妥瑞氏症候群+小儿抽动秽语综合征+抽动症+托雷氏症+杜雷氏症+创伤性脑损伤+威廉氏综合症+威廉斯氏综合症+感知障碍+知觉障碍+先天性风疹综合症+退行性疾病+蕾特氏症+瑞特综合症+雷特氏综合征)
2. China Science and Technology Journal Database (CSTJ, all available years)
(M=干预 + M=治疗+ M=矫正+ M=教育+ M=培训+M=育儿 +M=团体辅导 +M=训练 +M=正面管教) AND (M=家长+M=父母+M=祖父母+M=亲子+M=子女+M=儿童+M=青少年+M=青春期+M=少儿+M=幼儿+M=未成年) AND (M=亲子关系+M=代际关系+M=代际冲突+M=亲子冲突+M=沟通+M=家庭功能+M=家庭生活+M=父母行为+M=知识+M=育儿方法+M=素质提升+M=教养技能+M=养育方式+M=效能+ M=心理健康+M=压力+M=态度+M=理念+M=满意度+M=行为问题+M=攻击性行为+M=依附+M=亲密+M=儿童虐待 +M=儿童忽视+M=肢体惩罚+M=暴力+M=体罚+M=打骂+M=儿童发展+M=学校表现 +M=健康) AND (M=特殊需要儿童 + M=特殊儿童+ M=发展障碍 + M=发育缺陷 + M=智障 + M=智能发展迟缓 + M=弱智 + M=智力缺陷 + M=精神发育不全 + M=认知障碍 + M=脑性瘫痪 + M=脑瘫+ M=ASD + M=自闭症 + M=孤独症+ M=autism+ M=pdd+ M=阿斯伯格 + M=阿兹伯格+ M=亚斯伯格 + M=Asperger + M=星儿+ M=ADHD + M=多动症 + M=注意缺陷多动障碍 + M=天使人症候群 + M=安格曼症候群 + M=胎儿酒精综合症 + M=听直觉处理障碍 + M=听力损失 + M=听觉障碍 + M=唐氏综合症 + M= '21-三体综合征' + M=先天愚型 + M=言语障碍 + M=脆性X染色体综合征+ M=脆X综合征+ M=获得性癫痫性失语 + M=学习障碍 + M=学习困难症 + M=学习缺陷 + M=读写障碍+ M=读写困难+ M=失读症+ M=难语症+ M=阅读障碍 + M=诵读障碍 + M=失算症+ M=书写障碍 + M=书写困难 + M=沟通障碍 + M=克果纳杰氏症+ M=肌营养不良+ M=视力受损 + M=视力残疾 + M=神经系统疾病 + M=代谢 + M=甲减 + M=甲状腺功能减退 + M=苯丙酮尿症 + M=普拉德威利综合症+ M=低肌张力 + M=性腺发育低下 + M=肥胖综合征 + M=普达威利综合症+ M=癫痫 + M=妥瑞氏症候群+ M=小儿抽动秽语综合征+ M=抽动症 + M=托雷氏症 + M=杜雷氏症 + M=创伤性脑损伤 + M=威廉氏综合症+ M=威廉斯氏综合症+ M=感知障碍 + M=知觉障碍 + M=先天性风疹综合症+ M=退行性疾病+ M=蕾特氏症+ M=瑞特综合症+ M=雷特氏综合征)

3. Wanfang Database (all available years)
主题:(干预+治疗+矫正+教育+培训+育儿+团体辅导+训练+正面管教) AND 主题:(家长+父母+祖父母+亲子+子女+儿童+青少年+青春期+少儿+幼儿+未成年) AND 主题:(亲子关系+代际关系+代际冲突+亲子冲突+沟通+家庭功能+家庭生活+父母行为+知识+育儿方法+素质提升+教养技能+养育方式+效能+心理健康+压力+态度+理念+满意度+行为问题+攻击性行为+依附+亲密+儿童虐待+儿童忽视+肢体惩罚+暴力+体罚+打骂+儿童发展+学校表现+健康) AND 主题:("特殊需要儿童"+"特殊儿童"+"发展障碍"+"发育缺陷"+"智障"+"智能发展迟缓"+"弱智"+"智力缺陷"+"精神发育不全"+"认知障碍"+"脑性瘫痪"+"脑瘫"+"ASD"+"自闭症"+"孤独症"+"autism"+"pdd"+"阿斯伯格"+"阿兹伯格"+"亚斯伯格"+"asperger"+"星儿"+"ADHD"+"多动症"+"注意缺陷多动障碍"+"天使人症候群"+"安格曼症候群"+"胎儿酒精综合症"+"听直觉处理障碍"+"听力损失"+"听觉障碍"+"唐氏综合症"+"21-三体综合征"+"先天愚型"+"言语障碍"+"脆性X染色体综合征"+"脆X综合征"+"获得性癫痫性失语"+"学习障碍"+"学习困难症"+"学习缺陷"+"读写障碍"+"读写困难"+"失读症"+"难语症"+"阅读障碍"+"诵读障碍"+"失算症"+"书写障碍"+"书写困难"+"沟通障碍"+"克果纳杰氏症"+"肌营养不良"+"视力受损"+"视力残疾"+"神经系统疾病"+"代谢"+"甲减"+"甲状腺功能减退"+"苯丙酮尿症"+"普拉德威利综合症"+"低肌张力"+"性腺发育低下"+"肥胖综合征"+"普达威利综合症"+"癫痫"+"妥瑞氏症候群"+"小儿抽动秽语综合征"+"抽动症"+"托雷氏症"+"杜雷氏症"+"创伤性脑损伤"+"威廉氏综合症"+"威廉斯氏综合症"+"感知障碍"+"知觉障碍"+"先天性风疹综合症"+"退行性疾病"+"蕾特氏症"+"瑞特综合症"+"雷特氏综合征")

4. Chinese Electronic Periodical Services (CEPS, 1991 to August 8th, 2018, via Airiti Library)
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:特殊儿童
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:自闭症
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:孤独症 /阿斯伯格
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:智障
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:弱智
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:脑瘫
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:癫痫
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:唐氏综合症
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:学习困难症
([ALL3]:父母 OR [ALL3]:家长 OR [ALL3]:祖父母) AND [ALL]:言语障碍

5. Cochrane Central Register of Controlled Trials (CENTRAL)
#1MeSH descriptor: [Family Relations] this term only #2MeSH descriptor: [Child Rearing] this term only #3MeSH descriptor: [Child Abuse] this term only #4(child rearing):ti,ab,kw #5(family function):ti,ab,kw #6(family life):ti,ab,kw #7(parent efficacy):ti,ab,kw #8(parent child communication):ti,ab,kw #9(parental mental health):ti,ab,kw #10(maternal mental health):ti,ab,kw #11(parent education):ti,ab,kw #12(parental knowledge):ti,ab,kw #13(child emotional and behavioural adjustment):ti,ab,kw #14(child development):ti,ab,kw #15(school performance):ti,ab,kw #16(comorbidity):ti,ab,kw
#17{OR #1-#16} #18MeSH descriptor: [China] this term only #19MeSH descriptor: [Asian Continental Ancestry Group] this term only #20{OR #18-#19} #21MeSH descriptor: [Neurodevelopmental Disorders] explode all trees #22MeSH descriptor: [Angelman Syndrome] this term only #23MeSH descriptor: [Fetal Alcohol Spectrum Disorders] this term only #24MeSH descriptor: [Communication Disorders] this term only #25MeSH descriptor: [Hearing Loss] this term only #26MeSH descriptor: [Intellectual Disability] this term only #27MeSH descriptor: [Brain Damage, Chronic] this term only #28MeSH descriptor: [Epileptic Syndromes] explode all trees #29MeSH descriptor: [Kernicterus] this term only #30MeSH descriptor: [Muscular Dystrophies] explode all trees #31MeSH descriptor: [Vision Disorders] explode all trees #32MeSH descriptor: [Nervous System Diseases] explode all trees #33MeSH descriptor: [Hypothyroidism] this term only #34MeSH descriptor: [Rubella Syndrome, Congenital] this term only #35(special needs):ti,ab,kw #36(complex needs):ti,ab,kw #37{OR #21-#36} #38{AND #17, #20, #37}

6. MEDLINE (Ovid MEDLINE® Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MELIND® Daily, Ovid MEDLINE and Versions®, 1946 to August 27th, 2018), Embase (1974 to August 27th, 2018, via Ovid), and PsycINFO (1806 to August 27th, 2018, via Ovid)
#1exp parent/
#2exp caregiver/
#3exp mother/
#4exp father/
#5exp grandfather/
#6exp grandmother/
#7exp grandparent/
#81 or 2 or 3 or 4 or 5 or 6 or 7
#9Family relations/
#10Exp parent-child relations/
#11Exp child rearing/
#12Exp mother-child relations/
#13Exp family conflict/
#14Exp family function/
#15Exp family life/
#16Exp intergenerational relations/
#17Parenting.mp
#18Maternal behaviour.mp
#19Paternal behaviour.mp
#20Parental efficacy.mp
#21Parent child communication.mp
#22mental health.mp
#23Parent education.mp
#24Parental knowledge.mp
#25Parental stress.mp
#26Exp child abuse/
#27Exp child neglect/
#28Exp child maltreatment/
#29Child emotional and behavioural adjustment.mp
#30Child development.mp
#31Adaptive and executive functioning.mp
#32School performance.mp
#33Comorbidity.mp
#349 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
#35China.ti,ab
#36Chinese.ti,ab
#3735 or 36
#38Developmental disabilit$.ti,ab
#39Special needs.ti,ab
#40Complex needs.ti,ab

#41Intellectual disability.ti,ab #42Cerebral palsy.ti,ab #43(ASD OR Autism Spectrum Disorder OR PDD OR Pervasive developmental disorder OR asperger).ti,ab #44(Attention-Deficit Hyperactivity Disorder OR ADHD).ti,ab #45Angelman Syndrome.ti,ab #46Fetal alcohol spectrum disorders.ti,ab #47Central Auditory Processing Disorder.ti,ab #48Hearing loss.ti,ab #49Down Syndrome.ti,ab #50Expressive Language Disorder.ti,ab #51IsoDicentric 15.ti,ab #52Landau-Kleffner Syndrome.ti,ab #53(Learning Disabilities OR learning disorders).ti,ab54Dyslexia.ti,ab #55Dyscalculia.ti,ab #56Dysgraphia.ti,ab #57Language and speech disorders.ti,ab #58Kernicterus.ti,ab #59Muscular Dystrophy.ti,ab #60Vision Impairment.ti,ab
#61Nervous system disabilities.ti,ab #62Metabolic Disorders.ti,ab #63Hypothyroidism.ti,ab #64Neural Tube Defects.ti,ab #65Phenylketonuria.ti,ab #66Prader-Willi Syndrome.ti,ab #67Seizure Disorders.ti,ab #68Tourette Syndrome.ti,ab #69Traumatic Brain Injury.ti,ab #70Williams Syndrome.ti,ab #71(Sensory-related Disabilities OR sensory processing disorder OR sensory integration dysfunction).ti,ab #72Congenital Rubella Syndrome.ti,ab #73Rett Syndrome.ti,ab #74Pervasive development disorders.ti,ab. #75communication disorders.ti,ab. #76mental retardation.ti,ab #77neurodevelopmental disorder.ti,ab. #7838 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 #79 8 and 34 and 37 and 78

7. ProQuest Dissertations & Theses Global
(ab(parent*) OR ab(mother*) OR ab(father*) OR ab(caregiver*)) AND (ab(China) OR ab(Chinese)) AND (ab(Developmental disability*) OR ab(Special needs) OR ab(intellectual disability*) OR ab(Cerebral palsy) OR ab(autism) OR ab(ASD) OR ab(ADHD) OR ab(angelman syndrome) OR ab(fetal alcohol spectrum disorder) OR ab(central auditory processing disorder) OR ab(hearing loss) OR ab(down syndrome) OR ab(expressive language disorder) OR ab(isodicentric) OR ab(landau-kleffner) OR ab(learning disability*) OR ab(learning disorder) OR ab(dyslexia) OR ab(dyscalculia) OR ab(dysgraphia) OR ab(kernicterus) OR ab(muscular dystrophy) OR ab(vision impairment) OR ab(nervous system disability*) OR ab(metabolic disorder) OR ab(hypothyroidism) OR ab(neural tube defect*) OR ab(phenylketonuria) OR ab(prader-willi) OR ab(seizure) OR ab(Tourette) OR ab(traumatic brain injury) OR ab(Williams syndrome) OR ab(rett syndrome) OR ab(mental retardation) OR ab(communication disorder*) OR ab(pervasive developmental disabilit*) OR ab(neurodevelopmental disorder))

8. Clinical Trials.gov
Term: Parent Country: China

9. International Development Research Centre (IDRC)
Search term: Chinese, China. with filter: title contains parent*

10. Asian Development Bank
Filters: China, and (Health, Social Development and Protection, Social protection-social assistance program, Social protection-social insurance program)

11. World Health Organization clinical trials
Search term: parent* AND Chinese OR parent* AND China

12. Chinese Clinical Trial Registry (ChiCTR)
Search term: parents/父母 OR caregiver/照顾者

13. National Library of China-National Digital Library of China
Search term: 父母 Search term: 养育 Search term: 教养

14. WHO Global Health Library--The Western Pacific Region Index Medicus (WPRIM)
Search strategy: (((((Abstract:parent*) OR Abstract:father*) OR Abstract:mother*) OR Abstract:caregiver*) AND ((Abstract:China) OR Keywords:Chinese))

15. UNICEF Office of Research – Innocenti
Search term: parent, with geographic descriptor: China

16. Save the Children-Resource Center
Search term: parent*, with country filter: China

17. Asia Regional Network for Early Childhood (ARNEC)
Search categories: Child health and nutrition, early learning, ECD and policy, ECD workforce, responsive parenting/caregiving/safety and security

18. International Society for the Prevention of Child Abuse and Neglect (ISPCAN)
Search term: Parenting and China/Chinese

Source		Hits	Duplicates
Chinese Databases	CNKI	10040	336
	CSTJ	1048	33
	Wanfang	11165	2669
	Airiti	3691	508
English Databases	Cochrane	30	1
	Embase	104	0
	Medline		
	PsycINFO		
Grey Literature from Online Resources	ProQuest Dissertations & Theses Global	226	6
	WPRIM	224	0
	Clinical Trials.gov	121	0
	International Development Research Centre	4	0
	Asian Development Bank	18	0
	World Health Organization clinical trials	146	0
	Chinese Clinical Trial Registry	15	0
	National Library of China-Dissertation & Theses	17	0
	UNICEF Office of Research – Innocenti	0	0
	Save the Children-Resource Center	10	0
	Asia Regional Network for Early Childhood (ARNEC)	16	0
	ISPCAN	76	0

2. Characteristics of excluded studies

Author & Year	Notes
Bai & Niu, 2013	a narrative review of parenting interventions for ADHD
Cao, 2018	wrong intervention, rehabilitation, no parenting components reported in the trial
Chen et al., 2013	primarily hospital-based rehabiitation
Chen, 2013	wrong intervention, more sensory activities and adaptive living skills training
Chen, 2016	psychotherapy
Chen, 2016	wrong design
Chen, 2017	wrong intervention, no parenting components
Dai, 2013	only introducing intervention, no trial
Dong, Long & Xie, 2017	not measuring any primary outcomes of interest to this review
Du, 2012	not intervention study
Fan, Huang & Wu, 2014	only introducing intervention, no trial
Fang, 2016	parenting components not constituting 50%, qualitative

	analysis
Feng, 2010	cannot determine if parenting components constitute 50% of the intervention
Feng, 2013	wrong intervention, parent-led rehabilitation, did not measure any primary outcomes interested by this review
Gao & Zhao, 2015	not a primary study
Gao, 2015	teaching positive parenting principles indirectly through group activities and films; wrong study design
Geng, Chen & He, 2018	wrong intervention
Guan & Li, 2007	did not describe what was in the intervention; did not provide the outcome data
Guo, Sha & Zu, 2017	not a primary study
He, 2010	descriptive analysis
Hou & Yang, 2016	a review
Hu et al., 2015	parent components did not constitute 50%, no eligible outcome measurement, wrong design
Huang & Gao, 2012	conference abstract only
Huang, 2011	case study, qualitative data, measured tantrum and parenting,
Huang, 2011	the same one with the Huang 2011 Chinese thesis
Jiang, 2018	components delivered to parents seem not constituting 50% of the intervention; not measuring any primary outcomes of interest to this review
Jin & Wang, 2014	family-centered rehabilitation
Lei, Yang & Liu, 2010	only introducing intervention, no trial
Leung et al., 2013	conducted in Hong Kong
Leung et al., 2016	conducted in Hong Kong
Li & Jiang, 2016	wrong design
Li et al., 2013	wrong intervention-parent mental health support, only measured parental mental health
Li, 2007	wrong intervention, a similar study to Li, Zhai & Yang, 2007
Li, 2013	family-centered rehabilitation
Li, 2014	wrong intervention, systematic family therapy targeting family dynamic
Li, 2014 (2)	not parenting intervention
Li, 2015	qualitative case study
Li, 2015 (2)	only introducing intervention, no trial
Li, Chu & Li, 2009	the same study with Chu et al., 2007, changed the year of sampling, but the sample size and characteristics were exactly the same; did not measure any primary outcomes of interest
Li. Zhai & Yang, 2007	wrong intervention
Liao, 2017	not an intervention study

Lin, 2014	not a primary study
Liu & Ding, 2017	wrong design
Liu & Liu, 2010	not measuring any primary outcomes of interest to this review
Liu & Wang, 2007	wrong design
Liu & Wang, 2007	the same one with the Liu & Wang, 2007 Chinese thesis
Liu et al., 2015	wrong comparison: center-based program
Liu et al., 2016	not measuring any primary outcomes of interest to this review
Liu, 2004	cannot access full-text
Liu, 2018	wrong design
Lu, 2015	not measuring any primary outcomes of interest to this review
Ma, Yan & Chu, 2009	the same study with Chu et al., 2007, changed the year of sampling, but the sample size and characteristics were exactly the same; did not measure any primary outcomes of interest
Mei, 2012	wrong intervention
Mei, 2013	wrong intervention
Pan, Qian & Wang, 2018	wrong design
Qin et al., 2017	the intervention was parent-led TEACCH,
She & Yuan, 2015	just describing "Floortime"
Shuai et al., 2017	control group were typically developing children
Wang et al., 2016	wrong intervention, train parents to deliver home-based rehabilitation
Wang et al., 2017	introducing behavioural parent training, no trial
Wang, 2008	the same study with the thesis Wang 2005
Wang, 2012	not measuring any primary outcomes of interest to this review
Wang, 2014	wrong design
Wei & Cheng, 2017	the protocol met criteria, but contacted the trialist, who replied that the data was not ready and the paper had not been published.
Wu & Lu, 2015	wrong comparison: center-based program
Wu et al., 2012	wrong intervention, "structural family therapy"
Wu, 2009	wrong intervention, play therapy
Wu, 2018	not developmental disabilities
Xiao et al., 2011	wrong design
Xiao, Yang & Cui, 2015	unclear how much was for parenting remove the 50% criteria; wrong comparison: center-based program
Xiong et al., 2010	wrong design
Xu & Xu, 2011	wrong intervention, not measuring any primary outcomes of interest to this review
Yan, Xing & Deng, 2012	wrong intervention, not measuring any primary outcomes of

	interest to this review
Yang & Ge,, 2015	wrong design
Yang et al., 2016	testing the effect of medication-Ritalin
Yang, 2017	wrong intervention
Yang, Yang & Zhao, 2016	parenting components did not constitute 50% of the intervention
Yu et al., 2009	wrong comparison: center-based program; parenting intervention components did not constitute 50% of the intervention
Yu et al., 2015	wrong design
Yu et al., 2015(2)	wrong design
Zeng et al., 2011	wrong intervention
Zha, 2016	wrong design
Zhang & Zhao, 2010	not a primary study
Zhang et al., 2011	wrong design
Zhang et al., 2014	wrong design
Zhang et al., 2017	not parenting intervention
Zhang, 2014	wrong design
Zhao & Du, 2015	parenting components did not constitute 50% of the intervention
Zhao & Liu, 2014	family-centered rehabilitation/care
Zhao et al., 2008	conference abstract only
Zhao et al., 2014	wrong comparison: center-based program
Zhao, 2017	parents receive Pivotal Response Treatment training to reduce child behaviour problems; not RCT/quasi-experiment
Zheng & Wu, 2018	only describing an intervention, no trial
Zhou, Qin & Liu, 2018	wrong comparison: center-based program
Zhu & Kang, 2009	cannot determine if parenting components constitute 50% of the intervention
Zhu & Wang, 2010	cannot separate the effect of medication and intervention
Zhu, 2013	not parenting intervention

3. Ethical clearance

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Department of Social Policy and Intervention
University of Oxford

SPI_DREC_17_049

22nd June 2018

Parenting Interventions in Reducing Child Emotional and Behavioural Problems and Physical Abuse for Children with Developmental Disabilities in Mainland China- A Systematic Review and Meta-Analysis.

Your application for research ethics approval in connection with your thesis has been considered by the Departmental Research Ethics Committee (DREC) in accordance with the procedures laid down by the University for Ethical Approval.

I am pleased to inform you that, on the basis of the information provided, the proposed research has been judged as meeting appropriate ethical standards and DREC approval has been granted.

If any revisions to your research methodology are made subsequent to this approval, these must be detailed in writing and submitted to DREC immediately.

Yours sincerely,
Lucie Cluver
Professor Lucie Cluver
Chair of DREC

Point of contact: ethics@spi.ox.ac.uk | +44 (0) 1865 280734

Appendix D SREIA Evaluation Registered Protocol

Effect of a parent training programme for families of children with Autism Spectrum Disorder in China on child behavioural problems: Protocol for a mixed-methods quasi-experimental study

ABSTRACT

Introduction

Autism Spectrum Disorder is associated with elevated levels of child behavioural problems that limit child daily functioning and impose challenges to parenting. Parent training programmes have been shown to be effective in improving the behavioural functioning of children with Autism Spectrum Disorder, but there has been limited rigorous evaluation to date of the effectiveness of such programmes in China. The present study is aimed at evaluating the effectiveness of the Beijing Stars and Rain Education Institute for Autism (SREIA) programme in the context of routine service provision.

Methods and analysis

A quasi-experimental design with a mixed-methods approach will be used, involving two consecutive deliveries of the SREIA programme. Participants in the first wave will serve as the treatment group and those in the second wave as the waitlist control. Data will be collected at baseline, post-intervention, and six-month follow-up assessments (conditional to funding). The primary outcome is child behavioural problems measured using the Child Behaviour Checklist Externalising scale. A between-group comparison for the treatment and waitlist control groups will be made using a difference-in-differences design with an inverse propensity score weighting. A process evaluation will be undertaken in parallel to assess participant involvement, programme acceptability, delivery, and sustainability. Qualitative interviews will be conducted to explore stakeholder views about the programme, and to better understand the quantitative data obtained.

Ethics and dissemination.

Ethical approval has been obtained from the Social Science and Humanities Inter-divisional Research Ethics Committee at University of Oxford in the UK and Beijing Normal University Research Ethics Committee in China. Dissemination of the research findings will include publications in peer-reviewed journals, conference presentations, and annual SREIA reports. Registered in ClinicalTrials.gov (NCT04257331) and Open Science Framework (https://osf.io/vy69k)

Keywords

Parent Training, Autism Spectrum Disorder, Problem Behaviour, Quasi Experimental Design, Propensity Score Weights, Mixed-Methods Design

INTRODUCTION

Background and rationale

Autism Spectrum Disorder (ASD) is a developmental disability characterised by impairments in reciprocal communication and social interaction, as well as restricted and repetitive behaviours and interests.[31] The global prevalence of ASD in children has risen rapidly over the past two decades.[32] The pooled prevalence of ASD in China was around 25 per 10,000 in 2013 [33–35], suggesting that there could be in the region of 0.7 million Chinese children diagnosed with ASD.[36]

Children with ASD are much more likely to experience co-occurring behavioural problems than their cohorts with or without developmental disabilities.[37–42] Problems of this nature compound the ASD conditions, creating further limitations in children's daily functioning and imposing more challenges to parenting.[43–48] As such, research consistently shows an elevated risk of stress, depression, and anxiety among parents of children with ASD.[39,43,49–54] These problems interfere with children's learning, and ultimately limits the potential for optimal child development.[55]

Parent training is widely used to support families of children with behavioural concerns.[56–58] Parent training models for ASD often draw on Applied Behaviour Analysis (ABA), which is grounded in social learning and operant conditioning theory,[59–61] and integrates developmental theories,[62] which highlight the importance of following children's developmental sequences and establishing affective interactions between children and caregivers to promote social exchange.[63–67] Given the heterogeneity of functioning and difficulties experienced by children with ASD, such programmes are often tailored to varying degrees. Delivery strategies typically include facilitator teaching, modelling, parent practice, and in-vivo/video feedback. There is substantial variability in terms of programme length and intensity. However, in general, programmes for ASD are delivered with higher

dose and longer duration than those for typically developing children, thereby reflecting the complexity of working with children with ASD.[4–7,68–73]

Five quantitative systematic reviews showed that such programmes can reduce child emotional and behavioural problems,[6,8] improve parent-child interaction,[4,8] reduce ASD symptoms,[4,5] and improve child development.[5,7] Only one of them focuses on low- and middle-income countries,[8] showing a disproportionate geographic distribution of evidence. The review included Chinese studies and reported general high risk of bias, calling for rigorous evaluations of such programmes in China.[8]

Parent training programmes have been increasingly advocated as a cost-effective alternative to traditional interventions delivered by professionals in China, as a result of the large number of children with ASD,[33–35] accumulated parenting challenges,[74] limited local service provision,[24,75] and substantial economic cost of the ASD-associated consequences at both family- and state-levels.[74] One such programme was provided by the Beijing Stars and Rain Education Institute for Autism (SREIA). Since 1993, the programme has been delivered to thousands of families of children with ASD in China. Despite the long history and wide coverage, there is an absence of scientific evaluations of its effectiveness.

Objectives of this study

The primary objective of this study is to evaluate the effectiveness of the SREIA programme for parents of children with ASD aged three to six years in reducing child behavioural problems as measured by the Child Behaviour Checklist (CBCL) Externalising scale for Ages 1.5-5, in comparison to a waitlist control group, within the context of routine service provision.

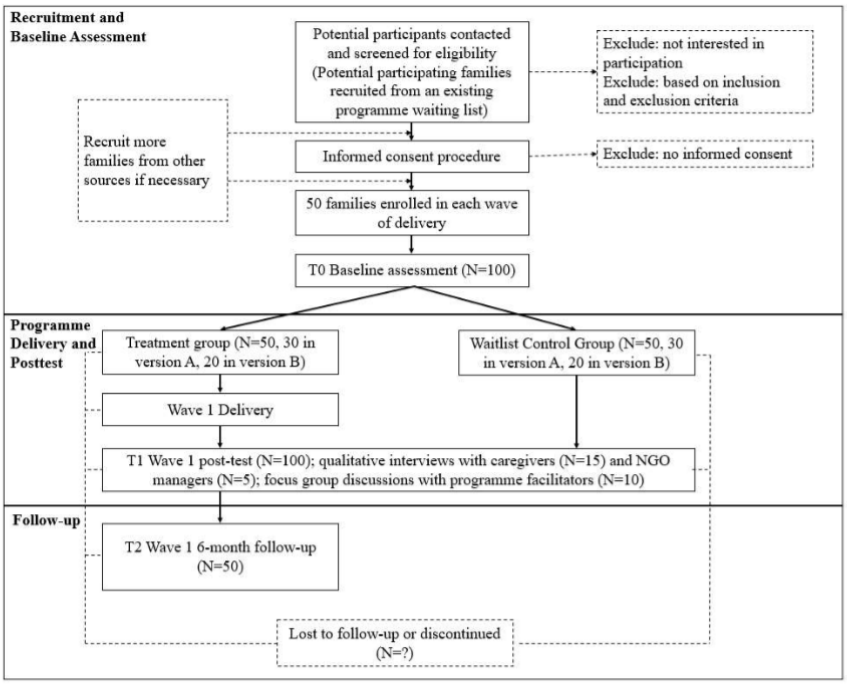
Secondary objectives are to examine its effectiveness in reducing ASD symptoms and improving parental and familial outcomes, including parental knowledge of ASD, parenting styles, parental mental health, and family functioning.

METHODS AND ANALYSIS

Study design

A pragmatic multi-wave quasi-experimental trial design will be conducted to examine the effectiveness of the SREIA programme. This study protocol has been developed accordance with the SPIRIT guidelines [76] and has been registered on ClinicalTrials.gov (NCT04257331) and Open Science Framework (https://osf.io/vy69k). A mixed-methods approach will be used with a nested design, in which the qualitative approach will be embedded within the quantitative method to better understand the quantitative data obtained.[77] The study will be conducted within the context of routine services. The study aims to recruit one hundred families of children with ASD age three to six and allocated them to two consecutive waves of delivery based on their availability and preference, with 50 families in each wave. The 50 families who choose to participate in the first wave will be the treatment group, and the 50 families in the second wave will service as the waitlist control group. Data will be collected at baseline (T0), immediate post-intervention (T1), and 6-month post-intervention (T2, conditional to funding) for all participants. Figure 1 shows the planned flow of participants through the study. The study is expected to start by the end of September 2020 and will last until June 2021.

Figure 1 Design Flowchart



Participants

The recruitment criteria of family participants will follow the existing strategies. The age range of children will be three to six years old, and all participating children will need to meet the diagnostic criteria for Autism Spectrum Disorder according to DSM-V and provide an official letter of ASD diagnosis. Families will be excluded if the child has been diagnosed with Cerebral Palsy. Each family will have one primary caregiver and one child participating in the programme. Participating primary caregivers will be those who 1) undertake the responsibility for the daily care of the child for at least five days a week and 2) provide informed consent to participate in the research. There will be no additional exclusion criteria.

Enrolment will be on a first-come, first-served basis. Potential family participants will first be recruited from an existing waiting list for the SREIA programme. When necessary, more participants will be recruited from elsewhere. Participation in the study will be voluntary. Reimbursements will be provided to participants who complete all data collection.

There will be approximately ten programme facilitators. Only facilitators who have provided informed consent will participate in the assessment of the programme implementation (see below for further detail). Five programme managers will be invited to take part in an interview, but only those who provide informed consent will take part.

Interventions

The SREIA parent training programme is delivered in the SREIA implementation organisation in Beijing. It is grounded in Applied Behaviour Analysis (ABA) and developmental theories.[59,60] It aims to promote positive behaviours and child development by improving parenting skills, teaching parents ABA techniques, changing parental attitude. It is delivered five days a week, with three hours in the morning and two hours in the afternoon, for 11 weeks. Fourteen two-hour lectures on weekly themes are offered throughout the 11 weeks and attended by all participating parents (Table 1). For the remaining time, additional hands-on trainings are provided and tailored for different functioning levels. The programme is delivered in person through a combination of individual counselling and group sessions, as well as a mixture of didactic and interactive delivery modes. Some sessions are only for parents, while others are participated by parent-child dyads. Childcare is provided during parent group sessions. A wide range of session types and delivery methods are used in the training and listed in Table 1.

The SREIA offers two versions of the programme, which are delivered concurrently, with the purpose of

exploring ways to reduce cost while improving outcomes. All teaching and practice sessions are delivered separately for each group. In Version A, families are divided into two groups based on the functioning levels of children, which is assessed using the Autism Treatment Evaluation Checklist (ATEC) and the VB-MAPP.[12,78] The two functioning groups in Version A practice new skills separately but attend all teaching sessions together. In Version B, participating families are divided into three groups based on children's levels of functioning. Apart from the different delivery formats, Version A also contains an extra individual therapist-child session that is provided each day. Other than that, the two versions share the same content.

Table 1 Programme topics and delivery techniques

Topics	Delivery Techniques
Knowledge of ASD and child development	Didactic presentation
Child behavioural problems and behaviour management techniques based on ABA, including reinforcement (praise & rewards), prompts, fading, shaping, and chaining	Facilitator observation
Instruction giving	Facilitator modelling new techniques
Ignore	Cases and stories
Redirect	Practice in sessions and in-vivo feedback
Parent-child communication and interaction	Homework and feedback
Emotional labelling	Group discussion
Fine and gross motor skills	Physical activity
Child cognitive development	Informal peer support group
TEACCH – "Structured TEACCHing"	Reinforcement and active listening by facilitators
Communicate with family members	
Parental self-regulation	
Parental attitude and expectation	
Skill maintenance and generalisation	
Make a plan for the future	

Sample size

The review conducted by Fang, Barlow, and Zhang[8] showed that parent training programmes for families of children with ASD aged one to eleven in China had an effect size of g = -1.37 (95% CI [-2.03, -0.71]) on child emotional and behavioural problems, whereas Postorino et al.[6] found a smaller effect size SMD = -0.59 (95% CI, [-0.88, -0.30]) in reducing disruptive behaviours in children with ASD aged between two to fourteen years. The power calculation was based on Postorino et al.[6] in order to increase the statistical power. The sample size calculation shows that with a significance level of 0.05 and statistical power of 0.8 in a two-sample, two-tailed t-test, the sample size necessary to detect any significant effect is 94 (47 in each arm).

Since the study will be conducted in a routine setting by an implementation organisation with limited capacity, it will involve two rounds of delivery with a total sample size of 100. This will enable a minimal detectable effect size of g = -0.57 on the primary outcome measure. Allowing for an attrition rate of 5%, the proposed sample size can give a detectable change in the region of approximately g = -0.58. The two rounds of delivery will also in total comprise of 60 families in Version A and 40 in Version B, which can potentially detect a difference of g = 0.-58 in the two versions.

Outcomes and Measures

Table 2 provides an overview of the measures that will be used to assess the outcomes in this study. For questionnaires that do not have a Chinese version, the translation followed the WHO guideline of *Process of Translation and Adaptation of Instruments*.[17]

Table 2. Outcomes and measures.

Outcomes	Time Points*			Measures	Hypotheses	Items
	1	2	3			
Demographic Characteristics	✔			A demographic questionnaire		23
Primary Outcome Child Externalising Problems	✔	✔	✔	Child Behaviour Checklist (CBCL) for Age 1.5-5, Externalising scale	The SREIA programme will significantly reduce child behaviour problems, in comparison to the waitlist control group.	24
Secondary Outcomes ASD Symptoms	✔	✔	✔	Autism Treatment Evaluation Checklist (ATEC), total score	The SREIA programme will significantly reduce child ASD symptoms, in comparison to the waitlist control group.	77
Parenting Style	✔	✔	✔	Arnold-O'Leary Parenting Scale (PS), Over-reactivity subscale	The SREIA programme will significantly reduce parental over-reactivity, in comparison to the waitlist control group.	10
				Parenting Young Children (PARYC), Supporting Positive Behaviour subscale	The SREIA programme will significantly increase positive parenting behaviours, in comparison to the waitlist control group.	7
Parental mental health	✔	✔	✔	Depression Anxiety Stress Scale-21 (DASS-21), total score	The SREIA programme will significantly reduce parental mental health symptoms, in comparison to the waitlist control group.	21
Family Function	✔	✔	✔	Adaptation, Partnership, Growth, Affection & Resolve (APGAR), total score	The SREIA programme will significantly improve family relationships, in comparison to the waitlist control group.	5
Parental Knowledge	✔	✔	✔	A questionnaire designed for the evaluation	The SREIA programme will significantly increase parental knowledge of ASD and child behaviours, in comparison to the waitlist control group.	21
Implementation Aspects						
Programme Acceptability		✔		A satisfaction questionnaire based on the Incredible Years® Autism Programme End of Course Satisfaction Questionnaire		44
			✔	Interviews with parents/primary caregivers and programme managers, focus groups with facilitators, and supervision sessions		
Participant Involvement	✔			Attendance sheet		

				Engagement checklist		
				Routine records (dropout rates)		
		✔		Interviews with parents/primary caregivers		
Implementation	✔			Facilitator checklists.		
				Hours of delivery		
				A quality of delivery questionnaire		24
		✔		Interviews with parents/primary caregivers and programme managers, focus groups with facilitators, and supervision sessions		
Programme Sustainability			✔	Interviews with programme managers		

Primary outcome

Child behavioural problems will be assessed using the *Externalising* scale of the Child Behaviour Checklist (CBCL) for Ages 1.5-5.[9] It measures child *attention problems* and *aggressive behaviours* using 24 items rated by parents with a 3-point -type scale. The study will administer the CBCL 1.5-5 for all families, because 1) it is anticipated that the majority of children will be under six, 2) Basen et al.[10] found the same level of internal consistency of CBCL 1.5-5 in children with ASD aged five and those aged six, and 3) many items in the *Externalising* scale of CBCL 6-18 (e.g. "drink alcohol", "lie/cheat", "use tobacco or drugs", and "truant") are not applicable for children with ASD aged six. Several studies have used the CBCL 1.5-5 for typically developing children slightly older than five years old[79–81] and for children with ASD of a broader age range,[82] and found it sensitive to capture behavioural concerns. To increase the sensitivity to change, the recall period of the questionnaire was set as the previous one month, instead of two. Lower scores suggest fewer behavioural problems.

The CBCL 1.5-5 has shown excellent internal consistency and factorial validity with children with ASD.[83] One study demonstrated good cross-cultural factorial validity of the Chinese version in mainland China,[11] and another study showed excellent internal consistency and marginal factorial validity among Chinese girls adopted into North American families.[84]

Secondary outcomes

ASD symptoms will be assessed using the Chinese version of the Autism Treatment Evaluation Checklist (ATEC),[12] which comprise four subscales to measure child *speech/language/communication*, *sociability*, *sensory/cognitive awareness*, and *health/physical/behaviour*. The scale has 77 items that are scored by parents recalling child performance during the previous month. Higher scores represent more ASD symptoms. The Chinese version of ATEC has shown sufficient internal consistency in children with ASD in mainland China.[85]

Parenting style will be measured using the *Over-Reactivity* subscale (10 items) of the Arnold-O'Leary Parenting Scale (PS),[13] and the *Supporting Positive Behaviour* subscale (7 items) of the Parenting Young Children Scale (PARYC).[14] The PS assesses dysfunctional discipline practices by parents self-reporting their parenting styles during the previous month using a 7-point Likert-type scale. Higher scores indicate more dysfunctional parenting practices. The *PS Over-Reactivity* subscale has demonstrated adequate internal consistency and test-retest reliability in Chinese population, as well as a significant correlation with CBCL.[13,86]

The PARYC *Supporting Positive Behaviour* subscale is rated by parents from 1 to 7 regarding the frequency with which they engaged in such parenting strategies during the previous month. Higher scores represent more positive and proactive parenting practices. The PARYC has been used to examine the association between child behavioural problems and positive parenting practice for children with and without developmental disabilities in the US.[87] It has also been commonly used in the parent training programmes delivered in other developing countries.[88–91] It has demonstrated sufficient construct and convergent validity and good internal consistency.[14]

Parental mental health will be assessed using the Chinese version of the Depression Anxiety Stress Scale-21 items (DASS-21),[15] which consists of three self-report subscales (*depression, anxiety,* and *stress*) rated from 0 to 3 based on performance over the past week. Lower scores indicate a better emotional state. The Chinese version has been shown to have good internal consistency, test-retest reliability, and convergent validity in mainland China and Chinese population in other parts of Asia.[92–97]

Family function will be assessed using the Chinese version of the Family APGAR scale,[16] which consists of 5 items rated from 0 to 2 based on experience during the past two weeks, to examine the five functional components of *adaptability*, *partnership, growth*, *affection*, and *resolve.* Higher scores indicate that parents are more satisfied with their relationships with other family members. The Chinese version of this scale has demonstrated good internal consistency in China.[98–100]

Parental knowledge will be measured using of a questionnaire designed for the SREIA evaluation to assess parental understanding of ASD and child development.

Process evaluation

The implementation of the programme will be explored regarding four criteria: *programme acceptability*, *participant involvement*, *programme delivery*, and *sustainability*.

Programme Acceptability will be assessed at post-intervention only using a questionnaire based on the Incredible Years® Autism Programme End-of-Course Satisfaction Questionnaire[18] tailored to the SREIA programme and Chinese context. The 30-item questionnaire covers a range of topics including

overall impression; teaching format; information and techniques; facilitators; and parent groups. High scores represent higher levels of satisfaction.

The level of *participant involvement* will be captured by calculating rates of *attendance*, *engagement*, and *programme dropout*. The *attendance rate* will be assessed with an attendance sheet, which will be reported by facilitators and collected once a day; *engagement rate* will be based on the percentage of families rated as highly engaged by facilitators, using the attendance and engagement registry; *programme dropout rate* will be calculated based on families who miss at least ten days.

Programme Delivery will be measured through two dimensions—fidelity and quality of delivery. *Implementation fidelity* will be measured using facilitator checklists filled out by facilitators each week. The fidelity score will comprise the ratio of delivered components to prescribed components. Dosage will be calculated using hours of delivery. *Quality of delivery* will be assessed by research staff observing sessions and filling out a quality of delivery survey.

Programme Acceptability, Participants involvement, and *Programme Delivery* will also be investigated by in-depth interviews with parents and programme managers, focus group discussion with facilitators, and supervision notes.

Programme Sustainability will be explored during the qualitative interviews with programme managers, which will be guided by the RE-AIM (reach, effectiveness, adopt, implementation, and maintenance) framework.[101] The interviews will focus on community- and policy-level factors that may affect programme sustainability and scale-up.

Data collection, management, and analysis

Data collection methods

All data collectors will be trained. The three data collection time points include baseline, immediate post-intervention, and six months after the end of delivery (conditional to funding). Data collectors will administer the questionnaires with parents online.

Qualitative individual interviews will be conducted with approximately 15 parents, with the final number depending on when data saturation is reached. Interviewees will be purposively sampled according to the engagement rates and satisfaction levels. Each interview will last for a maximum of 90 minutes. Interviews with parents will be undertaken online after the completion of the programme. Focus groups will be conducted with approximately ten SREIA facilitators online at post-intervention, with each lasting for two hours. Five programme managers will be also individually interviewed for 90 minutes. Supervision sessions will also be recorded by supervisors taking notes.

A semi-structured interview schedule will be developed to guide the interviews and focus groups. Open-ended questions will be used to stimulate reflection and discussion. The interviews with parents and facilitators will cover the following topics: 1) understanding and use of skills (parents), 2) perceived changes in child and parental outcomes (parents); 3) barriers to, facilitators of, and strategies to overcome the challenges of delivery (facilitators) and participation (parents); and 4) acceptability and appropriateness of programme delivery and content (parents and facilitators). The interviews with programme managers will be structured to probe five dimensions that affect intervention impact including programme reach, effectiveness, adopt, implementation, and maintenance (RE-AIM) [101].

Blinding

Due to the nature of parent training and the use of a waitlist control group, it will not be possible to blind participants or facilitators. However, research staff who collect the data will be blinded for the baseline and immediate post-intervention assessment. Data collectors will not be involved in the delivery process and will be trained on the topic of risk of bias. Parents will also be asked to keep their allocation condition private from outcome data collectors. Process evaluation data will be collected by a separate group of research staff. Blinding will be protected and monitored, while the violation of blinding will be detected and incorporated into the interpretation of results.

Data management

All electronic data will be transferred to the study's Nexus365 OneDrive for Business, which is supported by the University of Oxford and meets the University's security requirements. Electronic data will also be backed up regularly into an encrypt hard drive which will be stored in a password-protected closet. All data will be pseudonymised. An ID number will be assigned to each participants after they give consent. The linkage between the ID number and participant personal details will be stored with other electronic data. Only the research team will have access to data in the central drive and the locked closet.

Data analysis-quantitative data

Quantitative data analyses will be conducted using R Studio.[102] Data analysis will follow the principles of intent-to-treat, which involves assessing all participants as originally allocated, regardless of programme dropouts or the dose of treatment they received. Where appropriate, full-information maximum likelihood (FIML) will be used to compensate for missing data.[103]

A table showing the demographic characteristics of participants will be compiled (M±SD for continuous variables and percentages for categorical variables). Baseline differences in demographic characteristics and outcome measures will be explored using two independent samples t-tests and chi-square tests (significant level $p<0.05$).

The primary analysis will comprise a between-group comparison for the treatment and the waitlist control groups after the first wave of delivery (T1) to investigate the treatment effects. To reduce selection bias and improve baseline balance for the between-group comparison, the treatment effects of the intervention will be estimated using a difference-in-differences (DiD) design with inverse propensity score weights.[104] The weighting of propensity scores will help to keep all available data in the analysis, in order to improve the statistical power. Propensity scores will be calculated using logistic regression based on key variables that may affect intervention effects, including baseline outcome scores (i.e., child behaviour problems, ASD severity, parenting styles, parental mental health, parental knowledge, and family function) and child gender. With the propensity scores, the treatment and control groups will be weighted to be balanced on the key variables; weighted regression models will then be fitted for the DiD analyses, which further adjust for unobserved variables and secular time trends. Clustering effects within each treatment condition and child levels of functioning group will also be accounted for when appropriate. Exploratory statistical analyses will be conducted to understand the differences in treatment effects between the two different versions of delivery. Attrition weights for programme dropouts (if any) will be combined.

Means and standard deviations will be calculated for participant satisfaction, attendance rate, engagement rate, programme dropout rate, and quality of delivery. Implementation fidelity will be reported using a ratio of delivered components to prescribed components. Regression models will be created to explore potential predictors of participant involvement, as well as investigate possible associations between implementation aspect and treatment effects. Participant characteristics will be controlled for in the regression analyses.

Data analysis-qualitative data

Interview data will be transcribed and coded using ATLAS.ti 8. A thematic analysis will be carried out using a contextualist framework, which is a mixture of essentialist and constructionist perspectives and combines the traditionally data-driven approach with a theory driven approach.[105] A coding framework will be developed according to the topics covered by the interviews and focus group discussions. Transcripts will be read and re-read to generate initial codes, which will be organised into the priori framework. Initial codes will then be grouped into potential themes regarding participant involvement, programme acceptability, delivery, and sustainability. The codes and themes will be reviewed by another research member, together with whom, the themes will be refined, defined, and reported as key themes. Pseudoanonymised data will be extracted to present and discuss the themes.[105–107] To further understanding about the programme effects, the qualitative data will also be explored separately for parents who exhibit high and low attendance rates and satisfaction levels.

Several efforts will be made to improve the trustworthiness of the thematic analysis. The data will be collected from multiple sources. All interviews will be conducted privately with research staff reassuring participants about confidentiality. To capture all points made by the participants, all conversations (except supervision sessions) will be audio-recorded with permission and transcribed verbatim. To further improve the reliability, research member with substantial experience in thematic analysis will review all the codes and themes before they are finalised. A reflexive approach will be taken in order to take account of the fact that background and knowledge of research staff can shape the data collection and analysis.[107,108] The generalizability of interview data will also be discussed when interpreting the results.[108,109]

Patient and public involvement statement

The implementation organisation of Beijing SREIA was involved in the planning of the research, by contributing to the development of research questions, the demographic questionnaire, satisfaction survey, and the interview and focus group guides. The recruitment of participants and implementation of parent training programmes will be undertaken by the Beijing SREIA using its existing resources. Interviews with SREIA facilitators and managers will investigate their experiences of participating in the

research. The Beijing SREIA will assist in conveying the research findings to all participants, as well as disseminating the results to a wider community of ASD service providers in mainland China.

ETHICS AND DISSEMINATION

Research ethics approval

Ethical approval has been obtained from the Social Science and Humanities Inter-Divisional Research Ethics Committee at University of Oxford in the UK (R67619/RE001) and Research Ethics Committee at the School of Social Development and Public Policy of the Beijing Normal University in China (SSDPP-HSC2020001).

Oral informed consent will be obtained from all participants. Confidentiality will be maintained unless the participant indicates that he or she will conduct self-injurious behaviours, or there are any concerns about possible child abuse events, for which appropriate action will be taken in adherence to the Child Protection Protocol and in terms of informing the relevant authority.

Monitoring

The study protocol and data analysis plan have been registered in ClinicalTrials.gov and Open Science Framework in accordance with transparency in scientific research principles. Any potential harm or adverse events identified by the staff will be reported to the principal investigators, who will investigate the event and report to ethics committees before deciding whether to continue the study.

Dissemination

A brief report of study results in plain language will be shared with all participants. The study will result in several publications in peer-reviewed journals and presentations in local and international conferences. The findings will be used by the implementation organisation for programme modification and be incorporated into the organisation's annual report.

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Appendix E Data Collection Tools in Chapter 4 Paper 2

1. Baseline demographic questionnaire

Contact Details	
Adult Participant Name	
Address	
Telephone 1	
Telephone 2	
WeChat ID	
Child Information	
Name	
Gender	
Age	
Ethnicity	
Comorbidity	**□Intellectual Disability □Hearing Impairment** **□Vision Impairment □Language Disorder** **□Physical Impairment □Emotional Disorder** **□Learning Disorder □Epilepsy □Seizure** **□Sleep problems □other, _____**
Health History	**□Meningitis □Jaundice □Brain Injury** **□Encephalitis □Convulsion □Phenylketonuria** **□Gastrointestinal disease,** describe disease name and severity: _____ **□other, _____**
Previous Rehabilitation	**□Yes,** describe_____ **□No**
Family Information	
Hukou Type	**□rural □urban**
Family Annual Income	
Number of children in the household	
Adult Participant Information	
Age	
Ethnicity	
Education	**□middle school or lower □high school □college** **□graduate programme or higher □other, _____**
Employment	**□unemployed □self-employed** **□employed full-time □employed part-time** **□other, _____**
Spouse	**□unemployed □self-employed**

employment	**□employed full-time □employed part-time □other, _____**
Daily 1-on-1 time	**□<3h □3-6h □>6h**
Disability	**□Yes, describe_____ □No □Prefer not to say**

2. Outcome measures

i) Child Behaviour Checklist for Age 1.5-5, Externalizing scale

CAREGIVER REPORT FORM FOR AGE 1.5-5	
Below is a list of items that describe children. For each item that describes the child now or within the past one month. Please circle the 2 if the item is very true or often true of the child. Circle the 1 if the item is somewhat or sometimes true of the child. If the item is not true of the child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to the child. **0 = Not True (as fare as you know)** **1 = Somewhat or Sometime True** **2 = Very True or Often True**	
5 Can't concentrate, can't pay attention for long	□0 □1 □2
6 Can't sit sill, restless, or hyperactive	□0 □1 □2
56 Poorly coordinated or clumsy	□0 □1 □2
59 Quickly shifts from one activity to another	□0 □1 □2
95 Wanders away	□0 □1 □2
8 Can't stand waiting; wants everything now	□0 □1 □2
15 Defiant	□0 □1 □2
16 Demands must be met immediately	□0 □1 □2
18 Destroys property belonging to others	□0 □1 □2
20 Disobedient	□0 □1 □2
27 Doesn't seem to feel guilty after misbehaving	□0 □1 □2
29 Easily frustrated	□0 □1 □2
35 Get in many fights	□0 □1 □2
40 Hits other	□0 □1 □2
42 Hurts animals or people without meaning to	□0 □1 □2
44 Angry moods	□0 □1 □2
53 Physically attacks people	□0 □1 □2
58 Punishment doesn't change his/her behaviour	□0 □1 □2
66 Screams a lot	□0 □1 □2
69 Selfish or won't share	□0 □1 □2

81 Stubborn, sullen, or irritable	□0 □1 □2
85 Temper tantrums or hot temper	□0 □1 □2
88 Uncooperative	□0 □1 □2
96 Wants a lot of attention	□0 □1 □2
Total (out of 48):	

ii) Autism Treatment Evaluation Checklist

ARI/Form
ATEC-1/11-99

Autism Treatment Evaluation Checklist (ATEC)

Bernard Rimland, Ph.D. and Stephen M. Edelson, Ph.D.
Autism Research Institute
4182 Adams Avenue, San Diego, CA 92116
fax: (619) 563-6840; www.autism.com/ari

Project/Purpose:				
Scores: I	II	III	IV	Total

This form is intended to measure the effects of treatment. Free scoring of this form is available on the Internet at: www.autism.com/atec

Name of Child _____ _____ ☐ Male Age _____
Last First ☐ Female Date of Birth _____
Form completed by: _____ Relationship: _____ Today's Date _____

Please circle the letters to indicate how true each phrase is:

I. Speech/Language/Communication: *[N] Not true [S] Somewhat true [V] Very true*

N S V 1. Knows own name
N S V 2. Responds to 'No' or 'Stop'
N S V 3. Can follow some commands
N S V 4. Can use one word at a time (No!, Eat, Water, etc.)
N S V 5. Can use 2 words at a time (Don't want, Go home)
N S V 6. Can use 3 words at a time (Want more milk)
N S V 7. Knows 10 or more words
N S V 8. Can use sentences with 4 or more words
N S V 9. Explains what he/she wants
N S V 10. Asks meaningful questions
N S V 11. Speech tends to be meaningful/ relevant
N S V 12. Often uses several successive sentences
N S V 13. Carries on fairly good conversation
N S V 14. Has normal ability to communicate for his/her age

II. Sociability: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V 1. Seems to be in a shell – you cannot reach him/her
N S V 2. Ignores other people
N S V 3. Pays little or no attention when addressed
N S V 4. Uncooperative and resistant
N S V 5. No eye contact
N S V 6. Prefers to be left alone
N S V 7. Shows no affection
N S V 8. Fails to greet parents
N S V 9. Avoids contact with others
N S V 10. Does not imitate
N S V 11. Dislikes being held/cuddled
N S V 12. Does not share or show
N S V 13. Does not wave 'bye bye'
N S V 14. Disagreeable/not compliant
N S V 15. Temper tantrums
N S V 16. Lacks friends/companions
N S V 17. Rarely smiles
N S V 18. Insensitive to other's feelings
N S V 19. Indifferent to being liked
N S V 20. Indifferent if parent(s) leave

III. Sensory/Cognitive Awareness: *[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive*

N S V 1. Responds to own name
N S V 2. Responds to praise
N S V 3. Looks at people and animals
N S V 4. Looks at pictures (and T.V.)
N S V 5. Does drawing, coloring, art
N S V 6. Plays with toys appropriately
N S V 7. Appropriate facial expression
N S V 8. Understands stories on T.V.
N S V 9. Understands explanations
N S V 10. Aware of environment
N S V 11. Aware of danger
N S V 12. Shows imagination
N S V 13. Initiates activities
N S V 14. Dresses self
N S V 15. Curious, interested
N S V 16. Venturesome - explores
N S V 17. "Tuned in" — Not spacey
N S V 18. Looks where others are looking

IV. Health/Physical/Behavior: *Use this code: [N] Not a Problem [MI] Minor Problem [MO] Moderate Problem [S] Serious Problem*

N MI MO S 1. Bed-wetting
N MI MO S 2. Wets pants/diapers
N MI MO S 3. Soils pants/diapers
N MI MO S 4. Diarrhea
N MI MO S 5. Constipation
N MI MO S 6. Sleep problems
N MI MO S 7. Eats too much/too little
N MI MO S 8. Extremely limited diet
N MI MO S 9. Hyperactive
N MI MO S 10. Lethargic
N MI MO S 11. Hits or injures self
N MI MO S 12. Hits or injures others
N MI MO S 13. Destructive
N MI MO S 14. Sound-sensitive
N MI MO S 15. Anxious/fearful
N MI MO S 16. Unhappy/crying
N MI MO S 17. Seizures
N MI MO S 18. Obsessive speech
N MI MO S 19. Rigid routines
N MI MO S 20. Shouts or screams
N MI MO S 21. Demands sameness
N MI MO S 22. Often agitated
N MI MO S 23. Not sensitive to pain
N MI MO S 24. "Hooked" or fixated on certain objects/topics
N MI MO S 25. Repetitive movements (stimming, rocking, etc.)

iii) Arnold-O'Leary Parenting Scale, Over-reactivity subscale

For each item, circle the number that best describes your style of parenting.

When I'm upset or under stress... I am picky and on my child's back	1	2	3	4	5	6	7	I am no more picky than usual.
When my child misbehaves... I usually get into a long argument with my child	1	2	3	4	5	6	7	I don't get into an argument.
When my child misbehaves... I raise my voice or yell.	1	2	3	4	5	6	7	I speak to my child calmly.
After there's been a problem with my child... I often hold a grudge.	1	2	3	4	5	6	7	things get back to normal quickly.
When there's a problem with my child... things build up and I do things I don't mean to do.	1	2	3	4	5	6	7	things don't get out of hand.

iv) Parenting Young Children, Supporting Positive Behaviour subscale

Item	**Not at all**						**Most of the time**
Play with your child in a way that was fun for both of you?	1	2	3	4	5	6	7
Stand back and let your child work through problems s/he might be able to solve?							
Invite your child to play a game with you or share an enjoyable activity?							
Notice and praise your child's good behaviour?							
Teach your child new skills?							
Involve your child in household chores?							
Reward your child when s/he did something well or showed a new skill?							

v) Depression Anxiety Stress Scale-21

DASS21

Name: Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree or a good part of time
3 Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

vi) Adaptation, Partnership, Growth, Affection & Resolve

Table 3. Family APGAR Questionnaire

	Almost always	Some of the time	Hardly ever
I am satisfied with the help that I receive from my family* when something is troubling me.	____	____	____
I am satisfied with the way my family* discusses items of common interest and shares problem solving with me.	____	____	____
I find that my family* accepts my wishes to take on new activities or make changes in my life-style.	____	____	____
I am satisfied with the way my family* expresses affection and responds to my feelings such as anger, sorrow, and love.	____	____	____
I am satisfied with the amount of time my family* and I spend together.	____	____	____

Scoring: The patient checks one of three choices which are scored as follows: 'Almost always' (2 points), 'Some of the time' (1) point, or 'Hardly ever' (0). The scores for each of the five questions are then totaled. A score of 7 to 10 suggests a highly functional family. A score of 4 to 6 suggests a moderately dysfunctional family. A score of 0 to 3 suggests a severely dysfunctional family.
*According to which member of the family is being interviewed the physician may substitute for the word 'family' either spouse, significant other, parents, or children.

vii) Parental Knowledge Questionnaire

Family ID:	
Staff:	
Date:	
Questions	**Answers**
1. You think you child:	▫ Just can't talk ▫ Can talk but doesn't want to ▫ Just doesn't want to play with kids of the same age ▫ Has poor social skill in general

2. You consider a child with ASD as being able to talk, when he/she can:	▫ Repeat TV commercials or say Mom/Dad once in a while ▫ Sing kids songs ▫ Imitate upon adult requests ▫ Actively express needs ▫ Communicate with others and express feelings using verbal language
3. Do you think children should receive motor skill training?	▫ Yes ▫ No
4. Do you think child language development is related to child motor skill development?	▫ Yes ▫ No
5. How do you think your child's language skills can be improved?	▫ Force him/her to talk ▫ Imitate the sounds ▫ Start from imitating body movements
6. What do you think of child social skills?	▫ It's not important, as long as the child can speak. ▫ He/she will have social skills when he/she is older. ▫ We should work on that.
7. What do you think makes your child not being able to socialise?	▫ Being too timid. ▫ Lacking social skills. ▫ Living in an environment where there is a lack of opportunity to interact with others.
8. Do you take your child to public places?	▫ Never ▫ Sometimes to the park ▫ Often ▫ I encourage him/her to play with other children.
9. How do you feel when your child has behavioural problems?	▫ Being irritable and angry ▫ Blaming your child and losing self-confidence ▫ Being disappointed and giving up ▫ Never giving up and staying calm
10. What do you do when your child has a problem?	▫ Give in ▫ Threaten ▫ Make promises ▫ Don't know what to do ▫ Try to find a way to solve the problem
11. What do you do when your child has a behavioural problem?	▫ You don't know why and give in. ▫ You don't know why and reprimand him/her.

	▫ You find out why and give in. ▫ You find out why and reprimand him/her. ▫ You coax him/her. ▫ You ignore him/her.
12. What do you do if you child can't acquire a skill?	▫ You think he/she is not smart enough and reprimand him/her. ▫ You feel disappointed and give up. ▫ You believe that he/she will acquire the skill and he/she just needs some more time. ▫ You think you adjust your teaching methods and try again.
13. When you child does what you ask him/her to do, do you praise him/her?	▫ Never ▫ Sometimes ▫ Often
14. When you make a promise to your child, you:	▫ Never make a promise. ▫ Forget about it. ▫ Sometimes keep the promise. ▫ Always keep the promise.
15. When you help your child, you think:	▫ As long as it can cure the child, you don't have to consider what the child thinks or feels. ▫ You hope it can cure him/her but sometimes you also consider how he/she feels. ▫ You respect and understand your child.
16. What do you think is the best way to help your child?	▫ Medication ▫ Acupuncture ▫ Supernatural power ▫ Sensory integration training ▫ Hearing therapy ▫ Comprehensive educational training
17. When you teach your child, you	▫ Primarily use punishment (including reprimand), and sometime use physical punishment when needed. ▫ Combine rewards and punishment. ▫ Only use rewards and no physical punishment. ▫ Primarily use rewards and pay close attention to your child's reaction.
18. How long do you think your child will need intervention or treatment?	▫ Until he/she starts to speak. ▫ Until he/she goes to school. ▫ Until he/she starts to work. ▫ He/she needs lifelong intervention.
19. What do you think determine the effects	▫ Your child's intellectual ability.

of training? (multiple choices)	▫ Parental emotional state. ▫ Parental education level. ▫ Training methods.
20. How do you train your child? (multiple choices)	▫ Train without any plan or specific goal. ▫ Train once in a while. ▫ Train everywhere at anytime. ▫ Train with a plan and a clear goal. ▫ Train within a specific timeframe.
21. Regarding your child, you and your family:	▫ Have totally different opinions and can't communicate. ▫ Have different opinions but can communicate. ▫ Have reached consensus.

3. Implementation measures

i) Satisfaction questionnaire

Participant ID: _____

Date: _____

The following questionnaire is part of our evaluation of the SREIA parent training programme that you have participated in. It is important that you answer as honestly as possible. The information obtained will help us to evaluate and continually improve the programme we offer. Your cooperation is greatly appreciated. All responses will be strictly confidential.

➢ The Overall Programme

Please circle the response that best expresses how you honestly feel at this point as a result of participating this programme.

1. My child's behavioural problems are

Worse-0	The same-1	Improved-2

2. My child's emotional problems are

Worse-0	The same-1	Improved-2

3. My child's social and communicational skills are

Worse-0	The same-1	Improved-2

4. My overall feelings about my personal progress at using the skills taught in the SREIA programme are that I am

Pessimistic-0	Neutral-1	Optimistic-2

5. I feel that the approach used to improve my child's behavioural and emotional adjustment

in this programme is

Inappropriate-0	Neutral-1	Appropriate-2

6. I feel that the approach used to improve my child's social and communicational skills in this programme is

Inappropriate-0	Neutral-1	Appropriate-2

7. Would you recommend the programme to a friend or relative?

Recommend-0	Neutral-1	Recommend-2

➢ Teaching Format

In this section, we would like you to indicate how useful each of the following types of teaching is for you now. Please circle the response that most clearly describes our opinion.

1. Didactic large group sessions were

Useless-0	Neutral-1	Useful-2

2. Teaching sessions and lectures in small groups were

Useless-0	Neutral-1	Useful-2

3. Demonstration of skills through facilitator modeling was

Useless-0	Neutral-1	Useful-2

4. Practice of skills within sessions was

Useless-0	Neutral-1	Useful-2

5. Receiving in-vivo feedbacks was

Useless-0	Neutral-1	Useful-2

6. Homework was

Useless-0	Neutral-1	Useful-2

7. Sharing experiences in groups was

Useless-0	Neutral-1	Useful-2

8. Weekly review sessions to revisit skills learned in the previous week were

Useless-0	Neutral-1	Useful-2

9. Individual counseling sessions were

Useless-0	Neutral-1	Useful-2

10. Quizzes were

Useless-0	Neutral-1	Useful-2

➢ Specific Techniques

In this section, we would like to get your ideas of how useful each of the following techniques is in improving your interactions with your child. Please circle the response that most accurately describes the usefulness of the technique.

1. Knowledge of Autism Spectrum Disorder

Useless-0	Neutral-1	Useful-2

2. ABA techniques and Discrete Trial Training (DTT)

Useless-0	Neutral-1	Useful-2

3. TEACCH

Useless-0	Neutral-1	Useful-2

4. Behaviour management techniques—functional behaviour assessment

Useless-0	Neutral-1	Useful-2

5. Reinforcement

Useless-0	Neutral-1	Useful-2

6. Parent-child communication (Augmentative and alternative communication; Picture Exchange Communication System)

Useless-0	Neutral-1	Useful-2

7. Differential reinforcement and prompt

Useless-0	Neutral-1	Useful-2

8. Fading prompts

Useless-0	Neutral-1	Useful-2

9. Shaping

Useless-0	Neutral-1	Useful-2

10. Chaining

Useless-0	Neutral-1	Useful-2

11. Generation and Maintenance

Useless-0	Neutral-1	Useful-2

12. Fine motor skills

Useless-0	Neutral-1	Useful-2

13. Music and physical activities

Useless-0	Neutral-1	Useful-2

- Evaluation of Facilitators

In this section, we would like you to express your opinions about your group facilitators. Please circle the response to each question that best describes how you feel.

Facilitator #1 _____

1. I feel that the facilitator's teaching was

Poor-0	Average-1	Good-2

2. The facilitator's preparation was

Poor-0	Average-1	Good-2

3. Concerning the facilitator's interest and concern in me and my child, I was

Dissatisfied-0	Neutral-1	Satisfied-2

4. At this point, I feel that the facilitator in the programme was

Unhelpful-0	Neutral-1	Helpful-2

Facilitator #2 _____

1. I feel that the facilitator's teaching was

Poor-0	Average-1	Good-2

2. The facilitator's preparation was

Poor-0	Average-1	Good-2

3. Concerning the facilitator's interest and concern in me and my child, I was

Dissatisfied-0	Neutral-1	Satisfied-2

4. At this point, I feel that the facilitator in the programme was

Unhelpful-0	Neutral-1	Helpful-2

- **Parent Group**

In this section, we would like to get your idea about your group. Please circle the response that best describes how you feel.

1. I feel the group was

Unsupportive-0	Neutral-1	Supportive-2

2. Concerning other group members' interest in me and my child, I felt they were

Uninterested-0	Neutral-1	Interested-2

3. I would like to keep meeting in-person or online as a group

No-0	Don't know-1	Yes-2

4. How likely is it that you will continue interacting with one or more of the parents in your group?

Unlikely-0	Neutral-1	Likely-2

➢ Your Opinion

1. How could the programme have been improved to help you more?

2. At this time, do you feel the need for additional parenting assistance? Please explain.

3. What did you see at the main benefit of the SREIA parent training programme?

Thank you for your patience in answering all these questionnaires. Your input is very much appreciated, and really helps us to plan future programmes.

Total score (out of 84)	

ii) Attendance and engagement registry

SREIA ATTENDANCE AND ENGAGEMENT REGISTRY
Attendance: whether the caregiver attended all, part, or none of today's sessions.
Engagement: please judge the level of engagement by considering the following criteria: 1. responsiveness to practitioners 2. interactions with other caregivers 3. participation in group discussion 4. completion of homework activities

Please feel free to provide additional comments at the end of the survey. Thank You!			
Date:			
Family 1	Absence		0
	Partial attendance	with low engagement	1
		with average engagement	2
		with high engagement	3
	Full attendance	with low engagement	4
		with average engagement	5
		with high engagement	6
Family 2	Absence		0
	Partial attendance	with low engagement	1
		with average engagement	2
		with high engagement	3
	Full attendance	with low engagement	4
		with average engagement	5
		with high engagement	6
Family 3	Absence		0
	Partial attendance	with low engagement	1
		with average engagement	2
		with high engagement	3
	Full attendance	with low engagement	4
		with average engagement	5
		with high engagement	6
Family 4 - 10	……	……	……

iii) Quality of delivery survey

The following is a guide for conducting observation of programme delivery. Observers should also feel free to comment on each item and the overall process in a narrative format.

Observer	
Date	
Time	
Facilitator Name	
Group	
Session	

Number of participants	

- General skills

5. Knowledge of content

Poor-0	Average -1	Good-2	Superior-3
Comments			

6. Teaching skills

Poor-0	Average -1	Good-2	Superior-3
Comments			

7. Time management skills

Poor-0	Average -1	Good-2	Superior-3
Comments			

8. Create an atmosphere where participants feel comfortable and relaxed

Poor-0	Average -1	Good-2	Superior-3
Comments			

9. Review content discussed in previous sessions

Poor-0	Average -1	Good-2	Superior-3

Comments

10. Build on existing knowledge of participants

Poor-0	Average -1	Good-2	Superior-3
Comments			

11. Interested in and concerned with participants' responses

Poor-0	Average-1	Good-2	Superior-3
Comments			

12. Make participants feel heard and valued

Poor-0	Average-1	Good-2	Superior-3
Comments			

13. Sensitive to participants' feelings and experiences during the session

Poor-0	Average-1	Good-2	Superior-3
Comments			

14. Encourage participants to share their perspectives of the content being discussed

Poor-0	Average -1	Good-2	Superior-3
Comments			

15. Encourage participants to come up with their own problem-solving strategies

Poor-0	Average-1	Good-2	Superior-3
Comments			

16. Recognise and praise participants' progress

Poor-0	Average-1	Good-2	Superior-3
Comments			

17. Recognise and help to address participants' challenges

Poor-0	Average-1	Good-2	Superior-3
Comments			

18. Maintain focus throughout the session

Poor-0	Average -1	Good-2	Superior-3
Comments			

19. Summarise key points before ending the session

Poor-0	Average-1	Good-2	Superior-3
Comments			

20. Encourage interactions between participants

Poor-0	Average -1	Good-2	Superior-3
Comments			

21. Respect cofacilitators

Poor-0	Average-1	Good-2	Superior-3
Comments			

22. Handle tension and conflicts appropriately

Poor-0	Average -1	Good-2	Superior-3
Comments			

- Additional items for modelling and practice sessions

23. Set up the space appropriately

Poor-0	Average-1	Good-2	Superior-3

Comments

24. Give clear and simple instructions

Poor-0	Average-1	Good-2	Superior-3
Comments			

25. Provide adequate support during participant practice

Poor-0	Average-1	Good-2	Superior-3
Comments			

26. Make sure all participants have adequate chance to practice

Poor-0	Average-1	Good-2	Superior-3
Comments			

27. Give clear notice of activity change in advance

Poor-0	Average-1	Good-2	Superior-3
Comments			

28. Debrief with parents after practice

Poor-0	Average-1	Good-2	Superior-3
Comments			

- Overall comments

Total score (out of 72)	

Appendix F Translation of Questionnaires

Translation of the Arnold-O'Leary Parenting Scale (PS) (D. S. Arnold, O'Leary, et al., 1993) and the Parenting Young Children (PARYC) (McEachern et al., 2012), followed the WHO guideline of *Process of Translation and Adaptation of Instruments* (World Health Organization, 2020).

1. Forward translation from English to Chinese

Myself—a bilingual translator whose mother tongue is Chinese but proficient in English—translated the English questionnaires to Chinese. I am familiar with terminology of parenting and is sensitive to both Chinese- and English-speaking cultures. Conceptual translation was emphasised rather than literal translation. Simple and short translation using lay language was prioritised.

Arnold-O'Leary Parenting Scale (PS)—Over-reactivity Scale

- When I'm upset or under stress... I am picky and on my child's back. 1 2 3 4 5 6 7 I am no more picky than usual.

  当我沮丧不安或感受到压力时，我会变得很挑剔，总是批评孩子* 7--完全没有比平时更挑剔

- When my child misbehaves... I usually get into a long argument with my child. 1 2 3 4 5 6 7 I don't get into an argument.

  当孩子有问题行为时，我经常会和他/她进行长时间的争论* 7--我~~从来~~不和他/她争论

- When my child misbehaves... I raise my voice or yell. 1 2 3 4 5 6 7 I speak to my child

calmly.

当孩子有问题行为时，我说话声音会变大，或者吼叫* 7--我说话依然十分平静

- After there's been a problem with my child... I often hold a grudge. 1 2 3 4 5 6 7 things get back to normal quickly.

  每当出问题之后，我会持续郁闷、愤恨* 7--一切很快恢复正常

- When there's a problem with my child... things build up and I do things I don't mean to do. 1 2 3 4 5 6 7 things don't get out of hand.

  当孩子有问题行为时，事情总是越积越多，导致我做（说）一些本来不想做（说）的事情* 7--事情从来不会一发不可收拾

PARYC—Supporting Positive Behaviour

- Play with your child in a way that was fun for both of you?

  和孩子一起做你们俩都觉得有趣的事情*

- Stand back and let your child work through problems s/he might be able to solve?

  尝试让孩子自己解决问题*

- Invite your child to play a game with you or share an enjoyable activity?

  邀请孩子和你一起玩游戏，或做有趣的活动

- Notice and praise your child's good behaviour?

  注意到并表扬孩子的良好行为*

- Teach your child new skills?

  教孩子新技能*

- Involve your child in household chores?

  让孩子一同做家务*

- Reward your child when s/he did something well or showed a new skill?

  当孩子表现好或者掌握新技能时，给他/她奖励*

2. Translation panel

The bilingual translation panel consisted of the forward translator (myself), an expert in child protection in China, and a professional Chinese-English translator. All panel members were native Chinese speakers but also proficient in English. The panel aimed to identify and resolve discrepancies and/or inadequate expressions/concepts of the translation. Comparable versions of the questionnaires/items were provided when available. The panel produced a complete draft of the translated questionnaires, with word in red indicating the revisions.

Arnold-O'Leary Parenting Scale (PS)—Over-reactivity Scale

- When I'm upset or under stress... I am picky and on my child's back. 1 2 3 4 5 6 7 I am no smore picky than usual.

  当我沮丧不安或感受到压力时，我会变得很挑剔，总是批评孩子* 7--并没有比平时更挑剔。

- When my child misbehaves... I usually get into a long argument with my child. 1 2 3 4 5 6 7 I don't get into an argument.

  当孩子有行为问题时，我经常会和他/她进行长时间的争论* 7--我~~从来~~不和他/她争论

- When my child misbehaves... I raise my voice or yell. 1 2 3 4 5 6 7 I speak to my child calmly.

  当孩子有行为问题时，我说话声音会变大，或者吼叫* 7--我对孩子说话依然平静

- After there's been a problem with my child... I often hold a grudge. 1 2 3 4 5 6 7 things get back to normal quickly.

  每当我和孩子之间出了问题时，我会持续~~郁闷、~~愤恨* 7--一切很快恢复正常

- When there's a problem with my child... things build up and I do things I don't mean to do. 1 2 3 4 5 6 7 things don't get out of hand.

  每当我和孩子之间出了问题时，事态容易升级，导致我做~~（说）~~一些本来不想做~~（说）~~的事情* 7--情况不会失去控制

PARYC—Supporting Positive Behaviour

- Play with your child in a way that was fun for both of you?

  和你孩子一起做你们俩都觉得有趣的事情*

- Stand back and let your child work through problems s/he might be able to solve?

  让出空间，尝试让你孩子自己解决他/她可能有能力解决的问题*

- Invite your child to play a game with you or share an enjoyable activity?

  邀请你孩子和你一起玩游戏，或做有趣的活动

- Notice and praise your child's good behaviour?

注意到并表扬你孩子的良好行为*

- Teach your child new skills?

  教你孩子新技能*

- Involve your child in household chores?

  让你孩子一同做家务*

- Reward your child when s/he did something well or showed a new skill?

  当你孩子表现好或者掌握新技能时，给他/她奖励*

3. Back-translation

All items in the translated questionnaires were translated back to English by a translator whose mother tongue is English and who is not familiar with the original questionnaires. The translator was required to translate by considering cultural and conceptual aspects, rather than literal translation. Discrepancies were discussed with the panel. The satisfactory versions of translation were reached after revision.

Discrepancies between the original items and back-translated items (marked in colors)

Original Items in English	Back translation
When I'm upset or under stress... I am picky and on my child's back. 1 2 3 4 5 6 7 I am no more picky than usual.	When I am feeling down, dissatisfied, or under pressure, - I will become very picky/critical and always criticise my child - I am no more picky/critical than usual.
When my child misbehaves... I usually get into a long argument with my child. 1 2 3 4 5 6 7 I don't get into an argument.	When my child has behavioural issues (problems), - I will often argue with him/her for a

	long time. - I will not argue with him/her.
When my child misbehaves... I raise my voice or yell. 1 2 3 4 5 6 7 I speak to my child calmly.	When my child has behavioural issues (problems), - I speak in a louder voice, or shout. - I remain calm while speaking to my child.
After there's been a problem with my child... I often hold a grudge. 1 2 3 4 5 6 7 things get back to normal quickly.	Whenever an issue/problem arises between my child and I: - I stay angry [with them] - Everything returns to normal quickly
When there's a problem with my child... things build up and I do things I don't mean to do. 1 2 3 4 5 6 7 things don't get out of hand.	Whenever an issue/problem arises between my child and I: - the situation easily escalates, causing me to do things I had not originally wanted to do - the situation does not get out of hand
Play with your child in a way that was fun for both of you?	Doing things with your child that you both find fun
Stand back and let your child work through problems s/he might be able to solve?	Creating space to try to let your child solve the problems that he/she might be able to solve him/herself.
8. Invite your child to play a game with you or share an enjoyable activity?	Inviting your child to play a game with you, or doing a fun activity
9. Notice and praise your child's good behaviour?	Paying attention to and praising your child's good behaviour
10. Teach your child new skills?	Teaching your child new skills
11. Involve your child in household chores?	Having your child join in with housework
12. Reward your child when s/he did something well or showed a new skill?	Giving your child a prize when he/she performs well or gets the hang of a new skill

4. Revised translations (revisions marked in red)

1. 当我~~沮丧不安~~很烦或感受到压力时，我会变得很挑剔，总是批评孩子* 7--并没有比平时更挑剔。
2. 当孩子有行为问题时，我经常会和他/她进行长时间的争论* 7--我不和他/她争论
3. 当孩子有行为问题时，我说话声音会变大，或者吼叫* 7--我会平静地对孩子说话~~依然平静~~

4. 每当我和孩子之间出了问题时，我会~~持续愤恨~~怀恨在心* 7--一切很快恢复正常
5. 每当我和孩子之间出了问题时，事态容易升级，导致我做一些本来不想做的事情* 7--情况不会失去控制
~~6. 和你孩子一起做你们俩都觉得有趣的事情*~~ 7. 以一种你和孩子都觉得有趣的方式和你的孩子一起玩耍
8. ~~让出空间~~退后一步，尝试让你孩子自己解决他/她可能有能力解决的问题*
9. 邀请你孩子和你一起玩游戏，或分享愉快的~~做有趣的~~活动
10. 注意到并表扬你孩子的良好行为
11. 教你孩子新技能
12. 让你孩子一同做家务
13. 当你孩子表现好或者~~掌握~~表现出新技能时，给他/她奖励

5. Pre-testing and cognitive interviewing

The translated questionnaires were pre-tested with three parents of children diagnosed with Autism aged three to six None of these parents would be involved in the SREIA evaluation. After administering each question, I conducted a systematic debrief with the interviewees, by asking the following questions:

a) What do you think the question is asking? Can you repeat in your own words?

b) What came to your mind when hearing the word _____ ?

c) Why did you choose this answer?

d) Is there any word that you did not understand? What alternative word do you think would be better?

e) Is there any word or question that makes you feel offended or unacceptable?

Questions a-c were compared to their actual responses to the instruments to ensure consistency. A summary report of the pre-tests was created and shared with the panel.

Summary report

The participants found the questions easy to understand and culturally appropriate. The paraphrase of questions and explanations of answers suggested that, in general, the questions have good consistency. One small discrepancy was identified: the PARYC item “Invite your child to play a game with you or share an enjoyable activity?” was understood as an activity enjoyed by the child, whereas the original question does not seem to imply this. The 7-point scale was, to some degree, confusing to interviewee. It is important that the indication of each point is well explained at the beginning and for each question.

6. Final version

The translated questionnaires were finalised based on the pre-test interviews and feedback from the bilingual panel.

Arnold-O'Leary Parenting Scale (PS)—Over-reactivity Scale

- 当我很烦或感受到压力时，我会变得很挑剔，总是批评孩子* 1--并没有比平时更挑剔 7
- 当孩子有行为问题时，我经常会和他/她进行长时间的争论* 1--我不和他/她争论 7
- 当孩子有行为问题时，我说话声音会变大，或者吼叫* 1--我会平静地对孩子说话 7
- 每当我和孩子之间出了问题时，我会怀恨在心* 1--一切很快恢复正常 7
- 每当我和孩子之间出了问题时，事态容易升级，导致我做一些本来不想做的事情* 1-

-情况不会失去控制 7

PARYC—Supporting Positive Behaviour

- 以一种你和孩子都觉得有趣的方式,和他/她一起玩耍

1(从来无法这么做)234（有时）567（一直都在/能这么做）

- 退后一步，尝试让你孩子自己解决他/她可能有能力解决的问题
- 邀请你孩子和你一起玩游戏，或分享愉快的活动
- 注意到并表扬你孩子的良好行为
- 教你孩子新技能
- 让你孩子参与做家务
- 当你孩子表现好或者表现出新技能时，给他/她奖励

Appendix GData Collection Tools in Chapter 5 Paper 3

1. Parent interview guide

i) Aim

The qualitative individual interviews aim to explore parent's experience and perspectives of the SREIA programme. The interview will cover the following topics: 1) understanding and use of skills, 2) perceived changes, 3) barriers to, facilitators of, and strategies to overcome the challenges of participation and engagement in the programme, and 4) acceptability and appropriateness of programme delivery and contents.

ii) Method

A semi-structured approach was undertaken using open-ended questions that encourage parents to answer in their own words and in a way that reflects their unique perceptions and experiences. For each topic, a question was asked to start the conversation, with follow-up probes and questions to gain insights and clarity. Discussion also evolved as topics deemed important by parents emerge. The interview began with neutral questions and close with a question that empowers interviewees. Interviewees were informed that the conversations would be confidential and anonymous, and that data would only be used in this research to avoid socially desirable answers. All interviews were audio-taped with the consent of the participant.

iii) Contents

1) Opening words

Thank you very much for participating in the interview. The purpose of this interview is to learn

about your experience and perspective of the SREIA programme. Your feedback will help us think about how we should improve. There are no right or wrong answers. Any response from you is valuable to us.

Our interview will last for no more than 1.5 hours. We can take a break during the interview when you think it is necessary. With your permission I will audio-record the interview using this recorder so as to ensure that all your answers are captured. Your responses will only be used in this research and not be shared any further. This interview is anonymous, which means that when our research team look at your answers, your name or the name of your child will not be shown.

Please let me know if the question I ask is not clear and needs clarification. Please also remember that you have the right to answer or not to answer any question that I ask without telling me the reasons, and you can stop the interview at any time when you feel like doing so.

Before we begin, do you have any questions?

Thank you again for your participation!

2) Questions

Rapport Building Questions	
Question	*Probes*

♦ Where are you from? ♦ How is your child? ♦ How did you hear about the SREIA programme? ♦ What made you decide to attend the SREIA programme? ♦ Does your family support your decision? How?	♦ How are your other family members? ♦ When was your child diagnosed with ASD? What is your experience in seeking supports and treatments?
Perceived Change	
Question	*Probes*
♦ What impact do you think the programme has had on yourself; ♦ What impact has it had on your child; ♦ Are there things that have not changed and why do you think this is.	♦ Whether and how do you think it has changed… ○ your child? ○ your relationship with your child? ○ your discipline styles? ○ yourself? ○ your other family members?
Understanding and Use of Skills	
Question	*Probes*
♦ Overall, to what extent do you think you understood the skills taught in the programme? ♦ How have you been using these skills?	♦ What facilitated and/or inhibited your understanding and/or use of the skills?
Programme Content	
Question	*Probes*
♦ What did you like most about the programme? ♦ What did you like least about the programme? ♦ What did your child like most and least about the programme? ♦ What do you think of the following information and strategies? ○ Knowledge of Autism Spectrum Disorder ○ TEACCH (structural teaching) ○ Behaviour management techniques (understanding what happens before and after child behaviours, and the reasons behind) ○ Reinforcement (reward your child for good behaviours; ignore negative behaviours) ○ Parent-child communication (use visual and technology supports) ○ Prompt (give your child hints) ○ Generation and maintenance (teach your child to exhibit good behaviours and skills in different	♦ How useful is it? / Have you been using it? ♦ Which ones do you think you have been using most often or are more likely to use in the future? Why? ♦ Which ones do you think are the least helpful? Why? ♦ What is missing, regarding… ○ the support you need to use those strategies? ○ any techniques that you expected to learn / or could have benefited from but were absent in the programme?

situations)	
Programme Delivery	
Question	*Probes*
♦ How well did you get on with the programme facilitators; ♦ Were there some facilitators who seemed better than others and if so why? ♦ How much did you feel able to trust the facilitators? ♦ Do you think that your child like the programme and the facilitators? ♦ What do you think of the following aspects of the programme? ○ Individual sessions ○ Therapist-child sessions (version B) ○ Group sessions ○ Observational sessions ○ Teaching sessions ○ Facilitator modeling ○ Practice sessions ○ Review sessions ○ Homework	♦ Which ones do you think are the most helpful? Why? ♦ Which ones do you think are the least helpful? Why? ♦ How would you like to change them?
♦ What do you think of the following aspects of the programme? ○ Duration and intensity ○ Timing ○ Location and setting ○ Facilitator qualification ○ Group size ○ Flexibility ○ Communication with facilitators in and out of sessions	♦ How appropriate do you think they are? ♦ How would you like to change them?
Participation and Engagement	
Question	*Probes*
♦ What were the difficulties that you experienced in • joining this programme? • attending all sessions? • participating in activities during the sessions and completing the homework assigned by the facilitators? ♦ and how did you address them…	♦ If you encountered challenges, how did you (or did you not) overcome the challenges?

Closing Question	
Question	*Probe*
• How do you think the programme could be improved? • Is there anything else you would like to share?	

2. Facilitator focus group guide

i) Aim

The qualitative focus group discussions aim to explore SREIA implementers' experience and perspectives of delivering the programme. The discussion will cover the following topics: 1) barriers to, facilitators of, and strategies to overcome the challenges of programme implementation, and 2) acceptability and appropriateness of programme delivery and contents.

ii) Method

A semi-structured approach was undertaken using open-ended questions that stimulate reflection and discussion. For each topic, a question was asked to start the conversation, with follow-up probes and questions to gain insights and clarity. Discussions evolved as topics deemed important by implementers emerge. Implementers were informed that the conversations would be confidential and anonymous, and that data would only be used in this research. The discussions were audio-taped.

iii) Contents

1) Opening words

Thank you all very much for participating in this focus group. The purpose of this focus group discussion is to learn about your experience and perspectives of implementing the SREIA programme, and together we can think about how we should improve the programme. There are no right or wrong answers. Any honest comments from you are valuable to the programme.

The focus group will last for no more than 2 hours. Consensus should be reached if more time (less than 20 minutes) is required. We will take a 10-minute break after the first hour. The discussion will be audio-recorded to make sure all your comments are captured. Your responses will be anonymous, and only be used for the purpose of research. To keep the discussion confidential, we would also like to request that you do not share any points made by you or other implementers outside of this discussion. Please also be aware that we cannot control whether other participants disclose information shared in this focus group.

Disclosure of cases where a child has been or is at risk of being harmed will be further discussed by the research team and SREIA officers who will make joint decisions on appropriate actions to be taken (in accordance with the *Child Protection Protocol*).

Please let me know when the question I ask is not clear and needs clarification. Please also remember that you have the right to answer or not to answer any question that I ask without telling me the reasons, and you can opt out the discussion at any time when you feel like doing so.

Before we begin, do you have any questions?

Again, any honest feedback from you are valuable to the programme. Thank you once again for your participation!

2) Questions

Rapport Building Questions	
Question	*Probes*
♦ Where are you from? ♦ When did you join the Beijing Stars and Rain Education Institute for Autism? What did you do prior to joining the NGO?	
General Questions	
Question	*Probes*
♦ Tell us about your experience delivering the SREIA programme. ♦ What was one highlight during the delivery of the SREIA programme? ♦ What do you like most and least about the programme? ♦ Would you like to change it any way, if so how? ♦ How do you think parents and their children benefit from the programme? ♦ Do you witness any changes during the programme ♦ Are there parents who do not show change…which parents are they and why do they not change	
Programme Contents	
Question	*Probes*

♦ What do you think about delivering the following information and strategies to parents? ○ Knowledge of Autism Spectrum Disorder ○ ABA techniques and Discrete Trial Training (DTT) ○ TEACCH ○ Behaviour management techniques—functional behaviour assessment ○ Reinforcement ○ Parent-child communication (Augmentative and alternative communication; Picture Exchange Communication System) ○ Differential reinforcement and prompt ○ Fading prompts ○ Shaping ○ Chaining ○ Generation and Maintenance	♦ How do you think it is relevant to the challenges experienced by the families in your group? ♦ How difficult do you think it is to teach and engage parents in this strategy? ♦ Which ones do you think are the most and least helpful? Why? ♦ What is missing, regarding ○ the support you need to deliver those strategies in the future? ○ any additional techniques that you think should be covered in the programme?
Programme Delivery	
Question	*Probes*
♦ What do you think about the following aspects of the programme? ○ Didactic approach (one-way communication) ○ Collaborative approach (facilitators and parents are interactive) ○ Parent practice sessions ○ Different structures between version A and version B ○ The lack of a standardised manual for each session	♦ Which ones do you think are the most helpful? Why? ♦ Which ones do you think are the least helpful? Why? ♦ How would you like to change them?
♦ What do you think about the following aspects of the programme? ○ Duration and intensity ○ Timing ○ Location and setting ○ Facilitator qualification ○ Group size ○ Flexibility ○ Communication with parents outside of sessions	♦ How appropriate do you think they are? ♦ How would you like to change them?
Facilitators and Challenges	
Question	*Probes*
♦ What supported your delivery of the strategies? ♦ What else do you need to support your delivery?	♦ Have you received any supports in terms of the following aspects? Can you tell me more? ○ Training

	◌ Supervision ◌ Supplies ◌ Welfare ◌ Any other aspects
♦ What challenges did you encounter during the implementation?	♦ Did you have any challenges in terms of the following aspects? Please tell me more. ◌ Interaction with colleagues ◌ Interaction with parents and children ◌ Interaction with administrative staff ◌ Interaction with research staff ♦ Did you overcome the challenges? ♦ How did you (or did you not) overcome the challenges?
Closing Question	
Question	*Probe*
♦ How would you like to improve the SREIA programme? ♦ Is there anything else you would like to share?	

Appendix HEthical Clearance and Supporting Materials

1. Oxford approval letter

SOCIAL SCIENCES & HUMANITIES
INTER-DIVISIONAL RESEARCH ETHICS COMMITTEE

Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD
Tel: +44(0)1865 616576 Fax: +44(0)1865 280467
ethics@socsci.ox.ac.uk

UNIVERSITY OF OXFORD

28 January 2020

Zuyi Fang
Department of Social Policy and Intervention
University of Oxford

Dear Zuyi

Research Ethics Approval (CUREC 2)
Ref No: R67619/RE001
Title: Evaluation of a Parent Training Programme for Families of Children with Autism Spectrum Disorder in China: Protocol for a Mixed-Methods Quasi-Experimental Study

The above application has been considered on behalf of the Social Sciences and Humanities Inter-divisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly approval has been granted.

Should there be any subsequent changes to the project, which raise ethical issues not covered in the original application, you should submit details to the IDREC for consideration.

Please note that your study may be selected for review by the SSH IDREC during an annual audit. You may also be required to submit a brief annual progress report on each anniversary of study approval, until the study is completed.

Yours sincerely,



Kathryn Dally
Senior Assistant Registrar (Ethics and Integrity)

cc: Prof Jane Barlow
Olivia Thornton
Jamie Lachman

2. Local approval forms and ethical issues checklist

申请号：SSDPP-HSC2020001

北京师范大学社会发展与公共政策学院研究伦理审查

申 请 书

申请日期： 2019 年 12 月 22 日

项目名称：采用混合方法的准实验对中国自闭症儿童的父母培训进行评估		
请求审查类型： ☒新申请项目 ☐修订后项目 ☐延续审查课题		
项目负责人：方祖仪		**职称**：牛津大学博士候选人
如项目负责人为学生，请列出其导师姓名：Jane Barlow 教授，Jamie Lachman 博士		
项目联系人：方祖仪		
电话： +44 7404329402 /+86 13716165860	**传真**：/	**电子信箱**：zuyi.fang@spi.ox.ac.uk
合作研究单位：北京师范大学社会发展与公共政策学院		**负责人**：乔东平教授
电话：+86 13661112297	**传真**：/	**电子信箱**：qiaodping@bnu.edu.cn
拟研究时间： 2020 年 3 月 21 日 至 2021 年 6 月 7 日		
研究课题来源（包括资金 ID 号）：此项研究没有接受任何来自公共、商业或非营利组织的资金支持。实验将对北京星星雨（自闭症）教育研究所的 11 周家长培训项目进行评估，星星雨将提供相关材料、场所以及人力。		
资助者联系人：无		
电话：无	**传真**：无	**电子信箱**：无
星星雨联系人：陈爱春		
电话：+86 010 85373485	**传真**：/	**电子信箱**： chenaichun@guduzh.org.cn
研究内容摘要： **研究问题** 此研究主要目的是评估北京星星雨（自闭症）教育研究所为 3 到 6 岁自闭症儿		

童父母或其主要照料人提供的 11 周家长培训项目（简称，SREIA 培训）的效果。同时，研究也将对 SREIA 的培训过程进行评估，探索关于其实际操作的各个方面，以及参与者对项目的接受程度。

研究背景

自闭症儿童常伴有严重的情绪和行为问题，这些问题与自闭症临床症状相互影响，进一步妨碍了儿童的日常生活，并不断为父母带来挑战。北京星星雨教育研究所提供的SREIA培训旨在为自闭症儿童的主要照料人提供相关支持。此培训自1993年以来，服务了一万多个自闭症家庭，然而却从未对其效果进行科学的评估。此研究为首次系统化评估，研究结果将使 SREIA 培训的改良有证可循，并为其落地中国其它省份和城市提供支持。此次研究也将为针对自闭症家庭以及中低收入国家的教养干预的科学研究做出贡献。

研究方法

此研究将采用混合方法的准实验，对两轮 SREIA 培训进行评估。参与培训的父母将分别在基线、培训后以及培训 6 个月后，完成一系列问卷和标准化量表，内容包括培训家庭的基本信息，以及对家长和孩子的培训效果。实操过程的评估包括：收集出勤表，测量家长参与度，监控培训质量，观察课堂互动，和填写满意度问卷。培训结束后，将对一些家长、培训老师和星星雨管理者进行个人或小组访谈，以了解他们对培训的看法，并进一步解读定量数据的分析结果。

被访者隐私的主要保护措施：

收据数据时，将不会有第三者在场。一切研究数据和参与者的个人信息也都将被严格保密。参与者在签署知情同意书时，会获得一个 ID 号。他们所提供的数据将只显示 ID 号，数据中任何透露身份的信息都将被移除。所有的数据，包括 ID 号与参与者个人信息的对照表，都将被上传至牛津大学的加密服务器，并备份在加密硬盘中，硬盘将锁在星星雨的文件柜里。一切纸质文件（例如知情同意书）也将被锁在文件柜里。

任何有关参与者身份的数据（例如，知情同意书、家庭基本信息、ID 号与参与者个人信息的对照表）将在研究结果发表后，被保存三年，以供在资金允许的情况下，追踪 SREIA 培训的长期效果。知情同意书中将有关于长期追踪的信息，参与者可考虑是否也参加长期追踪。三年后，所有数据将从牛津大学服务器和硬盘中永久删除，纸质数据将被粉碎。一切录音将在研究结束后立即删除。我们也将在知情同意书中告知并请求参与者，允许我们在研究结果中直接引用他们在质性访谈中表达的观点，引用时将使用 ID 号，而不是他们的名字。

如上所述，参与者提供的一切信息都将被严格保密，以下情况除外。如果参与者透露任何人遭受了或可能遭受伤害，我们将在访谈后进一步了解事件；如必要，我们也将为参与者联系相关服务。

其他递交的审查资料（可多选）：

☐实验方案 ☒知情同意书 ☐伦理声明

☐对被访者的保护性措施 ☒其他资料 评估同意书，伦理问题清单

项目负责人签字：

☒ 方祖仪

2019 年 12 月 22 日

项目负责人导师签字（如项目负责人为学生）：

Jane Barlow

2019 年 12 月 22 日

审查意见：

审查批准号：SSDPP-HSC 2020001

审查委员签字（章）：

年 月 日

填表说明：

1. 请求审查类型中，延续审查课题为出于项目要求而需进行第二次审查的课题。
2. 如合作研究单位不止一个，可根据需要增添表格。
3. 具体到各个研究项目时，根据其研究性质和被访人特点的需要，可能还需提交其他资料。

Approval Number: SSDPP-HSC2020001

Application for Human Subjects Review
School of Social Development and Public Policy (SSDPP)
Beijing Normal University

Date: December 22, 2019

Project Title: Evaluation of a Parent Training Programme for Families of Children with Autism Spectrum Disorder in China: A Mixed-Methods Quasi-Experimental Study		
Type of Application: ☒New Application ☐Revised Application ☐Extended Review Application		
Principal Investigator(PI): Zuyi Fang		**Title of PI:** DPhil Candidate, University of Oxford
If PI is a student, name of advisor: Professor Jane Barlow, Dr Jamie Lachman		
Contact Person: Zuyi Fang		
Tel: +44 7404329402/+86 13716165860	**Fax:** /	**Email:** zuyi.fang@spi.ox.ac.uk
Collaborating Institution: Beijing Normal University		**Collaborating PI:** Professor Dongping Qiao
Tel: +86 13661112297	**Fax:** /	**Email:** qiaodping@bnu.edu.cn
Project Duration: March 21, 2020	**To** June 7, 2021	
Source of Funding (include grant ID number): This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. The trial will involve an evaluation of a parent training programme provided by the Beijing Stars and Rain Education Institute for Autism (SREIA). The SREIA will be responsible for all material, venue, and personnel support.		
Contact Person at Funding Agency: N/A		
Tel: N/A	**Fax:** N/A	**Email:** N/A
Contact Person at SREIA: Aichun Chen		
Tel: +86 010 85373485	**Fax:** /	**Email:** chenaichun@guduzh.org.cn
Research Summary: **Research Questions**		

The primary objective of this study is to evaluate the effectiveness of the Beijing Stars and Rain Education Institute for Autism (SREIA) parent training programme for families of children with Autism Spectrum Disorder (ASD) aged 3 to 6 years in mainland China within the context of routine services, as well as to explore programme implementation and acceptability through a process evaluation.

Background

ASD is associated with elevated levels of child emotional and behavior disturbance, which impair child daily functioning and impose challenges to parenting. The SREIA programme is a group-based parent training in China, that has been delivered since 1993 and reached over 10,000 families. However, there is an absence of scientific evaluations of programme effectiveness. This study aims to fill this evidence gap, and the findings will be used to inform future modification, replication, and dissemination of the programme in other parts of China. This study will also contribute to the literature on the effectiveness of parenting programmes for ASD and for families living in low- and middle-income countries.

Methods

A quasi-experimental design with a mixed-methods approach will be used, involving two consecutive waves of delivery of the SREIA programme. Parent participants will complete demographic and outcome questionnaires at baseline, post-intervention, and 6-month follow-up. The implementation components will be assessed by collecting attendance and engagement registry data, facilitators filling out fidelity checklists, research staff observing program sessions, and parents answering a satisfaction questionnaire. After the program, some parents, facilitators, and NGO managers will be invited to take part in qualitative interviews or focus group discussions so as to explore their views about the programme, and to better understand the quantitative data obtained.

Main Measures for Protecting Subjects' Confidentiality:

The research data and personal details will be collected in strict confidence. An ID number will be assigned to each participants after they give consent. The research data they provide will only show the ID number, and all further identifying information will be removed. The linkage between the ID number and participant personal details, as well as participants' answers, will be uploaded to an encrypted server in Oxford and an encrypted hard drive locked in a pass-word protected closet that only our research team will have access to. All non-electronic data (e.g. consent forms) will be stored in the closet.

All identifiable data (consent forms, personal information, and the pseudonymisation linkage) will be shredded or deleted from the Oxford server and the hard drive three years after publication, in case it is needed for further follow-up of the families. This

information will be provided to participants in the information sheet and their specific (and optional) consent will be obtained for this. All audio recordings will be erased immediately at the end of the study. We will request participants' permission to use direct quotes with their ID numbers (not their names) in future research outputs.

Any information that participants provide will be kept strictly confidential and private unless there is risk of significant harm to them or their child/ren. If there is any risk of harm to them or their child/ren, we will discuss possible sources of support following the discussion. If necessary, we may also make a referral to the appropriate services for further assistance.

Other Materials Submitted (mark all that apply):

□Research Design ☒Informed Consent Form □Ethics Statement

□Protective measures for respondents ☒Other (Specify): Assessment agreement, Ethics Issues Checklist

Signature of PI:

Zuyi Fang

Date: December 22, 2019

Signature of main advisor if applicant is a student:

Jane Barlow

Date: December 22, 2019

(To be filled out by the Human Subjects Committee)
Comments:

Approval Number: SSDPP-HSC 2020001
Signature of Human Subjects Committee: _____

Date: **(mm-dd-yyyy)**

Notes:

1. Extended Review refers to a second review sometimes required for certain projects.
2. If more than one collaborating institutions are involved, add more space in the form as needed.
3. More materials may be required according to the nature of the research, and the characteristics of the human subjects involved.

APPENDIX A: ETHICS ISSUES CHECKLIST FOR INTERNATIONAL RESEARCH[7]

The University of Oxford's Central University Research Ethics Committee (CUREC) and its sub-committees are responsible for reviewing all research involving human participants and personal data. Important topics for the review of human participant and personal data research conducted in international settings are listed below. This Checklist does **not** replace the CUREC 1A or CUREC 2 ethics application forms, but may be a useful prompt of potential ethical issues to consider when completing the application forms in certain cases, to ensure that the PI/researcher has given adequate consideration to address possible areas of concern in the local research context.

In the case of collaborations involving a large number of international sub-studies (see Best Practice Guidance on ethical review of social science-based research conducted outside the UK (above), this Checklist should be helpful to demonstrate thorough ethical consideration by collaborating lead institutions and/or local ethics review boards, and should be completed and signed by their ethics committees and sent to their CUREC sub-committee, together with relevant ethics approval letters.

Have you considered and addressed the following?	YES	NO	N/A
Whether local ethics structures of oversight have been found and consulted (see Best Practice Guidance, sections 5-7 above).	☑	☐	☐
Economic prosperity of the area	☑	☐	☐
Influence of local officials/government on the population and any conflicts of interest	☑	☐	☐
Literacy rate of the area	☑	☐	☐
Local legal rights of the population / potential legal issues or risks caused by the research	☐	☐	☑
Whether the research is likely to generate suspicion or adverse interest from local officials/government, local security agencies, and/or any other part of the community	☐	☐	☑
Status of children and vulnerable participants	☑	☐	☐
How complaints will be reported and to whom	☑	☐	☐
Relevance and benefits of the research to the area and to the participants	☑	☐	☐

[7] Based on guidelines produced by the University of California, Berkeley, and excerpts from WHO/EMRO/ERC guidance. (University of California, Berkeley, Committee for Protection of Human Subjects (CPHS), International Research Checklist, https://cphs.berkeley.edu/international_research_checklist.pdf (accessed 6 June 2019); and World Health Organization, Research Ethics Review Committee (ERC), ERC Checklist for Principal Investigators, https://www.who.int/rpc/research_ethics/en/checklist_for_PI.pdf (accessed 6 June 2019).

Have you considered and addressed the following?	YES	NO	N/A
Awareness of differences in understanding what counts as a benefit	☑	☐	☐
Possibility of including officials from the area in the monitoring of the research	☐	☐	☑
Provisions for safety monitoring	☑	☐	☐
Provisions for data monitoring	☑	☐	☐
Provisions to ensure that (vulnerable) participants are not being exploited (avoiding 'extractive research')	☑	☐	☐
Provisions for counselling research participants prior, during and/or after the research	☑	☐	☐
Unequal relationships between researcher and participants	☑	☐	☐
Whether all participants will be able to give voluntary, fully informed consent. If not, please outline alternative approaches to how consent will be obtained	☑	☐	☐
Justification for use of oral consent process (if applicable)	☐	☐	☑
Awareness of differences in cultural and societal norms and practices	☑	☐	☐
Differences in the role and status of women/other participant groups in society/ gender issues	☐	☐	☑
Differences in the role of family and community in the consent process	☑	☐	☐
Identification of local language(s)	☐	☐	☑
Whether documents/scripts are written in lay language, tailored to the participant groups' literacy level	☑	☐	☐
Local contact information for persons who can answer research-related questions, including local emergency contact information and participants' rights	☑	☐	☐
Nature and role of each participating/collaborating site	☑	☐	☐
For large consortiums: whether sub-studies have gained local ethics approval, and if so, whether local ethics approval letters will be sent to the relevant Oxford ethics committee, together with this Checklist.	☑	☐	☐
Consultation of CUREC's Best Practice Guidance documents, including on Researcher Safety, Expert/Elite interviews and Data collection and management, as well as relevant CUREC Approved Procedures	☑	☐	☐

Appendix A: Ethics Issues Checklist for International Research

Have you considered and addressed the following?	YES	NO	N/A
Whether legal/departmental advice on the project has been sought, including on data sharing agreements and confidentiality agreements	☐	☐	☐
Whether departmental/University travel insurance has been gained and a risk assessment completed (and, for non-Oxford fieldworkers, whether local fieldworkers will be locally insured)	☐	☐	☐
Political risks and/or contractual risks that your department/university should be aware of before the research begins	☐	☐	☐

For collaborations involving a large number of international sub-studies, the PI and local ethics committees should complete, sign and submit this Checklist to their CUREC sub-committee, together with relevant ethics approval letters.

Jane Barlow Zuyi Fang Dec. 22, 2019

Date and Signature of Principal Investigator (Oxford)

Date, signature and contact details of partner institution/University (if applicable)

Date, signature and contact details of local research ethics committee in country of fieldwork (if applicable)

3. Invitation letter and recruiting poster

4. Caregiver information sheet and oral consent form

DEPARTMENT CONTACT DETAILS

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DPhil Candidate
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Study of the benefits of the SREIA parent training programme for families of children with ASD

INFORMATION SHEET FOR PARENTS

Oxford Central University Research Ethics Committee (CUREC) Approval Reference: R67619/RE001
Beijing Normal University Approval Reference: SSDPP-HSC2020001

Dear Sir or Madam,

You are being invited to participate in a research study conducted jointly by the University of Oxford, Beijing Normal University, and Beijing Stars and Rain Education Institute for Autism. Before you decide whether to take part in the research, it is essential that you understand what this would involve. After reading the following information, you can ask any questions that you may have.

1. ***Why is this research being conducted?***

We are conducting this research, in order to understand how to better support families of children with Autism Spectrum Disorder (ASD) in mainland China. We are interested in exploring whether and how the SREIA parent training programme can help parents promote child development and tackle daily challenges.

2. ***Why have I been invited to take part?***

You have been invited because you meet the following criteria:

- You have agreed to participated in the Beijing SREIA parent training programme delivered from August to November 2020 (or from November 2020 to January 2021).
- Your child is between 3 to 6 years old.
- Your child meets the diagnostic criteria of Autism Spectrum Disorder according to DSM-V; or you have provided an official letter of ASD diagnosis.
- You are a primary caregiver of the child and undertake the responsibility for the daily care of the child for at least 5 days a week
- You have indicated a willingness to participate in the research.

Note: if you child has been diagnosed with Cerebral Palsy then you cannot be part of the study.

3. ***Do I have to take part?***

You do not have to take part. You can ask questions about the research before deciding whether to take part. If you do agree to take part, you may also withdraw from the study at any time, without giving a reason, by advising us of this decision. The deadline to withdraw data will be 1 month after the completion of programme (for follow-up data collection and qualitative interviews, it will be 1 month after the follow-up interviews) if you wish to do so.

You will have up to a week to decide whether to participate in the study. You can also decide to provide consent and participate after 24 hours once you have received all the information about the study.

If you agree to take part in the study, you will be asked to provide your oral consent. It is up to you to decide whether you want to take part, but you must provide oral consent in order to participate.

4. *What will happen to me if I take part in the research?*

Before the SREIA begins:

1) Once you have provided oral consent, we will ask you some questions about your child, yourself, and your family. These questions will be asked in a private setting with no one else around. We will confirm with you that you are in a private setting before we start to ask you any questions. If there are any questions that you feel uncomfortable answering, you will not have to answer them.
2) The questions will be administered using an online survey, but will read each question to you out loud to make sure you understand.
3) The questionnaire will take a maximum of one and half hours to complete, and we will take a short break half-way through. You can also ask to pause or stop at any time.

After you answer the questions:

1) You and your child will participate in the Beijing SREIA parent training programme. The programme teaches parents skills to manage child emotional and behavioral problems and promote child development. If you do not want to attend some of the sessions, you are free not to do so, and you can still continue with the remainder of the programme
2) Your attendance and engagement will be recorded by your facilitators on a daily basis.
3) A research staff will also remotely observe some sessions using video conferencing via Microsoft Teams, to understand how the program is being delivered.

After the programme finishes:

1) Within one month after the SREIA programme ends, you will again be asked the same questions in the same manner as we did at the beginning of the study.
2) Within one month after the programme, you may also be selected for a one-on-one interview to discuss your experience in and perspectives of participating in the programme. The interview will take a maximum of one and half hours. It will also be private. We will, with your permission, audio record the interview to ensure we have an accurate record of your thoughts, and the recordings will be kept confidential. You can choose to stop the interview at any time, and if you want, you can ask us not to use any information that you have provided.
3) We will follow up again 6 months after the SREIA programme ends, and you will again be asked the same questions in the same manner as we did at the beginning of the study.

5. *Are there any potential risks in taking part?*

We do not expect there to be any risks involved in participating in this study. If you become distressed or upset when answering the questions, we are happy to discuss any issues you may have, and to help refer you to support services if you would like.

To reduce any potential risks, your personal data will be anonymised or pseudonymised if we decide to quote your answers as part of the reporting of the study.

6. *Are there any benefits in taking part?*

As a way of showing our gratitude for your participation, you will receive a reimbursement of 1000 to 1500 RMB that will be directly reduced from the programme fees. The exact amount of reduction will depend on the financial capacity of the NGO. All families who complete data collection at all time points will receive the same amount of reduction. You will also receive two certificates for completing the programme and participating in the research.

7. ***What happens to the data provided?***

Your consent forms will be stored in a locked cupboard in the SREIA, and will be password protected. Only the researchers will have access to these files.

The research data and your personal details will be collected in strict confidence. After each interview, your answers will be uploaded to an encrypted server in Oxford and an encrypted hard drive that only our research team will have access to. This means that no one else will ever be able to see your name or any of your answers to the questions. Your answers will not be written down anywhere else.

Any information that you provide will be kept strictly confidential and private unless there is risk of significant harm to you or your child/ren. If there is any risk of harm to you or your child/ren, we will discuss possible sources of support following this discussion. If necessary, we may also make a referral to the appropriate services for further assistance.

You will receive an ID number once you give consent. The research data you provided will only show the ID number, and all further identifying information will be removed. The document that records the link between your identity and ID number will be kept in the encrypted server in Oxford and the encrypted hard drive lock in the NGO. These data will be stored for three years after publication of the research results. If needed, we may use your personal details to contact you for follow-ups. You will need to give consent if you allow us to do this. All audio recordings will be erased immediately upon the completion of the research.

We will request your permission to use direct quotes with your ID number (not your name) in future research outputs.

We will also request your permission to use anonymised data in future studies, and to share data with other researchers. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

8. ***Will the research be published?***

The findings of this study may be published in journals, at conferences, and on the SREIA websites, so that others may learn from this research. Your name and your child's name will not appear in any publications or reports about the results of this study. After the study is finished, we would be delighted to share with you the results as soon as they are available.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

9. ***Who has reviewed this study?***

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R67619/RE001) and Beijing Normal University (Reference number: SSDPP-HSC2020001).

10. ***Who do I contact if I have a concern about the study or I wish to complain?***

If you have a concern about any aspect of this study, please contact ***Zuyi Fang, +86 10 85373485, zuyi.fang@spi.ox.ac.uk***, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Social Sciences & Humanities Inter-Divisional Research Ethics Committee; Email: ethics@socsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

11. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.
The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.
Further information about your rights with respect to your personal data is available from https://compliance.web.ox.ac.uk/individual-rights.

12. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Zuyi Fang
zuyi.fang@spi.ox.ac.uk
Department of Social Policy and Intervention, University of Oxford
32 Wellington Square, Oxford, UK, OX1 2ER
SREIA NGO telephone: +86 10 85373485
Oxford University telephone: +44 (0)1865 270325
Oxford University email: info@spi.ox.ac.uk

Oral Information Giving and Consent Seeking Script -- Parents

1. Oral information giving

Hi, my name is xxx (my name or name of a research assistant). We're doing a DPhil project at the University of Oxford in the Department of Social Policy and Intervention. We wondered if you'd be interested in being involved.

In the study, we want to understand how to better support families of children with Autism in mainland China. We are interested in learning how the SREIA parent training programme can help parents promote child development and tackle daily challenges. If you choose to be a part of this project, here is what will happen:

We will have a conservation with you before, after, and 6 months after you participate the programme. Each conversation will take less than 1.5 hours. In the conversations, we will ask a range of questions about your child, yourself, and your family.

Your answers will form the basis of a DPhil thesis at the University of Oxford and some publications. We will store your information and answers safely and confidentially in an encrypted server in Oxford and an encrypted hard drive that only our research team will have access to. This means that no one else will ever be able to see your name or any of your answers to the questions. You will also receive an ID number once you give consent. The research data you provided will only show the ID number, and all

further identifying information will be removed. We will keep the data for three years after publication. We would like to be able to use your anonymised information/data in future studies, and to share this information/data with other researchers.

We do not expect there to be any risks involved in participating in this study. If you become distressed or upset when answering the questions, we are happy to discuss any issues you may have, and to help refer you to support services if you would like. To reduce any potential risks, your personal data will be anonymised or pseudonymised if we decide to quote your answers as part of the reporting of the study.

You don't have to agree to take part. You can ask us any questions you want before or throughout. You can also withdraw at any stage without giving a reason. You can withdraw your data until one month after the completion of the programme. For follow-up interviews, you can withdraw until one month after the follow-up interview.

Within one month after the programme, you may also be selected for a 1.5-h one-on-one interview to discuss your experience in participating in the programme. With your permission, we would like to audio record the interview to make sure we have an accurate record of your thoughts, and the recordings will be kept confidential. Instead of recording you, we can take notes in a notebook. Which would you prefer? We may want to re-contact you to clarify information you gave me in your interview.

A copy of the thesis will be deposited both in print and online in the Oxford Research Archive. The results will also be published in journals, at conferences, and on the SREIA websites, so that others may learn from this research. Your name and your child's name will not appear in any publications or reports.

If you have any complaints or concerns, please feel free to contact our project leader (or me) in the first instance. Her (or my) number is +86 10 85373485. You can also reach her (or me) at zuyi.fang@spi.ox.ac.uk.

This research project has been reviewed and approved by an Oxford University ethics committee. If, after contacting us with any concern, you're still unhappy and wish to make a formal complaint, please contact the ethics committee. Their email address is ethics@socsci.ox.ac.uk. You can also find their postal address and this project's ethics reference numbers in the information sheet we gave to you.

Do you have any questions?

2. Oral consent seeking stage

- Do you give your permission for us to interview you?
- Do you give your permission for us to audio record you if you are selected to participate in a qualitative interview?
- [If no] Do you give permission for us to re-contact you to clarify information?
- Do you give us permission to quote you using your ID number?
- Do you give your permission for us to use your anonymised data in future studies and to share this data with other researchers?
- Are you happy to take part?

Ok, thanks, let's start!

5. Practitioner information sheets and oral consent form

Study of the benefits of the SREIA parent training programme for families of children with ASD

INFORMATION SHEET FOR FACILITATORS

Oxford Central University Research Ethics Committee (CUREC) Approval Reference: R67619/RE001
Beijing Normal University Approval Reference: SSDPP-HSC2020001

Dear Sir or Madam,

You are being invited to participate in a research study conducted jointly by the University of Oxford, Beijing Normal University, and Beijing Stars and Rain Education Institute for Autism. Before you decide whether to take part in the research, it is essential that you understand what this would involve. After reading the following information, you can ask any questions that you may have.

1. ***Why is this research being conducted?***

We are conducting this research, in order to understand how to better support families of children with Autism Spectrum Disorder (ASD) in mainland China. To achieve this, we need to monitor the implementation process, as well as understand your experience and perspectives of delivering the SREIA programme. With the information you provide, we will together explore how we can improve the programme.

2. ***Why have I been invited to take part?***

You have been invited because you meet the following criteria:

- You are over 18 years old.
- You will deliver the Beijing SREIA parent training programme from August to November 2020 (or from November 2020 to January 2021).
- You have indicated a willingness to participate in the research.

3. ***Do I have to take part?***

You do not have to take part. You can ask questions about the research before deciding whether to take part. If you do agree to take part, you may also withdraw from the study at any time, without giving a reason, by advising us of this decision. The deadline to withdraw any data you provided will be 1 month after the first round of programme delivery if you wish this to be done.

You will have up to a week to decide whether to participate in the study. You can also decide to provide consent and participate within 24 hours after you have received all the information about the study. You can also change your mind at any time if you decide that you do not want to participate, and we will destroy any information that you provide us.

If you agree to take part in the study, you will be asked to provide your oral consent. It is up to you to decide whether you want to take part, but you must provide oral consent in order to participate.

4. *What will happen to me if I take part in the research?*

During the SREIA programme:

- Once you have provided oral consent, some of your sessions may be observed remotely by a trained research staff using video conferencing via Microsoft Teams to learn how the sessions go. You will be noticed which sessions will be observed. If you feel uncomfortable, you can choose to stop the observation at any time.
- You will be asked to fill out an online checklist each day to record participant attendance and their engagement in activities and homework. You will also need to fill out an online fidelity checklist that asks you which content you have delivered each week. Both checklists will take less than two minutes to complete.
- Your supervisor will take notes from your supervision sessions. You can choose to stop the note-taking at any time, and if you want, you can ask us to erase any information that you provide.
- Your own attendance of supervision and parent sessions will be shared with us by your manager.

After the SREIA programme:

- We will invite you to an online focus group discussion to learn more about how the program works to improve the lives of children and their parents. The discussion will be held with other facilitators and managers at a time that will be agreed on by consensus. The discussion will take about two hours. Consensus should be reached if more time (less than 20 minutes) is required. We will take a ten-minute break after the first hour. The discussion will, with your permission, be audio-recorded to ensure we have an accurate record of your thoughts. You have the right to answer or not to answer any question that we ask without telling us the reasons. You can opt out the discussion at any time when you feel like doing so, and ask us not to use your part of recording if you want.

  The discussion will cover the following themes:
  1) Your perspectives of and experiences in delivering particular content
  2) Your perspectives of and experiences in particular delivery methods and programme structure.
  3) The supports you received and challenges you encountered during the programme delivery.

5. *Are there any potential risks in taking part?*

We do not expect there to be any risks involved in participating in this study. If you become distressed or upset when answering the questions, we are happy to discuss any issues you may have, and to help refer you to support services if you would like.

To reduce any potential risks, your personal data will be anonymised or pseudonymised if we decide to quote your answers as part of the reporting of the study.

6. *Are there any benefits in taking part?*

There will be no direct or personal benefit to you from taking part in this research, but you will receive a formal Thank You letter and a certificate for participation from the research team upon completion of evaluation.

7. *What happens to the data provided?*

The research data and your personal details will be collected in strict confidence. After each interview, your answers will be uploaded to an encrypted server in Oxford and an encrypted hard drive that only our research team will have access to. This means that no one else will ever be able to see your name or any of your answers to the questions. Your answers will not be written down anywhere else.

Any information that you provide will be kept strictly confidential and private unless there is risk of significant harm to you or other people. If there is any risk of harm, we will discuss possible sources of support following this discussion. If necessary, we may also make a referral to the appropriate services for further assistance. If it concerns a child, the research team will decide on a course of actions based on our child protection protocol.

You will receive an ID number once you give consent. The research data you provided will only show the ID number, and all further identifying information will be removed. The document that records the link between your identity and ID number will be kept in the encrypted server in Oxford and the encrypted hard drive lock in the NGO. These data will be stored for three years after publication of the research results. If needed, we may use your personal details to contact you for follow-ups. You will need to give consent if you allow us to do this. All audio recordings will be erased immediately upon the completion of the research.

We will request your permission to use direct quotes with your ID number (not your name) in future research outputs.

We will also request your permission to use anonymised data in future studies, and to share data with other researchers. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

8. ***Will the research be published?***

The research may be published in journals, at conferences, and on the SREIA websites, so that others may learn from this research. Your name will not appear in any publications or reports about the results of this study. After the study is finished, we would be delighted to share with you the results as soon as they are available.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

9. ***Who has reviewed this study?***

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R67619/RE001) and Beijing Normal University (Reference number: SSDPP-HSC2020001).

10. ***Who do I contact if I have a concern about the study or I wish to complain?***

If you have a concern about any aspect of this study, please contact ***Zuyi Fang, +86 10 85373485, zuyi.fang@spi.ox.ac.uk***, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Social Sciences & Humanities Inter-Divisional Research Ethics Committee; Email: ethics@socsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

11. ***Data Protection***

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.

The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.
Further information about your rights with respect to your personal data is available from https://compliance.web.ox.ac.uk/individual-rights.

12. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Zuyi Fang
zuyi.fang@spi.ox.ac.uk
Department of Social Policy and Intervention, University of Oxford
32 Wellington Square, Oxford, UK, OX1 2ER
SREIA NGO telephone: +86 10 85373485
Oxford University telephone: +44 (0)1865 270325
Oxford University email: info@spi.ox.ac.uk

Oral Information Giving and Consent Seeking Script -- Facilitators

2. Oral information giving

Hi, my name is xxx (my name or name of a research assistant). We're doing a DPhil project at the University of Oxford in the Department of Social Policy and Intervention. We wondered if you'd be interested in being involved.

In the study, we want to understand how to better support families of children with Autism in mainland China. We are interested in monitoring the implementation process, as well as understanding your experience and perspectives of delivering the SREIA programme. If you choose to be a part of this project, here is what will happen:

Some of your sessions may be observed by a trained research staff to learn how the sessions go. You will be asked to fill out a participant attendance and engagement registry each day, and a fidelity checklist that asks you which content you have delivered each week. Both checklists will take less than two minutes to complete. Your supervisor will take notes from your supervision sessions. Your own attendance will also be shared with us.

After the programme, we will invite you to a 2-hour focus group discussion to learn more about how the program works to improve the lives of children and their parents. With your permission, we would like to audio-record the discussion to make sure we have an accurate record of your thoughts. Instead of recording, we can take notes in a notebook. Which would you prefer? We may want to re-contact you to clarify information you gave me in the discussion.

Your answers will form the basis of a DPhil thesis at the University of Oxford and some publications. We will store your data safely and confidentially in an encrypted server in Oxford and an encrypted hard drive that only our research team will have access to. This means that no one else will ever be able to see your name or any of your answers to the questions. You will also receive an ID number once you give consent. The research data you provided will only show the ID number, and all further identifying information will be removed. We will keep the data for three years after publication. We would like to be able to use your anonymised information/data in future studies, and to share this information/data with other researchers.

We do not expect there to be any risks involved in participating in this study. If you become distressed or upset when answering the questions, we are happy to discuss any issues you may have, and to help

refer you to support services if you would like. To reduce any potential risks, your personal data will be anonymised or pseudonymised if we decide to quote your answers as part of the reporting of the study.

You don't have to agree to take part. You can ask us any questions you want before or throughout. You can also withdraw at any stage without giving a reason. You can withdraw your data until one month after the completion of the first round of the programme delivery.

A copy of the thesis will be deposited both in print and online in the Oxford Research Archive. The results will also be published in journals, at conferences, and on the SREIA websites, so that others may learn from this research. Your name will not appear in any publications or reports.

If you have any complaints or concerns, please feel free to contact our project leader (or me) in the first instance. Her (or my) number is +86 10 85373485. You can also reach her (or me) at zuyi.fang@spi.ox.ac.uk.

This research project has been reviewed and approved by an Oxford University ethics committee. If, after contacting us with any concern, you're still unhappy and wish to make a formal complaint, please contact the ethics committee. Their email address is ethics@socsci.ox.ac.uk. You can also find their postal address and this project's ethics reference numbers in the information sheet we gave to you.

Do you have any questions?

3. **Oral consent seeking stage**
   - Do you give your permission for us to monitor your implementation process?
   - Do you give your permission for us to audio record you during the focus group discussion?
   - [If no] Do you give permission for us to re-contact you to clarify information?
   - Do you give us permission to quote you using your ID number?
   - Do you give your permission for us to use your anonymised data in future studies and to share this data with other researchers?
   - Are you happy to take part?

Ok, thanks, let's start!

6. Certificate of participation

7. Child protection protocol

Child Protection Protocol

Parent Training Program by the Beijing Stars and Rain Education Institute for Autism – SREIA Evaluation

Overview
The SREIA evaluation will be conducted with families and children (defined as those under 18 years) in Beijing China, who may be particularly at risk of child maltreatment, financial stress, and other adversities. Given these circumstances, staff are expected to uphold certain values, to refrain from prohibited behaviour when interacting with children, and to follow the below procedure if he or she observes or receives information that a child has been significantly harmed or is at risk of significant harm. In order to be in compliance with the *Law of the People's Republic of China on the Protection of Minors (2012)*, and the *Anti-Domestic Violence Law of the People's Republic of China (2016)*, as well as to meet international standards for upholding child rights to protection, all staff will follow this Child Protection Protocol while they are employed under the project.

Values based on the 1989 United Nations Convention on the Rights of the Child

All staff must uphold the following values:

1. **Best interests of the child**: The best interests of the child are our primary concern.
2. **Respect**: All adults and children with whom we interact must be treated with respect.
3. **Non-discrimination**: Children have a right to be protected from discrimination on the basis of ethnicity, legal status, class, age, gender, sexual orientation, ability, religion, or expressed opinions or beliefs.
4. **Privacy**: Children should not be subjected to arbitrary of unlawful interference into their lives, including any attacks on their reputation.
5. **Right to participation**: Children have a right to meaningfully participate in decisions that affect their lives.

Prohibited conduct when interacting with children

1. **Physical abuse**: Hit, pinch, kick, slap or otherwise physically harm children, including threatening to physically harm them.
2. **Sexual abuse**: Make sexual comments to children, share sexually explicit images with children, develop sexual relationships with children, or otherwise interact with children in ways that may be deemed sexually abusive or exploitative.
3. **Emotional abuse**: Shout at or threaten children, or otherwise act in ways intended to frighten, shame, humiliate, or belittle children.
4. **Inappropriate language:** Use language, make suggestions or offer advice that would be deemed inappropriate, offensive or abusive.
5. **Compromising safety**: Condone or participate in the behaviour of children that is illegal or unsafe.
6. **Discrimination**: Discriminate against, show differential treatment to, or favour particular children to the exclusion of others.
7. **Exposure to harmful substances**: Smoke, consume alcohol or use other addictive substances while working with children and families.
8. **Inappropriate proximity or contact**: Taking a child participating in the project to your home or another location, or spending excessive time alone with children away from others.
9. **Photography and social media:** Photographs of children (unless strictly for research purposes) or posting images of children on social media, or sharing contact or social media profile information with children.

Confidentiality

The SREIA evaluation follows guidelines from UNICEF that child confidentiality must be maintained except where a child is shown to be at risk, in which case referral and emergency protocols will be followed.

- All adult respondents must be informed at the consent stage that everything that is said or occurs during the study will be confidential unless it becomes clear that they or another person in their family or household are at risk of significant harm.
- If information is disclosed that suggests that any member of the household is at risk of significant harm, research staff and community partners will discuss concerns with the family.
- Unless there is potential for a child to be put at risk by this, the caregiver will be informed and research staff and community partners will discuss the possibilities for referral to the Child Welfare and Protection Unit in Beijing, Beijing Children Hospital, and/or local health service agencies.

The staff member and Principal Investigator should ensure that any information regarding the child protection concern, especially the child's identity, is shared strictly on a "need to know" basis, and that these details are not shared with any other staff.

If the staff member observes or information is disclosed that suggests that harm, or risk of harm, has been perpetrated to a child by someone other than the child's parent or primary caregiver, the staff member will discuss this directly with the local co-PI, Zuyi Fang, and a designated person in the NGO, who will then make a judgment in cooperation with local social workers or law enforcement, as appropriate, in order to determine how best to protect the child from further harm. However, if the parent or caregiver has allegedly perpetrated the significant harm, or is likely to cause significant harm to the child, the staff member will follow the procedures below.

Examples of reasonable grounds for concern are:

- Specific indication from the child that he/she was abused or neglected;
- An account by the person who saw the child being abused or neglected;
- Evidence, such as an injury or behaviour which is consistent with abuse and/or neglect, and unlikely to be caused in another way;

Where harm or risk of harm remains uncertain, Zuyi Fang will consult with the local co-PI, Professor Dongping Qiao, who have years of experience in child protection, for informal advice relating to the allegation, concern or disclosure.

Child protection procedures

Significant harm

For the purpose of this Child Protection Protocol, the following constitute "significant harm" to the child.

The following definitions further elaborate on the types of abuse that children may have experienced, or be at risk of experiencing:

- **Physical abuse**: Abuse that results in actual or potential physical harm from an interaction or lack of an interaction, which is reasonably within the control of a parent or person in a position of responsibility, power or trust.

- **Sexual abuse**: Involving a child in sexual activity that he or she does not fully understand, is unable to give informed consent to, or for which the child is not developmentally prepared and cannot give consent. Child sexual abuse may occur between a child and an adult or another child who by age or development is in a relationship of responsibility, trust or power.

- **Neglect**: Failing to provide for the development of the child in terms of health, education, emotional development, nutrition, shelter, and safe living conditions, when such provisions are reasonably available to the family or caretakers, and which has a high probability of causing harm to the child's health or physical, mental, spiritual, moral or social development. This includes the failure to properly supervise and protect children from harm as much as is feasible.

- **Emotional abuse**: Acts toward a child that have a high probability of causing harm to the child's health or physical, mental, spiritual, moral or social development. These acts are reasonably within the control of a person in a relationship of responsibility, trust or power. Such acts may include threats, discrimination, ridicule, and other non-physical forms of hostile or rejecting treatment.

Staff Member: Process for internal reporting and making a referral

A staff member who observes, receives information regarding, or legitimately suspects that a child has been significantly harmed or is at risk of significant harm is required to undertake the following:

1. **Collect basic information**: Gather basic information regarding what may have taken place for the purpose of providing a report.

2. **Address the child's immediate needs if appropriate**: Before reporting, ensure that the child is safe and that any urgent medical needs are addressed. Dial 120 for emergency medical assistance if needed. If the child is in immediate danger, make arrangements for the child to move to a temporary place of safety in consultation with Zuyi Fang and the designated officer in the NGO.

3. **Contact the local Principal Investigator and the Designated Officer**: Verbal reports regarding a child protection concern should be made immediately if the case is urgent, or at least within 24 hours in non-emergency cases. The Principal Investigator (Zuyi Fang) and the designated officer will then work with the staff member to complete the Child Protection Referral Form.

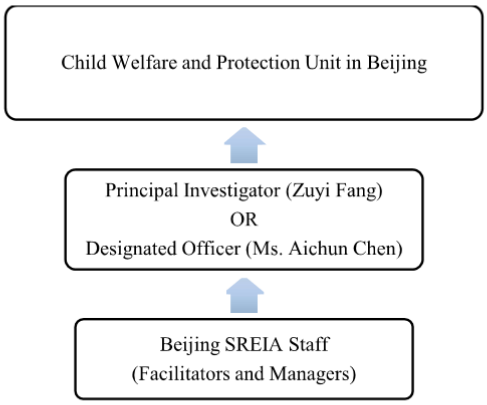
Principal Investigator and Designated Officer: Process for making a referral

1. **Completing the Child Protection Referral Form**: The Principal Investigator and Designated Officer will complete the Child Protection Referral Form in consultation with the reporting staff member.

2. **Contacting the appropriate 'competent official':** Depending on the nature of the reported case, the Principal Investigator will share the completed Child Protection Referral Form in confidence with the Child Welfare and Protection Unit in Beijing who will advise on whether to call the police. All cases will be responded to immediately.

3. **If the alleged abuse concerns a staff member:** The Principal Investigator and the Designated Officer will immediately suspend the staff member, pending further investigation. If the actions or allegations indicate a possible criminal offence, referrals will be made to the local police. The Principal Investigator will subsequently call an urgent meeting with the other Principal Investigators to update them on the situation and to discuss steps for any internal investigation and either termination or reinstatement of the staff member in question, as well as steps to prevent the actual or alleged abuse from reoccurring.

Flow chart for making an internal report and referral



Handling Disclosures

DO:

1. Give the person who disclosed your full attention.
2. Remain calm.
3. Reassure the person it is right to tell.
4. Accept the person will disclose only what is comfortable and recognize the bravery/strength of the person for talking about something that is difficult.
5. Let the person take his or her time.
6. Let the person use his or her own words.
7. Tell the person what you plan to do next.
8. Clarify but DO NOT investigate.
    - Paraphrase/repeat what the person said to validate the information given (do not probe for more information).

DO NOT:

1. Do not react in shock of disbelief.
2. Do not confront the perpetrator.
3. Do not accuse the person of lying.
4. Do not ignore anyone's disclosure.
5. Do not investigate the abuse.
    - Do not corroborate the allegations with witnesses or the accused.
    - Do not ask children to remove or lift clothing to show you marks.
    - Do not ask leading questions
6. Do not promise to keep a secret for the person.
7. Do not indiscriminately discuss the abuse with others not directly involved in helping the child.
8. Do not say that "everything will be fine now."

How sure about the abuse should you be before you report?

- Report if anyone has a reason to suspect that abuse is happening (e.g., a child said something, third party information, the behavior of a child's parent has cause for concern).
- You do not have to prove that abuse has happened. Reporting is a request for assessment into the condition of the child.

IMPORTANT:
Data Collectors and Facilitators should refer suspected/reported cases of potential harm and/or abuse.
DO NOT investigate the case yourselves.

DECLARATION

Name of staff member (Print): _____

I understand:

- ☐ I have received the Child Protection Protocol, and have read its contents.
- ☐ All questions I have regarding the Child Protection Protocol have been answered to my satisfaction.
- ☐ I understand that I am required to comply with the Child Protection Protocol and will follow the described procedure in the event that I have any child protection concerns during the course of my work on the SREIA evaluation.

Date: _____

Signature: _____

PARENT TRAINING PROGRAM BY THE STARS AND RAIN EDUCATION INSTITUTE FOR AUTISM (SREIA)
SREIA EVALUATION CHILD PROTECTION REFERRAL FORM

Date concern raised: _____

Date this form completed: _____

Dear Sir or Madam,

The SREIA evaluation is a project being undertaken in the Beijing Stars and Rain Education Institute for Autism (SREIA) by the University of Oxford, the Beijing Normal University, and the NGO of Beijing SREIA.

During the course of an activity under this project, our staff became aware of a child (under 18 years of age) who has either recently experienced significant harm or is at risk of experiencing significant harm.

We request that your office follows up on this matter directly with the child in question. For our own records, we will follow-up with your office to find out the date on which the child was met by your staff and provided with assistance.

The following particulars of the case were recorded:

Staff member reporting the concern:

Case appears to be acute and requiring an urgent response: Yes/No/Unsure

Name of the child:

Sex:

Age:

Child's address:

Name of caregiver and relationship to child:

Details regarding the child protection concern:

We appreciate your attention to this concern; if you need any further information, please do not hesitate to contact us using the details below.

Sincerely,

Zuyi Fang
Department of Social Policy and Intervention
University of Oxford
Email: zuyi.fang@spi.ox.ac.uk
Mobile: +86 13716158626

Aichun Chen
Beijing Stars and Rain Education
Institute for Autism
E-mail: chenaichun@guduzh.org.cn
Mobile: +86 10 8537-3485

PLH Philippines MaPa Feasibility Study Contact Details

Principal Investigators	Professor Jane Barlow Email: jane.barlow@spi.ox.ac.uk Mobile: +44 1865 270323
	Dr. Jamie Lachman Email: jamie.lachman@spi.ox.ac.uk Mobile: +1 202 763 2085
Investigator	Professor Dongping Qiao Email: qiaodping@bnu.edu.cn Mobile: +86 10 58801508

8. Staff personal safety protocol

Staff Safety Protocol

The safety of our team members is the paramount concern of the project. This document aims to outline a general procedure that will be implemented to ensure the safety of all SREIA Evaluation staff. All staff should read this document and sign the declaration included. The structure for the reporting and documenting of any safety issues that might arise is outlined below. Appended to this document are also procedures put in place regarding personal safety, dealing with participants, staff health, trip safety, substance misuse, and climate and disasters.

Procedure

1. Any staff safety concerns should be raised with Zuyi Fang immediately. Zuyi Fang will make a decision about whether to deal with this immediately, to discuss with other Principal Investigators;

2. Zuyi Fang and the research team should determine whether the safety concern is likely to impact the other research activities. If it is deemed that the concern may impact other research activities, Zuyi Fang and the research team should discuss the issue and any possible safety procedures that could be implemented to address it.

3. If a safety procedure is decided upon, the initial concern and the proposed procedure should be documented (using a copy of the attached Safety Documentation Form).

4. All accidents and incidents involving physical damage or theft to project property and physical or emotional harm to staff need to be reported to Oxford.

Safety Procedures to be Followed by All SREIA Evaluation Staff

1. **Personal Safety**
   a) Staff should carry a well-charged cell phone at all time in case of accident or emergency.
   b) Where there is an immediate emergency and Zuyi Fang is not easily contactable, staff should inform Professor Dongping Qiao and Ms. Aichun Chen.
   c) Always inform another member of the SREIA Evaluation team about your destination and estimated time of return.
   d) Staff should know the closest location to the local authorities (e.g. police station) to seek refuge if danger arises
   e) If danger arises, staff should remove themselves from danger immediately, without taking time to inform Zuyi Fang. Inform Zuyi Fang only once you are in a safe space to make a phone call.
   f) Your life is more important than project property such as surveys and consents. In the event of robbery, do not put yourself at risk for project materials. Give

project materials away. We also recommend that in the event of robbery you give up your own belongings, but the project will not be able to cover the loss of personal belongings.

g) If interviewing in a space where you feel unsafe, inform Zuyi Fang before starting work as early as possible.

h) When inside a house, make sure you are close to the door and there are no obstacles standing in the way between you and the door.

i) Staff are encouraged to always walk in teams of two or more.

2. Dealing with participants

a) Violent Participants:

- Staff should carry a well-charged cell phone at all times in case of violence or danger
- If staff encounter someone who is violent, they should immediately remove themselves to a safe place (ie. clinic, school, policy office, shop)
- Staff should not solve the matter independently
- Staff should not respond violently (so as not to promote escalating emotions)
- Do not confront a mob
- Walk away and ignore the accusations
- Inform Zuyi Fang as soon as possible
- If violent accusations result in physical harm, Zuyi Fang should open an assault case at the police station

b) Unhappy Participants and Caregivers/Family members:

- Staff should be aware of escalating emotions. If a participant or caregiver is becoming emotional or upset/suspicious about the project, stop and remind them that their participation is voluntary
- When possible, re-address the objectives of the study, privacy guidelines for disclosure, and remind the participants that authorities in the areas are aware of the project study
- Always carry Beijing Normal University and Oxford University ethical approval letters, to prove the legitimacy of the project. It is also helpful to point to the contact number provided in the letter and offer the participant to call this number
- If participant is not satisfied with the explanation, offer to make appointment with Zuyi Fang
- Appease the unhappy participant by ensuring that their concerns will be heard and handled
- Contact and inform Zuyi Fang of the encounter

3. Health of staff members:

a) Supervisions will be conducted during the data collection at a time that is convenient, in order to discuss any issues and distressing events.

b) If any staff is experiencing vicarious trauma, actively seek psychological

support and counselling services in the student counselling centre at the Beijing Normal University.

c) It is strongly encouraged that staff report vicarious trauma to Zuyi Fang, who will provide supports and work out solutions together with the staff, but it is up to staff to decide whether to disclose his/her mental health status.

4. Trip safety

a) All staff members are requested to register a telephone number of a relative or friend that can be contacted in case the member of staff is involved in an accident at work. Emergency numbers are to be emailed/messaged to Zuyi Fang.

b) Don't walk around with earphones in. You must be able to hear and be aware of your surroundings at all times.

c) Avoid expensive-looking jewellery, shoes or clothing.

d) Avoid visible valuables such as wallets or cell phones in pockets, and laptop bags.

e) Follow your intuition. If it doesn't feel right, don't worry about manners or about causing offense. Get out of the situation.

5. Alcohol and substance use

a) The SREIA evaluation is a drug-free and alcohol-free project. This means that the consumption or possession of alcohol and illicit drugs whilst at work is unacceptable and employees should present themselves for work and remain, while at work, capable of performing their work duties safely.

b) The effects of drugs and alcohol abuse (ie hangovers or any other affects that will lead to impairment) will furthermore not be tolerated.

c) Any staff found to be under the influence of alcohol or drugs may not enter or remain on the project premises and will be released from employment immediately.

6. Climate and disasters

a) Heat: when having fieldtrips, staff should bring enough water during the summer months.

b) In any case of environmental hazard, consider your own safety and that of your team first and remove yourself from danger.

c) Do not attempt to cross a fire in order to get yourself to interviews

d) Zuyi Fang and the research team will make a decision for longer-term work should there be undergoing natural disasters. This will be done in consultation with the NGO managers, about how best to deal with these issues.

7. Responsibility of Zuyi Fang

a) Zuyi Fang should make sure all staff have a copy of documented safety procedures and ask staff to sign for confirmation of having read and accepted adherence to them. Staff should also be encouraged to provide suggestions or

highlight guidelines that are not working.

b) Monitor staff, as violent encounters can be traumatic. Offer psychological counselling (with local psychologists in hospitals) or debrief team members.
c) Provide reminder trainings on the safety protocol for all fieldwork staff.

"I have read, understood and discussed these terms and conditions with Zuyi Fang. I commit to follow these guidelines whilst collecting data."

Name: _____

Signature: _____

Date: _____

Safety Concern Documentation and Response Form

Date concern raised: _____

Describe the safety concern:

Proposed response:

PIs signatures: _____Date: _____

_____Date: _____

_____Date: _____

_____Date: _____

9. RA confidential agreement

Department of Social Policy and Intervention
32 Wellington Square, Oxford, OX1 2ER, UK
+44 (0)1865 270325:
Email: info@spi.ox.ac.uk
Website: https://www.spi.ox.ac.uk/

I, _____, being appointed a Research Assistant for the purposes of a research project in Beijing, China—*Evaluation of a Parent Training Programme for Families of Children with Autism Spectrum Disorder in China: A Mixed-Methods Quasi-Experimental Study* (the "Research Project")—on behalf of the University of Oxford (the "University"), agree:
本人，_____，将在牛津大学于北京开展的研究项目——评估星星雨 11 周家长培训（以下简称“研究”）——中担任研究助理一职，并同意遵守以下条款：

(1) Complete all training sessions and attend supervisions which will be arranged for times that are convenient for the Research Assistant and the Principal Investigator.
参与研究助理培训，接受研究负责人的督导。

(2) That all information (whether or not recorded in documentary form, or stored on any magnetic or optical disk or memory) about the Research Project including and in particular personal information regarding the participants of the Research Project coming into my possession or of which I am made aware in the course of my involvement in the Research Project will remain confidential ("Confidential Information").
严格保密一切与本研究项目有关的信息（纸质或电子），包括被试的个人信息。

(3) Not to disclose any Confidential Information to any person, company or other organisation whatsoever at any time other than to the Principal Investigator named below or persons nominated in writing by this Principal Investigator, and to use my best endeavours to prevent the publication of or disclosure of any Confidential Information. that I shall only use the Confidential Information for the purposes of conducting research activity for the Research Project and not for any other purpose, unless the use of the information is approved by the Principal Investigator. The information may only be obtained from the Principal Investigator and may not be distributed or received by any other means.
不向除项目负责人以外的任何人、公司或组织透露任何保密信息；只将我所收集的信息用于本研究，而不是其它任何目的，除非获得项目负责人的同意。

(4) That all the documents and recordings (including but not limited to forms, notes, voice recordings and electronic documents) regarding the Research Project given

to me for the duration of the Research Project will remain the property of the University and that I will handle with care and protect all such documents and recordings.
一切关于本研究项目的文件和记录（包括但不限于表格、笔记、录音和电子文档）都归牛津大学所有；我将保护文件不受损害。

(5) The conclusion of the Research Project or on termination of my appointment, whichever is earlier, to return all documents and recordings provided to me or produced by me for the purposes of discharging my duties as a Research Assistant during the Research Project to the University, and to delete irretrievably any Confidential Information (including any copies) stored on any magnetic or optical disk or memory, including personal computer networks, personal e-mail accounts or personal accounts on websites, and all matter derived from such sources which is in my possession or under my control outside of the University's premises
当研究（或我的任期，以更早的为准）结束时，我将上交一切与此研究相关的文件和记录，并将其从我所有的设备中删除，包括但不限于电脑、邮箱和个人网页。

(6) Inform the Principal Investigator immediately if I become aware or suspect that any Confidential Information has been disclosed to any person, company or organisation other than the Principal Investigator or any person nominated in writing to receive that Confidential Information by the Principal Investigator.
如果我发现任何信息泄露的情况，必须立即向项目负责人报告。

Principal Investigator: Zuyi Fang
项目负责人：方祖仪

Signed as a deed on [DATE]
日期

_____

by [FULL NAME OF PARTY]
姓名（打印）

_____

……
[signature of party]
研究助理签字

in the presence of:

……
[signature of witness]见证人签名

[NAME OF WITNESS] 见证人姓名

_____
[ADDRESS OF WITNESS]见证人地址

_____
[OCCUPATION OF WITNESS]见证人职业

_____

Appendix I Reporting Guidelines

1. SPIRIRT Guideline

SPIRIT 2013 Checklist: Recommended items to address in a clinical trial protocol and related

documents*

Section/item	Item No	Description	Page Number (Appendix D)
Administrative information			
Title	1	Descriptive title identifying the study design, population, interventions, and, if applicable, trial acronym	1
Trial registration	2a	Trial identifier and registry name. If not yet registered, name of intended registry	2,4
	2b	All items from the World Health Organisation Trial Registration Data Set	N/A
Protocol version	3	Date and version identifier	N/A
Funding	4	Sources and types of financial, material, and other support	23
Roles and responsibilities	5a	Names, affiliations, and roles of protocol contributors	1, 23
	5b	Name and contact information for the trial sponsor	1
	5c	Role of study sponsor and funders, if any, in study design; collection, management, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication, including whether they will have ultimate authority over any of these activities	N/A
	5d	Composition, roles, and responsibilities of the coordinating centre, steering committee, endpoint adjudication committee, data management team, and other individuals or groups overseeing the trial, if applicable (see Item 21a for data monitoring committee)	N/A
Introduction			

Background and rationale	6a	Description of research question and justification for undertaking the trial, including summary of relevant studies (published and unpublished) examining benefits and harms for each intervention	3-4
	6b	Explanation for choice of comparators	4
Objectives	7	Specific objectives or hypotheses	3-4
Trial design	8	Description of trial design including type of trial (eg, parallel group, crossover, factorial, single group), allocation ratio, and framework (eg, superiority, equivalence, noninferiority, exploratory)	4
Methods: Participants, interventions, and outcomes			
Study setting	9	Description of study settings (eg, community clinic, academic hospital) and list of countries where data will be collected. Reference to where list of study sites can be obtained	5
Eligibility criteria	10	Inclusion and exclusion criteria for participants. If applicable, eligibility criteria for study centres and individuals who will perform the interventions (eg, surgeons, psychotherapists)	4
Interventions	11a	Interventions for each group with sufficient detail to allow replication, including how and when they will be administered	5-7
	11b	Criteria for discontinuing or modifying allocated interventions for a given trial participant (eg, drug dose change in response to harms, participant request, or improving/worsening disease)	15
	11c	Strategies to improve adherence to intervention protocols, and any procedures for monitoring adherence (eg, drug tablet return, laboratory tests)	4, 15
	11d	Relevant concomitant care and interventions that are permitted or prohibited during the trial	N/A

Outcomes	12	Primary, secondary, and other outcomes, including the specific measurement variable (eg, systolic blood pressure), analysis metric (eg, change from baseline, final value, time to event), method of aggregation (eg, median, proportion), and time point for each outcome. Explanation of the clinical relevance of chosen efficacy and harm outcomes is strongly recommended	8-12
Participant timeline	13	Time schedule of enrolment, interventions (including any run-ins and washouts), assessments, and visits for participants. A schematic diagram is highly recommended (see Figure)	Fig 1.
Sample size	14	Estimated number of participants needed to achieve study objectives and how it was determined, including clinical and statistical assumptions supporting any sample size calculations	7-8
Recruitment	15	Strategies for achieving adequate participant enrolment to reach target sample size	4
Methods: Assignment of interventions (for controlled trials)			
Allocation:			
Sequence generation	16a	Method of generating the allocation sequence (eg, computer-generated random numbers), and list of any factors for stratification. To reduce predictability of a random sequence, details of any planned restriction (eg, blocking) should be provided in a separate document that is unavailable to those who enrol participants or assign interventions	4
Allocation concealment mechanism	16b	Mechanism of implementing the allocation sequence (eg, central telephone; sequentially numbered, opaque, sealed envelopes), describing any steps to conceal the sequence until interventions are assigned	N/A

Implementation	16c	Who will generate the allocation sequence, who will enrol participants, and who will assign participants to interventions	4
Blinding (masking)	17a	Who will be blinded after assignment to interventions (eg, trial participants, care providers, outcome assessors, data analysts), and how	13
	17b	If blinded, circumstances under which unblinding is permissible, and procedure for revealing a participant's allocated intervention during the trial	13
Methods: Data collection, management, and analysis			
Data collection methods	18a	Plans for assessment and collection of outcome, baseline, and other trial data, including any related processes to promote data quality (eg, duplicate measurements, training of assessors) and a description of study instruments (eg, questionnaires, laboratory tests) along with their reliability and validity, if known. Reference to where data collection forms can be found, if not in the protocol	12-13
	18b	Plans to promote participant retention and complete follow-up, including list of any outcome data to be collected for participants who discontinue or deviate from intervention protocols	4
Data management	19	Plans for data entry, coding, security, and storage, including any related processes to promote data quality (eg, double data entry; range checks for data values). Reference to where details of data management procedures can be found, if not in the protocol	13
Statistical methods	20a	Statistical methods for analysing primary and secondary outcomes. Reference to where other details of the statistical analysis plan can be found, if not in the protocol	13-14

	20b	Methods for any additional analyses (eg, subgroup and adjusted analyses)	13-14
	20c	Definition of analysis population relating to protocol non-adherence (eg, as randomised analysis), and any statistical methods to handle missing data (eg, multiple imputation)	13-14
Methods: Monitoring			
Data monitoring	21a	Composition of data monitoring committee (DMC); summary of its role and reporting structure; statement of whether it is independent from the sponsor and competing interests; and reference to where further details about its charter can be found, if not in the protocol. Alternatively, an explanation of why a DMC is not needed	N/A
	21b	Description of any interim analyses and stopping guidelines, including who will have access to these interim results and make the final decision to terminate the trial	15
Harms	22	Plans for collecting, assessing, reporting, and managing solicited and spontaneously reported adverse events and other unintended effects of trial interventions or trial conduct	15
Auditing	23	Frequency and procedures for auditing trial conduct, if any, and whether the process will be independent from investigators and the sponsor	N/A
Ethics and dissemination			
Research ethics approval	24	Plans for seeking research ethics committee/institutional review board (REC/IRB) approval	15

Protocol amendments	25	Plans for communicating important protocol modifications (eg, changes to eligibility criteria, outcomes, analyses) to relevant parties (eg, investigators, REC/IRBs, trial participants, trial registries, journals, regulators)	N/A
Consent or assent	26a	Who will obtain informed consent or assent from potential trial participants or authorised surrogates, and how (see Item 32)	15
	26b	Additional consent provisions for collection and use of participant data and biological specimens in ancillary studies, if applicable	N/A
Confidentiality	27	How personal information about potential and enrolled participants will be collected, shared, and maintained in order to protect confidentiality before, during, and after the trial	15
Declaration of interests	28	Financial and other competing interests for principal investigators for the overall trial and each study site	23
Access to data	29	Statement of who will have access to the final trial dataset, and disclosure of contractual agreements that limit such access for investigators	N/A
Ancillary and post-trial care	30	Provisions, if any, for ancillary and post-trial care, and for compensation to those who suffer harm from trial participation	N/A
Dissemination policy	31a	Plans for investigators and sponsor to communicate trial results to participants, healthcare professionals, the public, and other relevant groups (eg, via publication, reporting in results databases, or other data sharing arrangements), including any publication restrictions	15
	31b	Authorship eligibility guidelines and any intended use of professional writers	N/A

	31c	Plans, if any, for granting public access to the full protocol, participant-level dataset, and statistical code	4,15
Appendices			
Informed consent materials	32	Model consent form and other related documentation given to participants and authorised surrogates	S2 Appendix
Biological specimens	33	Plans for collection, laboratory evaluation, and storage of biological specimens for genetic or molecular analysis in the current trial and for future use in ancillary studies, if applicable	N/A

*It is strongly recommended that this checklist be read in conjunction with the SPIRIT 2013 Explanation & Elaboration for important clarification on the items. Amendments to the protocol should be tracked and dated. The SPIRIT checklist is copyrighted by the SPIRIT Group under the Creative Commons "Attribution-NonCommercial-NoDerivs 3.0 Unported" license.

2. STROBE Reporting Guideline Combined with CONSORT Items

	Item No.	Recommendation	Section No.
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Section 4
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Section 4.1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Section 4.2
Objectives	3	State specific objectives, including any prespecified hypotheses	Section 4.2
Methods			
Study design	4	Present key elements of study design early in the paper	Section 4.3.1
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up,	Section 4.3.1

		and data collection	
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	Section 4.3.1
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Interventions (CONSORT item)		*The interventions for each group with sufficient details to allow replication, including how and when they were actually administered*	Section 4.3.2
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Section 4.3.4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Section 4.3.4
Bias	9	Describe any efforts to address potential sources of bias	Section 4.3.5
Study size	10	Explain how the study size was arrived at	Section 4.3.1
Allocation (CONSORT item)		*Method used to generate the allocation sequence*	Section 4.3.1
		Mechanism used to implement the allocation sequence	Section 4.3.1
		Who generated the random allocation sequence, who	Section

		enrolled participants, and who assigned participants to interventions	4.3.1
Blinding (CONSORT item)		*If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how*	Section 4.3.5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Section 4.3.4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	Section 4.3.5
		(*b*) Describe any methods used to examine subgroups and interactions	Section 4.3.5
		(*c*) Explain how missing data were addressed	Section 4.3.5
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	Section 4.3.5
		(*e*) Describe any sensitivity analyses	Section 4.3.5
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Section 4.4, Figure 18
		(b) Give reasons for non-participation at each stage	Figure 18
		(c) Consider use of a flow diagram	Figure 18
Results			
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Section 4.4, Table 8
		(b) Indicate number of participants with missing data	Section

		for each variable of interest	4.3.5
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	Section 4.4, Table 8
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Section 4.4.1, Table 10
		(*b*) Report category boundaries when continuous variables were categorised	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Section 4.4.2, Table 11-13
Summary and Discussion			
Key results	18	Summarise key results with reference to study objectives	Section 4.5.1 & Section 4.5.2
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Section 4.5.3
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Section 4.5.1, Section 4.5.2, and

			Section 4.5.4
Generalisability	21	Discuss the generalisability (external validity) of the study results	Section 4.5.4
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Section 4.9
Registration (CONSORT item)		*Registration number and name of trial registry*	Section 4.1
Protocol (CONSORT item)		*Where the full trial protocol can be accessed, if available*	Appendix D

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

3. Standards for Reporting Qualitative Research

	Item No.	Recommendation	Section No.
Title and abstract			
Title	1	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Section 5
Abstract	2	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Section 5.1
Introduction			
Problem	3	Description and significance of the problem/phenomenon	Section

formulation		studied; review of relevant theory and empirical work; problem statement	5.2.1
Purpose or research question	4	Purpose of the study and specific objectives or questions	Section 5.3
Methods			
Qualitative approach and research paradigm	5	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	Section 5.4.4
Researcher characteristics and reflexivity	6	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Section 5.6.2
Context	7	Setting/site and salient contextual factors; rationale[b]	Section 5.4.2
Sampling strategy	8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Section 5.4.3
Ethical issues pertaining to human subjects	9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Section 5.4.1
Data collection methods	10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	Section 5.4.4
Data collection instruments	11	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for	Section 5.4.4

and technologies		data collection; if/how the instrument(s) changed over the course of the study	
Units of study	12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Section 5.4.3
Data processing	13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Section 5.4.4
Data analysis	14	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Section 5.4.4
Techniques to enhance trustworthiness	15	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Section 5.6.2
Results/findings			
Synthesis and interpretation	16	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Section 5.5
Links to empirical data	17	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Section 5.5
Results/findings			
Integration with prior work, implications, transferability, and contribution(s) to the field	18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Section 5.6.1
Limitations	19	Trustworthiness and limitations of findings	Section 5.6.2
Other			

Conflicts of interest	20	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Section 5.7
Funding	21	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Section 5.8

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.