IS THE PREVENTION AND/OR CURE OF AUTISM A MORALLY LEGITIMATE QUEST?

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ABSTRACT

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The thesis explores the ethical questions underlying important contemporary debates about how society should respond to autism; whether autism is ‘disease’, ‘disability’ or ‘difference’, and whether it requires ‘treatment’ or ‘acceptance’. Part 1 comprises a historical overview of how knowledge about autism has evolved through the perspective of contrasting stakeholders – clinicians and researchers, parents, professionals, the neuro-diversity movement. It reviews the main areas of academic ethical discussion to date with regard to autism, and proposes a new analytic framework – structured in terms of six ‘categories of intervention’: from pre-conceptual measures to post-birth interventions targeted towards infants and adults, and from individuals through to wider societal measures. Part 2 then conducts an ethical analysis using this framework. Examples are offered at each stage of intervention, along with a discussion of the ethical questions posed at each one.

Part 3 reflects on the questions to which Part 2 has given rise, addressing the way ethical positions on how to respond to autism rely on wider views about quality of life and wellbeing; parental virtues; the impact of local decisions on wider states of affairs (the Big Conundrum); and views on “where autism sits” in comparison with other conditions (the Analogy Challenge). It is argued that to conflate autism and suffering is to fail to do justice to extreme variations among autistic people, and disguises the extent to which external barriers may be the main obstacles to flourishing for autistic people and their families. The real-life conditions in which autistic people and their families struggle for recognition and support are therefore held to be of crucial significance for making both global and localised ethical judgements. It is therefore concluded that cure and/or prevention are not morally defensible as global targets for autism as a whole, but should be clearly distinguished from the ethical importance of supportive and therapeutic interventions to address particular problems that autistic individuals may have. The implications, for research and practice, are spelled out, with particular emphasis on the need for further dialogue among all stakeholders.
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Chapter 1 Introduction

In the autumn of 2007 a “bitter ideological war” (Laurance, 2007) was for a while the focus of extensive media attention in the UK. It was played out in the letters page of the Independent newspaper,¹ and led to a debate on the BBC Radio 4 Today programme (Today, 2008). The conflict arose from the Think Differently About Autism campaign, which had been launched by the National Autistic Society (NAS) in October 2007 (NAS, 2007).

The exchanges to which the NAS campaign gave rise came to be known as the treatment vs acceptance debate, and they reflected themes that, as the mother of a severely disabled autistic teenager and a campaigner within the autism movement, I had been trying to resolve for some time. The themes reflected two distinct debates: the measles, mumps, rubella (MMR) controversy, in which some parents firmly believed that their children had been damaged and that their autism was a consequence of a toxic external agent; and the early intensive behavioural intervention (EIBI) controversy, which featured passionate disagreements about whether or not EIBI was an appropriate or effective approach to teaching very young autistic children. Increasingly I had come to the view that, despite major differences

in the content of the debates, there were some underlying ethical themes that they shared.

The debates incorporated polarities of perspective about how “autism” should be interpreted. Then, as now, standpoints differed on whether autistic people want to, or should, be treated, according to whether they are viewed as either (1) suffering an illness or (2) being a certain type of person. Whereas (1) had given rise to a focus on prevention and cure – the stated goals of many scientific enquiries into the biology of autism – (2) had raised questions about whether or not autistic people need specific help and services at all, or – rather – a wider societal and attitudinal change towards embracing difference.

I realised that the intellectual bases of these debates incorporated elements of medical and psychological science, sociological frames of reference and disability studies in particular, overlaid with disparate personal narratives and experiences in the “real world”. But there had been little systematic ethical enquiry. My hope was to try to pull these elements together within the framework of a bioethical analysis, and my motivation was to explore whether, beneath the controversies, there might be areas of common ground, given that the good intentions of many or most of the protagonists seemed evident. The fact that an underlying desire to “make lives better” led to such dispute, bitterness and vitriol in some quarters created considerable cognitive dissonance and discomfort. I felt that if I was correct in my observation that most of the protagonists were motivated by a sincere belief in improving the quality of life of autistic people – that is, they seemed to be motivated by beneficence and non-maleficence – then at the core of the disputes was a fundamental ethical dispute about “the right thing to do” for autistic people. And if ubiquitous references to cure and
prevention were causing offence to some, while being self-evidently good goals to others, then these concepts in particular required unpacking, in terms of both conceptual coherence and the ethical implications of practical application.

My personal interest was fuelled not only by being the mother of an autistic young man but also by having friends and colleagues both from among autistic people and their families, and from among practitioners and academics. Between them they cover a wide range of beliefs, experience and knowledge. It would be hard to exaggerate the extent of divergence among their views on my research question, so I am extremely grateful to them all for providing such a rich context from which to launch my enquiry.

But my desire to undertake the research was not based just on personal interest. I believed – and still do – that the implications of the enquiry have wide relevance and that even if I was not the right person to be doing the research, and even if I didn’t do a very good job, someone had to make a start. As it happened, contributions in the field of ethics were starting to be published just as I embarked on my own studies, so this thesis turns out, fortunately, not to be the start but rather a further contribution to an ongoing – though still fledgling – discourse.

Such publications reflect the wider relevance of the questions I am exploring. This in turn points to the fact that autism needs to be taken seriously: it is frequently presented as a significant challenge for autistic people, for families and for wider society, and for medical science. It has been described in some quarters as an epidemic and as a national emergency (Wright, 2013), it has been the subject of
specific legislation in both the USA\(^2\) and the UK\(^3\) and it hits the headlines in sensationalist ways.\(^4\) Autism is no longer regarded as a rare condition; estimates of prevalence have risen from 4–5 per 10,000 in the early 1990s to over 1% today. This increase has led to wide-ranging interpretations and explanations; views differ about whether it reflects biological or institutional factors or both,\(^5\) and – if biological – what this says about the aetiology of autism. Further, it is regarded as a challenge because some extreme images of autism – reflecting harsh realities of lived lives for some – portray it as something profoundly “other” to neurotypical (NT) people, as something distressing and destructive, offering “nothing good” (\textit{Autism: Challenging Behaviour}, 2013, comment by Gunnar Frederiksen) for the autistic person him-/herself, or for those around him/her. Countering this image, though, we see portrayals of autism as equating with genius and remarkable talent. Once again, by virtue of the sheer extremeness of giftedness that is experienced and portrayed, autism is conveyed as something profoundly “other” to NTs. Neither extreme on its own can convey even a small part of the variety of ways lives are lived, for the “big middle”\(^6\) of autistic people whose existence is not captured by such depictions.

Perhaps not surprisingly, therefore, autism is also regarded as a condition that is intriguing and enigmatic. As such, it has found a place in culture as a metaphor for certain types of people and institutions, and it has stimulated an array of cultural references in the fields of literature, cinema, theatre and art.\(^7\)

\(^2\) Combating Autism Act (United States Congress, 2006).
\(^3\) Autism Act (Great Britain, 2009).
\(^4\) See for example Bovell (2013).
\(^5\) Possible explanations of a rise in prevalence are covered in Chapter 2.
\(^6\) Thanks to Adrian Wyatt for introducing me to this phrase.
\(^7\) The place of autism within wider culture is discussed in Chapter 2.
Despite this, autism is widely regarded as a challenge, although it is clear that there are differing views as to what the nature of the challenge is. In addressing this from an ethical perspective, the biggest moral challenge, I feel, is to establish how society should respond to autism, in the context of dramatic polarities of (1) calls for prevention and cure and (2) demands that autistic people should be treated as a minority group with assertion of the right to be different and free from pathologising external attitudes. The linked ethical challenge is to translate “how society should respond”, at some general level, to the morality or otherwise of decisions and choices that are made locally, by individuals in particular situations.

The thesis

Rather than trying to generate new empirical data, I set out to analyse and put into some kind of organising ethical framework the existing literature and commentaries that pertained to my research question. To do this I relied primarily on published works, both academic, (auto)biographical and from the news media; on the array of web-based discussions and ideas that exist with regard to autism; on the material presented at a range of conferences; and on personal conversations and correspondence. I undertook a literature search (see Appendix 1), and beyond that my material was sourced by following its leads, by regular bulletins regarding scientific and media developments in autism and bioethics, and by recommendations from colleagues.

The thesis has three parts:
Part 1 Exploring the nature of autism and the response it has elicited to date

From all that I have said so far, it follows that considerable groundwork is needed to set out what autism is, or at least how it has come to be viewed and understood. In Chapter 2 I therefore focus first on the knowledge and ideas around autism that have evolved and which have dominated clinical texts. Next, I review the same history from the point of view of the key players – the families and autistic people whose lives have been the focus of external scrutiny – and the professional responses that have grown up, highlighting areas of conflict and overlap across these stakeholders.

In doing this, my purpose has been to enable a newcomer to the field of autism to appreciate the complexity and breadth of responses to autism, according to the prism through which it is viewed and the experiences of those on whom it impacts. Is autism a within-body pathology or is it rather a reflection of broader societal attempts to classify and pathologise ‘difference’? I therefore draw out the parallel approaches of clinical science on the one hand, and critical social models on the other hand. (The latter incorporate themes from sociologies of disability and illness, the social model of disability and the linked concept of the neurodiversity paradigm – all of which either challenge or augment traditional scientific approaches.) The ethical implications of this conceptual difference relate to whether the appropriate response to autism is to focus on individuals (preventing or curing their autism), or instead on wider societal/environmental measures that would celebrate diversity and be supportive of autistic people.
In Chapter 3, I explore whether or not these debates have been reflected within the field of academic ethics. This is in keeping with my original view that ethics plays a central role in determining appropriate responses to autism, so that a preparatory review of the specifically ethical literature around autism is clearly necessary. Having outlined the main concerns addressed by ethics to date, I offer my analysis of its chief omissions, and – thus – what remaining work needs to be done. In particular, the ‘disconnect’ between contrasting medical and socio-cultural perspectives on autism – and the implications of this disconnect in generating contrasting ethical perspectives - is taken as a key dimension requiring further investigation. I introduce a framework of six categories of intervention, which I believe capture the main themes of debate and which offer some organising principles by which to address the ethical principles of particular scenarios.

**Part 2 Applying a framework to unpack the ethical content of contrasting types of intervention: Exploring the six categories of intervention**

In Part 2 I apply the framework developed in Chapter 3. The first three categories of intervention with regard to autism are covered in Chapter 4. Although autism itself has not been explored with any great specificity within the ethics literature on antenatal selection, there are extensive discussions within bioethics of a whole range of ideas about pre-birth selection and disability from which to draw. These debates – both for and against selection – are relevant to appraising the different ways one might seek to prevent autism before a baby is born and the different arguments that might be put forward to challenge these types of preventative measures. In exploring these arguments, I conclude that antenatal prevention of autism is by no means a self-
evidently good goal. I suggest that there are substantial outstanding questions that are of key relevance in answering my research question. These are (1) Perspectives on “the good life” assessing quality of life as it applies to autism; (2) Parental virtues and values: what ethical issues underscore parental responses to having an autistic child?; (3) “The big conundrum”; the relationship between local decisions and wider states of affairs - where the latter may have significant impact on the former and vice-versa, and how this complicates the ethical landscape; (4) “The analogy challenge”: how contrasting views on “where autism sits” in comparison with other conditions are fundamental to the ethical dimensions of contrasting responses to autism.

In Chapter 5 I go on to explore the next three categories of intervention set out in my framework. These relate to contrasting ways of viewing interventions that take place post-birth, the extent to which the concepts of prevention and cure are applied and/or challenged, and what additional ethical principles come into play. Unlike the ubiquity of general bioethical references to antenatal selection referred to in Chapter 4, Chapter 5 draws more heavily on particular controversies within the field of autism itself – by revisiting the treatment vs acceptance debate, and by using debates around EIBI as a case study to draw out wider points of ethical significance. What becomes clear is that the language of “prevention” and “cure”, along with “treatment” and “acceptance”, is not sufficiently nuanced to reflect what may be a more qualified attitudinal approach amongst at least some stakeholders; it disguises the potential for overlap of perspective in some, though not all, contexts. In particular, there are different understandings of the concept of “normalisation”, a term that, when used to describe
outcomes from intervention, generates both hope and repulsion from contrasting standpoints.

Once again, the four big ethical issues identified in chapter 4 emerge as of key significance. It is shown that the research question cannot be answered without a deeper look at “the analogy challenge” and contrasting views about “the good life”. Also, the real-life conditions in which autistic people and their families struggle for recognition and support are shown to be of relevance in appraising the ethical content of parental responses to autism. This in turn reflects the complex inter-relationship between wider conditions and local choices that I refer to as “the big conundrum”.

Part 3 Discussion and Recommendations

In Part 3 I seek to pull together the conclusions that I have drawn thus far, and to explore in greater detail the significant areas of enquiry that have been flagged but not addressed in detail in Parts 1 and 2. This is the aim of Chapter 6, prior to drawing some final conclusions and making recommendations in Chapter 7.

Chapter 6 therefore extends the exploration of concepts of a good outcome – and a good autistic life – from the contrasting approaches of consequentialism, deontology and virtue ethics (including feminist ethics and the ethics of care). In so doing, I carry forward issues that were identified in preceding chapters, including an enquiry into whether, how and on whom autism places a burden, and the nature of the “suffering” – and benefits – with which it is associated. I also explore how autism sits according to contrasting views on concepts of traditional bioethical concern, including both
membership of the moral community and the attainment of flourishing. I offer, finally, my own conclusions in relation to the big conundrum and the analogy challenge. Thus, and carrying forward arguments from preceding chapters, I conclude that the wider societal/culture barriers facing autistic people and their families are sufficiently significant to establish a requirement for primary responses to autism to be at this wider level. Where additional individually-focused interventions are morally legitimate, this is when they seek to help individuals thrive – rather than to remove/prevent/cure their autism. However, I further suggest that local (or ‘micro’) ethical considerations are highly sensitive to context and multiple situational nuances that can in principle allow for contrasting answers to my research question to apply in individual cases. This does not permit a broad overturning of the higher-level, macro position rejecting prevention/cure as legitimate goals. Rather, it actively reflects and permits an appreciation of how wider social and environmental conditions can impact significantly on factors influencing the moral considerations underlying localised choices.

The recommendations in Chapter 7 follow, along with a final summing-up of the main findings of my enquiry.

Notes

My thesis is Anglo-American in focus. It is written from the perspective of someone living in a developed, mixed economy and a liberal democracy. I have drawn on literature primarily from English-speaking countries, particularly the UK, Canada and the USA. I do not presume that the perspective and recommendations would translate straightforwardly to other societies.
Terminology

The field of my research question is full of acronyms, so I have provided a glossary in Appendix 2.

The language around autism is highly sensitive to underlying attitudes towards autism and autistic people. There are disputes about the validity and acceptability of several terms, some of which will become clear in the main body of the thesis.

I have chosen to stick with “autism”, while recognising that this is a term that is used as an umbrella, referred to as Autism Spectrum Disorder(s) (ASD) in official resources such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), and also in some places as Autism Spectrum Condition (ASC).

I have followed those autistic advocates who prefer “autistic” as a preface, or “autistics” as a collective noun, rather than using “people first” language. Hence I will often refer to “autistic people” or “autistics” rather than to “people with autism”.

Finally, and again following the lead of those who are active within autism self-advocacy, I will adopt the useful shorthand term “neurotypical” (NT) to refer to the population of people whose “style of neurocognitive functioning … falls within the dominant societal standards of ‘normal’” (Walker, 2014).
Part 1

Exploring the nature of autism and the response it has elicited to date
Chapter 2 Autism – the emerging picture of what it is (or is not):
exploring the standpoints of the key players

Introduction – what is autism?

As a first step in examining whether or not it is ethical to attempt to cure or prevent autism, it is important to appreciate the nature of “this thing called autism” (Verhoeff, 2012). This is not a straightforward task, because understanding of what autism is, and of what responses it should elicit, has developed and evolved over time. In addition, at any one time there has been, and continues to be, a wide disparity of perspectives on, and attitudes towards, autism. By this I do not just mean that more has been discovered and learned about autism. Rather, the very entity of autism itself has shifted over time and moreover the various “stakeholders” in the lives of autistic people have perceived it very differently from one another.

Pinning down what autism is resembles trying to pin down a cloud, and I therefore ask for the reader’s patience while I refrain at this stage from trying to do that; all definitions carry the risk of closing down alternative ways of viewing autism, whereas what I wish to do is demonstrate and explain the breadth of perspectives.

To understand how ideas about autism have evolved and broadened, it is important to take a historical perspective on how knowledge and thinking about it have emerged. I have therefore chosen to organise my literature review in terms of the contrasting responses it has elicited over time:

1. From the clinical and scientific community;
(2) From parents and professionals;

(3) From autistic people.

My decision to separate (1) – (3) is a reflection of what I will try to demonstrate is a conceptual and normative distinction that can be so marked that it contributes to contrasting standpoints about the very nature of autism and the status of autistic people, and, as a result, contrasting views on what should be done about autism, including the goals of prevention and/or cure.

To guide the reader, I offer a summary of the contrasts right away:

1. Responses to autism from the clinical and scientific community have largely been driven by a quest to categorise, understand, and possibly treat and/or prevent autism, based on a view of autism as “a distinct nosological entity with a particular essential core deficit” (Verhoeff, 2012, p. 411).

2. Responses from those who live or work with autistic people, specifically parents and professionals, have comprised a range of views as to the appropriate way of conceptualising autism, and hence a range of perspectives on the social and organisational – rather than exclusively clinical – measures for addressing autism.

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8 I have not included siblings as a distinct group, partly because their perspective has not yet been the focus of extensive academic analysis and partly because I have not found examples of collective or cohesive sibling responses that combine to form a distinct force akin to what I will write concerning (1) – (3). I may be wrong about this. Still, I will be incorporating the position of siblings in my subsequent discussions, particularly in Chapter 6, and in general I will be discussing siblings along with parents in terms of what is felt to be right for a family. I do recognise, though, that perceptions of what is in the family interest may sometimes disguise conflicting perspectives within families.
3. The experiences and lives of autistic people, articulated in particular by verbal autistic people, have introduced critical perspectives towards both the clinical and parent/professional dominance of what is known about the condition, and fuelled a relatively new interest in ethical issues with regard to autism.

Having explored these three areas, I will then be in a position to offer a critical account of the current state of knowledge around autism, address what has been written so far about the ethical issues that the varied perspectives give rise to, and finally to outline the themes that need further exploration in the rest of the thesis.

1. **Autism within clinical and medical science – a survey of the history and contemporary knowledge**

There are multiple accounts of the emergence of autism as a distinct phenomenon. Adam Feinstein’s account (2010) offers a particularly thorough exploration of the first 50 years of scientific enquiry and “lay” responses. Most textbooks incorporate a trawl through the origins and evolution of medical science’s attempts to define and understand autism (see for example Amaral, Dawson and Geschwind (2011), Baron-Cohen (2008), Lorna Wing (2002), Utta Frith (2003)). In this overview I propose to provide an outline for a reader new to autism and to highlight what I consider to be significant themes of relevance in answering my research question.

I will review how autism has been approached in terms of psychiatry, psychology and biology, with resultant implications for the process of diagnosis and estimates of
prevalence, and introduce some of the challenges that these issues pose with respect to how the questions of cure and prevention should be viewed.

1.1. Autism as a distinct psychiatric phenomenon

The first individuals to identify a discrete phenomenon that would come to be known as autism are Leo Kanner (1943; 1946) and Hans Asperger (1944) – working in the field of psychiatry in the USA and Austria respectively in the 1940s. Both separately observed a cluster of attributes in groups of children, and this cluster they suggested combined to form a unique syndrome which would come to be known as Autism Spectrum Disorder (ASD). (“Autism”, from the Greek word “autos” – self – had been used previously by the Swiss psychiatrist Bleuler in 1908, as part of his research into schizophrenia – another term he introduced. He used the word to describe extreme withdrawal.)

Kanner identified that a number of children had in common an unusual pattern of behaviour which he named “early infantile autism”. He said the children’s fundamental disorder was their “inability to relate themselves” in the ordinary way to people and situations, displaying an “anxiously excessive desire for the maintenance of sameness”, and that they displayed “extreme autistic aloneness” which disregarded anything or anyone coming at them from the outside (1943, pp. 242 and 245, italics in original). Other features he observed in this group of children included a profound lack of affective contact with others; self-chosen, unusual and elaborate repetitive routines; muteness or marked abnormality of speech; fascination with/dexterity in manipulating objects; high levels of visuo-spatial skills or rote memory (“islets of ability” – special talents and abilities in areas as diverse as painting, music, or
mathematics), in contrast to learning difficulties in other areas; attractive and alert appearance. He later said that the first two were sufficient for diagnosis. He observed that these features had been present from birth or within the first 30 months of life.

The children in Asperger’s group were observed to have a behaviour pattern of naïve, inappropriate social approaches to others; intense circumscribed interest in particular subjects; good grammar and vocabulary but monotonous speech and no two-way conversation; poor motor coordination; average to superior ability yet specific learning difficulties in some subjects and marked lack of common sense. His work became well-known outside continental Europe only in the 1970s onwards. “Asperger Syndrome” became a diagnostic category in its own right, but has since been incorporated as a condition within a wider ASD in the Fifth Edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013).

The contrasts within Kanner’s and Asperger’s lists of symptoms, discussions of who “discovered” autism first, and why, are well covered in the literature (see for example Adam Feinstein (2010, pp. 1–53); Murray (2012, pp. 39–53)). In addition, debate as to whether Asperger Syndrome is a distinct condition or whether it should be subsumed within the overall category of autism persists, despite the merging of two separate diagnostic categories (in the Fourth Edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (American Psychiatric Association, 2000)) into one (DSM-5 (American Psychiatric Association, 2013)) (see below p. 22). Despite this, “autism” is recognised as a broad spectrum condition; the core features may be shared but there is nonetheless significant heterogeneity in terms of their
impact and presentation across individuals. That this heterogeneity has fuelled debates amongst stakeholders, which in turn may pose distinct ethical questions, will be a theme to which I will return in the thesis.

Of significance at this point in my analysis is that both Kanner’s and Asperger’s work was rooted in psychiatry and based on observation of behaviour – later to be supplemented with a detailed exploration of developmental history from birth – rather than distinct organic features. They did not enter the terrain of biology to ascribe physiological explanations for the features they observed and described. ⁹

This lack of precision in terms of any underlying biological processes has allowed “autism” to be subjected to a wide range of interpretations over time. Initially, it allowed hypotheses as to causation to be made which were only later overturned by scientific research. Stuart Murray suggests that the hypothesis of parental responsibility for their child’s condition started with Kanner, whose “observation established the family unit, and an idea of parental care and love, as one of the prisms through which autism might be understood. With the kind of neurology that would later develop to aid in understanding autism still in its infancy, the fields of psychiatry and psychology instead offered multiple avenues to explore the mysteries of the condition” (2008, pp. 172–3).

Most notoriously, Bruno Bettelheim’s assertion that autism was caused by failed bonding held sway in an era when psychoanalytic models predominated in the

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⁹ Kanner’s own views give rise to contrasting interpretations: he seems both to have implied a belief in the biological determination of autism and to have inferred an association between parental coldness and autism in children. See Feinstein (2010, pp. 37–38 and Chapter 3).
practice of psychiatry and psychology. Bettelheim (1967), using the term “refrigerator mothers”, concluded that children with autism did not relate to people as a result of failure of parental response at a key moment of childhood development. According to Bettelheim, the infants/children who become autistic wanted to reach out to the world but the nature of the caring relationship they received prevented a “normal” self from developing. He was unclear at what stage the inadequacy of the mothering tipped the child into an autistic response, though it “may be a very early reaction to their mothers that was triggered during the first days and weeks in life” (1967, p. 399). The recommended treatment was thus that the children should be removed from their mothers.

Although Bettelheim has been discredited (see for example Seversen, Aune and Jodlowski (2008)), there is still a psycho-analytical legacy that holds sway, particularly in France (Feinstein (2010, pp. 103–106) and see Schofield (2012)).

1.1.1. Reframing autism – moving away from psychodynamic explanations

During the late 1960s, a reframing of the nature of autism was taking place. This was due to the extension of scientific enquiry and the emergence of new responses to autism from those parents who had managed to withstand the pressures of the culture of blame. (See section 2 below, p. 53).

Within the UK, Rutter’s empirical approach showed that the behaviour of autistic children made sense if viewed as an organic developmental disorder starting from birth/early years of childhood, and emphasised the presence of cognitive deficits in autism (Rutter, 1968; Rutter and Bartak, 1971). At this time it was also being
established firmly that autism was distinct from the very rare condition of childhood schizophrenia (Kolvin (1971)).

Respectability was given to a proposed genetic contribution to the aetiology of autism by Folstein and Rutter (1977), who carried out a systematic study of twins with autism. Monozygotic pairs were more likely to be autistic than were dizygotic twins, although concordance was not absolute. Further, dizygotic twins often displayed features that, though not meriting a strict diagnosis of autism, marked them out as distinct in similar domains, for example social awkwardness, cognitive or language difficulties.

Following this, several twin studies were undertaken. For example Bolton et al. (1994) found that 3% of siblings of autistic children had autism and a similar number had a general ASD (based on the Tenth Revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10) (World Health Organisation, 2010), and 20% had more subtle communication and interaction impairments. This was in comparison with a control group with Down Syndrome where there were no autistic siblings. This highlighted a significant genetic load in the aetiology of autism and again hinted at a finding from the Folstein/Rutter study above – i.e. that the observed heritability related to a broad predisposition to a range of difficulties, rather than a single phenotype or unique syndrome.

### 1.1.2. Recognising heterogeneity within autism

The idea of autism as a spectrum rather than a single condition was first asserted with confidence as a result of Lorna Wing’s and Judith Gould’s Camberwell study (1979).
Wing and Gould identified not only a group who fitted typical Kanner autism, but also a group who had many autistic behavioural features yet didn’t precisely fit. Findings from the Camberwell cohort revealed the complexity of the spectrum and its overlaps with other developmental features that are often associated but distinct, but also identified common features that became described as autism’s Triad of Impairments: the absence/impairments of social interaction, communication and development of imagination. In addition, narrow, rigid, repetitive patterns of activities and interests were identified, along with other, additional features of observed behaviours. Within the triad, manifestations of behaviour under the various headings could be markedly different, yet still fit the broad impairment category.

The Camberwell study therefore led a shift from the notion of a single condition (Kanner’s autism) towards a view of a broader spectrum or continuum of difficulties along the three dimensions of the triad of impairments, which would itself undergo revision in the early twenty-first century. Likewise, the work of Gillberg et al. (1986) in Sweden pointed to autism being part of a wider spectrum of disorders – a broader autism phenotype. These developments broadened understanding of what might fall within a broader autism spectrum, yet rendered far more complex the task of being able to “pin down” autism to simple or unitary biomarkers, be these specific genes or other physiological features. (See Section 1.2 below p. 28).

1.1.3. Diagnosis and prevalence

The idea of autism as a spectrum condition, affecting people with no language and profound learning difficulties as well as those who are intellectually able and verbal, has been well-established since the 1980s. The evolving criteria have been reflected in
the modification and revisions to international classification systems of autism, most recently the merging of Asperger Syndrome into Autism Spectrum Disorder, and the reconfiguration of a triad of impairments into two key areas in DSM-5. DSM-IV included “autistic disorder”, “Asperger’s disorder” and “pervasive developmental disorder not otherwise specified” (PDD-NOS) as types of autism. The more recent edition (2013) replaced these subtypes with a single “autism spectrum disorder” while giving recognition under this umbrella to the multiple manifestations including different levels of “severity”.

The alterations in diagnostic criteria over time have also, it is suggested, had a dramatic effect on our knowledge of prevalence. The studies in the 60s and early 70s led to a belief that autism was a rare condition, affecting 5 in every 10,000, or 0.05%. This was partly because of adherence to strict Kanner criteria. In contrast, at the time of writing, the accepted prevalence rate for ASD in the UK is at least 1% (see Baird et al. (2006) and NAS (2014)). This supersedes the estimate of 1 in 166 that was adopted in the UK in 2001 (Medical Research Council, 2001). In the USA, the Centers for Disease Control and Prevention (CDC) has recently announced a figure of 1 in 68 children (CDC, 2014).

The substantial change in recognised prevalence is frequently attributed to two factors: growing awareness of the autism spectrum per se leading to improved diagnosis, plus the widening of the criteria (Ehlers and Gillberg (1993)). However, although the widening of the definitions of autism, alongside growing awareness, usually serve to explain the apparent increase in prevalence, some experts now acknowledge that there may also be a real increase in incidence and hence prevalence,
which raises questions about what mechanisms might be contributing to such an increase (Charman et al., 2009). It is suggested by some, for example Roy Grinker (2009) and Eyal et al. (2010), that social and institutional forces also play a part in rising rates of diagnosis and hence official prevalence estimates.

1.1.4. Exploring the mechanisms that lie beyond, behind or beneath outward behaviour

Alongside developments in recognising autism as a spectrum, attempts have been made to explore what might be going on beyond, behind or beneath the behavioural manifestations necessary for an autism diagnosis. First, such explorations have taken the form of psychological models that might explain the behaviours in terms of internal mental processes. The influence of these psychological models of autism has been immense, and – as will be seen below – reaches to the heart of some of the ethical discourse around autism. Second, such explorations have introduced a greater focus on biological processes that, it is suggested, may explain both the causes and the manifestations of autism. An outline of these two areas of development forms the next two sections.

1.1.5. Unifying psychological theories

Within psychology, new propositions about what was unique and/or different within the cognitive processing of people with autism emerged during the 1980s and 1990s. Attempts to explain the phenomenon of autism were made through a series of models that sought to bring together the empirical observations about autistic behaviour in unifying cognitive frameworks. Of these, the most frequently referenced psychological models relate to Theory of Mind, Central Coherence, and Executive
Functioning. It was suggested that it was in one or all of these key areas that individuals with autism possessed their main difficulties, relative to their non-autistic peers. There is a huge literature on these three models, but here is a summary outline:

Theory of Mind deficit: This theory examined difficulties in “mind-reading” – in the sense of understanding that others’ mental states have a separate existence from one’s own, that other people may have different beliefs, desires and intentions. This idea of “mindblindness” was set out as fundamental across the autism spectrum based on the false-belief tests (the “Sally-Anne” and “Smarties” tests) (see for example Baron-Cohen (1995), Frith and Happe (1999) and Baron-Cohen (2000b, p. 3)). These tests showed that typically developing children with an intact theory of mind were able to pass these false-belief tests with a great deal of accuracy by the age of three or four, whereas they posed much greater difficulties for children with autism.

The idea of a deficit in theory of mind has taken centre stage within discussions of the ethics of autism, as will be shown in the discussion in Chapter 3. In contrast, the other two models have received less attention within the ethical literature, so I will outline them here even more briefly, although there is a vast literature about all three cognitive models.

Weak Central Coherence: The weak central coherence (WCC) thesis of autism ascribes autistic behaviours to a failure to see the whole, with a corresponding hyper-focus on details (Frith, 2003; Happe and Frith, 2006). Adherents of the WCC model feel it explains factors associated with autism that are not associated with mind-reading (Happe, 2000).
Of interest here is the fact that while explaining some of the “weakness” of autism, the central coherence model also allows for and explains strengths and assets within autism, such as the ability to focus on detail. This has contributed to a reframing of the psychological models in some quarters, pointing to autism as a difference in cognitive style rather than a deficit (Happe, 2011). This idea of difference rather than deficit is an important one, to which I will return.

Weak Executive Function: Executive function enables an individual to plan and organise, by overriding automatic behaviours, inhibiting inappropriate impulsive actions and resolving conflicting responses (Frith, 2003, pp. 177–178). Autistic people have weak executive function (WEF), it is argued, and it is this that best explains the repetitive, stereotypical behaviour of people with autism, and the difficulties they experience in updating beliefs on the basis of new information/switching ideas based on new evidence (perseverating on first impressions) (Nichols and Stich, 2003) – which is an alternative explanation to the behaviours identified in the Sally-Anne test.

1.1.6. The limitations of these cognitive models

These theories have been very influential on approaches to teaching children with autism, and also on the ethics of autism. To take one example, Deborah Barnbaum (2008), whose work will be discussed in detail below, relied for the bulk of her ethical exploration of autism on the single feature of lack of theory of mind.
However, it is increasingly recognised that, while useful, these theories do not fully explain autism. As early as 1996, Lorna Wing commented that the level of development of theory of mind relates to language comprehension, and that young adults with Asperger Syndrome can pass the tests. “More sophisticated tests need to be developed to reveal the precise nature of the social impairment” (2002, p.82).

In addition, both the WCC and WEF theories have been found lacking in full explanatory power for the range of behaviours associated with autism. For example, the motor issues that are characteristic of many autistic individuals are not captured, and the inferences drawn from the experiments that purport to support the theories have been criticised (for example Boucher (2009) and Cushing (2013)).

A further criticism of the above models is their overall emphasis on the impairments linked with autism. Instead, some explorations, for example those conducted by Laurent Mottron et al. (1999; 2006; 2007) and others (Nauert, 2012) have countered these deficit models with postulates of areas of superior functioning, such as enhanced visual functioning (Samson et al., 2011) and pitch processing (Heaton, Hermelin and Pring, 1998).

Chown (2013) argues that alternative models, for example those focusing on sensorial disturbance (McGeer, 2002), the time-parsing deficit hypotheses (Boucher, 2003) and the monotropism theory (Murray, Lesser and Lawson, 2005) contribute to a better understanding of autism than the cognitive models above and reflect more accurately the first-person accounts of autism.
My purpose is not to assert or dispute the validity of any one particular model, but rather to demonstrate the way cognitive models have played an important part in the history of exploring and describing autism. For all that they do not explain the totality of autism, these models and experiments have provided a way of postulating key underlying differences in mental processing in a way that may help neurotypicals (NTs) gain a greater understanding of (some) autistic people and therefore provide a guide for practical strategies for mutual learning and interaction. Through cognitive neuroscience, the models have also provided pointers for neurological studies of the brain. Thus, Happé (2011) argues that while not all-encompassing, cognitive models do play an important part in emerging understanding of the nature of autism. For example, it is argued that an understanding of the mind assists scientists to identify what areas to focus on both in neuroimaging and genetic investigations.

This interplay of a cognitive model with neurological investigation is reflected in a more recent proposition – that of the Extreme Male Brain, originally argued by Simon Baron-Cohen – whereby autism is viewed as an extreme version of the tendency for systemising (more frequently occurring in males), as opposed to empathising (more frequently occurring in females).¹⁰

In some regions of the brain that on average are smaller in males than in females, people with autism have even smaller brain regions than typical males. In contrast, in some regions of the brain that on average are bigger in males than in females, people with autism have even bigger brain regions than typical males. (Baron-Cohen, 2008, p. 74)

¹⁰ Fuller accounts of Baron-Cohen’s ideas, and criticisms of them, can be found in Cushing, 2013, pp. 30–34, and Chown, 2013.
The fact that experiments using neuroimaging emerge from initial ideas is described by Boucher thus:

The implications of findings on brain function are easily identified because the research is always hypothesis-driven. That is to say each study is designed to test a specific hypothesis concerning the neural activity that occurs when the person being tested is carrying out a specific task. (2009, p. 139)

Critics thereby suggest that the process of moving from theory to brain imaging and then finding one’s theory confirmed is self-fulfilling, just as the process of psychiatric diagnostic labeling is held in some discourses to be self-fulfilling (for example Greenberg (2013)). Clearly the idea of circularity between hypotheses and findings/diagnosis is not one that is confined to autism. Nonetheless, the quest to find organic differences between those diagnosed as autistic and NTs has become a multi-million dollar endeavour, and what follows is an attempt to sum up how this scientific enquiry has turned out so far.

1.2. Biological models (the quest for biomarkers)

In retrospect it is clear that during the 1980s and early 1990s, much of the scientific enquiry in the field of autism was in effect (if not in intent) oriented to refuting the dominant idea of autism as caused by style of parenting. On the one hand genetic enquiry suggested biological heritability rather than failed nurturing, seeking to identify candidate genes. On the other hand, psychological and neurological enquiry – with an emphasis on mental processes, brain structure and function – located autism as an organic developmental disorder of the brain, rather than an infant’s emotional response to the mother’s aloofness. Science progressed from seeing causes and areas
of difficulty in “bonding and emotions” respectively to a model focusing on “brains and genes”.

The drive for biological evidence to support psychological explanations of autism has been for many, therefore, a welcome development. It offers an empirical way of rebutting damaging and false claims such as those put forward by Bettelheim. It also holds out the lure of “fixing” a diagnosis of autism to something more concrete than the constellation of observed behaviours listed in successive DSMs and ICDs, or indeed to theoretical models of the mind. So, although the classification of autism remains a descriptive list of how autism presents in an individual (from the behavioural characteristics in the Triad, refined and expanded in successive DSMs to incorporate new factors such as sensory differences), scientific understanding of autism drills down below the behavioural emphasis of the international diagnostic criteria.

What follows is an attempt to offer an overview of a vast and ongoing area of research. My purpose in doing this is not to replicate or to evaluate the state of knowledge (that would be too vast a task and also one for which I am not qualified) but rather to provide a taster of the multiple areas of scientific enquiry. This in turn will highlight some areas of potential intervention and treatment in which the ethical issues surrounding prevention and cure arise.

There are several ways of categorising and subcategorising the research (see for example Pellicano, Dinsmore and Charman (2013, pp. 18–19) and Charman and Clare (2004)) but outside the research community the chief domains of medical
investigation are explained to lay people as the interplay of neurology and genetics.\textsuperscript{11} Summing this up, Herbert and Anderson describe the orthodox view of autism as “an incurable behavioural disorder resulting solely from genetic defects impacting brain development” (2008, p. 429). Reflecting this, I will organise the following sections according to the straightforward genes/brains demarcation, before expanding on ways in which this categorisation is beginning to “creak”.

1.2.1. Genes

The identification of autism as a heritable condition generated a wave of enthusiasm to pin down the genes involved in autism. But this has proved to be a protracted endeavour. Although it is now generally appreciated\textsuperscript{12} that there is a strong genetic basis to autism, given the clear heritability, it is also accepted that no single gene is responsible for autism, and that an array of micro-duplications and micro-deletions (copy number variants) are likely to be involved. The fact that multiple genes are involved contributes to the heterogeneity of how autism manifests in any one individual, and the picture is further clouded by the role of epigenetics. New studies about genetic influences on autism are published weekly\textsuperscript{13} and the medical/scientific anthologies all contain detailed accounts of this highly complex field. The most accessible “lay” summary of the state of contemporary knowledge about the link

\textsuperscript{11} For a lay person approaching the scientific literature, the field is overwhelming not only in terms of the volume of research papers but also in terms of the seemingly disparate areas of enquiry and the plethora of technical processes that fall under the headings of neurology and genetics. For example, the headings under which the biological research is organised vary according to different anthologies. What the lay person might look for under the general heading of \textit{Brains} would lead us to a single section in Amaral, Dawson and Geschwind (2011) headed \textit{Neurobiology}. Yet in Zimmerman (2008) the material is separated into two substantial sections, \textit{Neurotransmitters and Cell Signalling} on the one hand, and \textit{Neuro-anatomy and Neural Networks} on the other. Likewise Bauman and Kemper (2006) distinguish between \textit{Neuro-anatomic Investigations} and \textit{Neurobiological Research}.

\textsuperscript{12} There are some detractors, for example Timimi, Gardner and McCabe (2011) – see below Section 4.1 in this chapter.

\textsuperscript{13} I have used the weekly Simons Foundation Autism Research Initiative (SFARI) updates as background to this research.
between genes and autism is offered by Solomon (Solomon, 2013, pp. 248–252) and Hall (2014).

Despite this, many scientists are confident in stating that the molecular genetic basis of autism is now known in 10%–20% of cases (see Geschwind (2011)). However, there is no predictability around a specific genotype and the presenting phenotype: “these data implicate gene-gene and gene-environment interactions in molding the phenotype in most cases of autism, leading to a very complex picture, even in the individual” (Geschwind, 2011, p. 819).

Further work to link the genetic and neurological features of autism will, according to Geschwind, need to focus on neural systems involved in social cognition and language, implicating several areas of the brain:

… areas of frontal, anterior temporal and cingulate cortex, and their major connections in the posterior superior temporal and parietal lobes, as well as subcortical regions such as the striatum. …

So, as more and more autism genes are identified, putting them within a rubric of both molecular pathways … and brain circuitry … will be critical to understand how they lead to autism and other related neurodevelopmental disabilities.

This effort to understand how genes influence brain development and function to cause ASD will require going beyond conventional pathway analysis to network biology, so as to understand the systems level organization of gene and protein networks …

So too, is it necessary to carefully integrate animal model work, along with a consideration of evolutionary issues … (Geschwind, 2011, p. 819)

To say there is a lot of work still to be done is, therefore, clearly an understatement.
In any case, genetic research is also raising questions about the extent to which a unifying diagnostic umbrella based on the idea of a core biological unity is detectable in autism. Even when autism was still defined as a triad of impairments, research showed that actually the three features of the triad are not tightly bound – except for their grouping within one diagnostic category. For example, Happe and Ronald (2008) found only a modest correlation between the three traits both in terms of presentation and in terms of genetic association influencing them. This has led Frith (2011) to conclude that autism is not an artefact, but within the unifying umbrella of autism there are “autisms plural”.

1.2.2. Brains

In order to demonstrate the perceived linkage between genes and brains, the most accessible model that I have found is that put forward by Minshew and Payton (1988). They developed an integrated model in which the behavioural disorder was clearly stated as secondary to the neurologic disorder originating in the brain, caused in turn by abnormalities in the genetic code for brain development. Autism was described as “a disorder of complex information processing-connectivity-neuronal organisation”, “a widespread disorder of association cortex and the development of its connectivity” (Minshew, Williams and McFadden, 2008, p. 401 n.). Studies involving neuroimaging and neuropathology provided data to support the model, which I reproduce in simplified format below (from Minshew, Williams and McFadden, 2008, p. 382):

14 For convenience, while acknowledging the joint authorship in several of Minshew’s works, I will refer hereafter to “Minshew’s model”.

32
Pathophysiologic sequence of a neurodevelopmental disorder

Abnormalities in genetic code for brain development

Abnormal mechanisms of brain development

Structural and functional abnormalities of brain

Cognitive and neurologic abnormalities

Behavioural syndrome

Thus Minshew’s five-stage model located the neurologic disorder as the ultimate consequence of genetic influences, with the behavioural presentation being “merely” the end-point of the sequential chain. The authors’ neurological research focused on the middle level in the sequence, whilst locating the underlying explanation in the first and second levels, and locating the ultimate expression of these difficulties at the fifth level.

Amongst other things, it usefully serves to demonstrate how complex and varied are the research activities within the field of neurology (occupying all but the final level of the model). Thus, contemporary neurological research embraces a vast range of discrete endeavours – such as enquiry into brain structure, development, functioning, circuitry and biochemistry. This is a broad field, and I will merely illustrate it here with a few examples. Rossman and DiCicco-Bloom (2008) place emphasis on the
structural abnormalities of the autistic brain, particularly the cerebellum (the “most consistently abnormal region of the ASD brain” (2008, p. 4)), while also endorsing the presence of extracerebellar function deficits. They refer to the multi-faceted nature of additional brain abnormalities being explored in ASD – cortical dysgenesis, ectopic grey matter, poor differentiation of grey-white matter boundary; abnormally dense cell packing in hippocampi, entorhinal cortices, etc. Social cognition and emotion recognition deficits are correlated with reduced amygdalar activation in people with ASD (Pelphrey, Adolphs and Morris, 2004; Wang et al., 2004), and abnormal amygdalar coding of emotional information in facial expressions is thought to lead to disrupted social behaviours associated with ASD (Rossman and DiCicco-Bloom, 2008, pp. 16–17 n.).

Another line of enquiry is of abnormal brain overgrowth in ASD, with this overgrowth happening in specific areas and at particular stages (Courchesne, Carper and Akshoomoff, 2003; Hazlett et al., 2005; Sparks et al., 2002). Several studies (Dager et al., 2008) have explored hypotheses to explain the phenomenon of normal head circumference at birth but enlarged between three and four years of age in autistic individuals, looking at possible explanations for accelerated brain growth. Minicolumnar size variability has also been identified, with diminished minicolumnar size in the cortex of autistic patients versus controls.

Collectively, though, these data describe the ASD brain as abnormal in structure, and accordingly in function, thus highlighting the importance of normal brain development. It is likely that multiple brain abnormalities exist within and between ASD patients and that the heterogeneity of clinical presentation is mediated by these brain differences. (Rossman and DiCicco-Bloom, 2008, p. 5 n.)
There is also an emerging focus on brain tissue, through both posthumous study of brains and the growth of brain tissue from stem cells from live subjects (Dolmetsch, 2011).

1.2.3. Discussion (implications of genes and brains research)

Although there have been subsequent challenges to the Minshew model, it still serves as useful in several ways.

First, the authors say the model helps to explain the difficulties Lorna Wing had described in terms of wide heterogeneity across the spectrum. Significantly Minshew postulated different types of disturbances in high- and low-ability individuals. Further, it allowed for the coexistence of multiple facets, rather than seeking a hierarchy of behavioural attributes, some of which are essential and others are as it were “add-ons” in terms of obtaining a diagnosis of ASD. “There are several affected domains not considered to be integral parts of the autism syndrome, … autism involves the brain far more generally than the DSM-IV diagnostic triad indicated” (Minshew, Williams and McFadden, 2008, p. 391) (e.g. sensory-perceptual, motor and memory domains).

Thus Minshew et al. have emphasised a constellation of neurologic signs and symptoms, and pointed out how neurologists do not view disorders or diseases in terms of single primary deficits. Further, they stressed that developmental disorders will entail different aspects and periods of brain development, with different cellular and molecular events at different stages. The authors have also argued that the neurological model is much more effective than the focus purely on symptoms, both at explaining heterogeneity and also at incorporating the series of co-morbidities that
do not form part of the international classifications but are often described as a kind of add-on.

From a clinical perspective, idiopathic autism is characterized by deficits in complex behaviour and higher order cognition, mental retardation in 60-70%, and seizures in 30%. In neurology, this constellation is classic evidence of dysfunction of cortical gray matter and specifically association cortex. (Minshew, Williams and McFadden, 2008, p. 386)

In pointing all this out, they are inadvertently raising fundamental questions of great relevance to my research question. In advocating cure and/or prevention, what do people actually mean? The presence of such broad heterogeneity, combined with the possibility of a range of co-morbidities, gives rise to divergent interpretations. For example, there is a suggestion of a range of possible interventions that in principle present themselves in the quest to “cure” or “prevent” autism. In theory, interventions at each or all of the first four stages of Minshew’s model above might serve to prevent the manifestation of behavioural symptoms, while “cure” could take place at all five stages. Minshew et al. also point out that in trying to find “the causes” of autism, one can mean many things – from the originating genetic level of the sequence, through to triggers that are antecedents to specific autistic behaviours. Thus an immediate or proximate cause can relate at one level within the overall model, but “such models have a different view or concept of ‘cause’ than a model of the entire pathophysiologic sequence” (Minshew, Williams and McFadden, 2008, p. 388).

Addressing causes or triggers, with the goal of prevention or cure, therefore can in theory imply a whole series of measures, some of which may be more realisable than others, and some of which may have widely different purposes and impacts.
To take another example, the postulated differences of neurological presentation between high- and low-ability individuals (see above p. 35) may or may not be significant, depending on one’s view of whether such differences are relevant at all, or relevant in terms of judging which types of presentation of autism should, or should not, be subjected to interventions aimed at cure or prevention. I will have a lot more to say about this during the passage of the thesis, and I will give it particular attention in Chapter 6.

The model therefore raises questions about what kinds of interventions are involved, if we aim for “prevention” and/or “cure”. One could presume that those who advocate such goals are primarily concerned with level five (“the behavioural syndrome”) of the model – the outward behaviours of autism: if there were no concerns about level five, then there would be no interest in scientific exploration of its antecedents. And yet Minshew et al. question the adequacy of diagnostic criteria, which currently define the components of level five. They suggest that the emphasis on level five – the criteria for diagnosis – is inadequate as an explanation for what is really happening in autism. “There are several affected domains not considered to be integral parts of the autism syndrome, … autism involves the brain far more generally than the DSM-IV diagnostic triad indicated” (Minshew, Williams and McFadden, 2008, p. 391). If this is the case, then proponents of prevention and/or cure might say that it is not level five per se that needs eliminating – since level five is inaccurate or misleading – but, rather, the hinted difficulties that lie beneath and below these behaviours – for example the cognitive issues of level four.
But at this point we are reminded that for some the cognitive differences are perceived as strengths and differences rather than deficiencies (see above p. 26), and so the question about prevention/cure moves from being not just about “what does it mean?” and “what does it involve?” to the further question of “why pursue it?” I will say more about this below.

Before leaving the terrain of clinical/medical science, along with these yet-to-be-answered questions, I wish to address a more recent model of autism that widens the net yet further in terms of the biological processes that might be involved in autism. In so doing, this newer model also raises further questions about what features should be candidates for scientific investigation and, importantly, for ameliorative interventions with regard to autism.

1.2.4. Beyond genes and brains

In order to inform this thesis, three regular digests have been used, and each contains scores of articles each week.\(^{15}\) New findings in relation to molecular science – including genetics, epigenetics, brain structure and circuitry, experimental and applied science – including learning and perceptual processes and so on – reflect a broad and intense international research endeavour around autism. As more becomes known about conditions that are often associated with autism, so the list of “co-morbidities” is extending beyond the strictly neurological (e.g. epilepsy, severe learning disability and sleep disturbance) to the metabolic, immunological and gastro-intestinal. This expanded appreciation of the complexity, as well as the heterogeneity, of autism is further augmented by a growing consensus that notwithstanding the genetic

\(^{15}\) These include: SFARI and Research Autism bulletins (n.d. (a) and (b))
component in autism, there are as yet unknown environmental factors contributing to its development. Candidate theories include a linkage with fetal testosterone (Auyeung and Baron-Cohen, 2008) and organic pollutants (Pessah and Lein, 2008). Thus, successor models to Minshew’s have been postulated, incorporating these wider factors, processes and influences, broadening the investigation beyond “genes and brains” to highlight autism as a “whole-body/whole-being” condition, with several systems being affected by, and affecting, each other. In addition, the mediating role in genetic and neurological mechanisms played by particular chemicals and inflammatory responses has widened even further the gap between the biological processes at work in autism and the narrow behavioural symptoms that govern its official definition. “Emerging evidence suggests that autism affects many organ systems beyond the brain and that some neuropathological and somatic pathophysiological processes are active even into adulthood.” (Herbert and Anderson, 2008, p. 429; Herbert, 2005)

Herbert and Anderson (2008) incorporate these newer observations into a model of “how this systemic and persistent disease process might impact brain function and ultimately impair behaviour through potentially reversible mechanisms” (my underlining). They contrast a “bottom-up, modular, genes-brain-behaviour” model with a more inclusive “middle-out, multi-system biology” model, and look at autism’s development over an individual’s life rather than fixating on the early developmental signs.

They cite a high prevalence of gastro-intestinal and immune symptoms among autistic people, which “challenges the idea that autism, or what many are coming to call
‘autisms’, is purely ‘brain and behavior’ disorders. … The description of pathophysiological features such as persistent immune responses, oxidative stress, and mitochondrial dysfunction in multiple tissues suggests systemic rather than brain-specific perturbation” (Herbert and Anderson, 2008, p. 430).

This model has many implications in terms of the range of practical interventions that may be introduced in the future in order to “reverse” autism (their term), and, therefore, the span of ethical considerations that may need to be applied across the spectrum of these interventions. I will therefore quote extensively below. (The citations given below incorporate what is a concluding list of references in the original.)

Prognostically, substantial improvements and even loss of rigorously ascertained autism diagnoses are being reported in some autistic individuals (Kelley et al., 2006; Fein et al., 2005); this observation is becoming an object of study, because validation … would challenge both the presumption of incurability and the neurobiological models based on that presumption. (Herbert and Anderson, 2008, p. 430 n.)

Subsequent work has supported their assertion that a small section of people who acquired an autism diagnosis in childhood do seem to “outgrow” their autism (see Padawer (2014) referring to Fein (2013) and Anderson, Liang and Lord (2014)).

In addition, they take further the points raised by Minshew et al. in relation to the limitations of contemporary diagnostic criteria. In the following quotation they clearly assert that the diagnostic criteria are under strain, both in terms of their inadequacy in capturing “what is really going on” in autism/for autistic people and – crucially – whether a unifying category may actually disguise several, disparate conditions:
We must remember that autism is defined by a specific set of behavioral abnormalities in the DSM manual, but just like motor impairments, abdominal pain and even social phobias, autism is not a single disease, but instead a condition caused by multiple etiologies. … Viewing the behavioural impairments that define autism as reflecting an ongoing effect of biological dysregulations rather than a fixed neurodevelopmental defect carries the implication that autism includes more than the traditional “triad” of deficits that define it in … DSM-IV.

… From the broader whole-body vantage point, approaches that define autism in purely behavioural terms can be seen as limiting treatment targets, and is vulnerable to the criticism of some members of the autism community who see treatment as focusing upon those symptoms that are troubling to caregivers (e.g. behaviours seen as “inappropriate” by neurotypical individuals), whereas a whole-body approach can address a further range of symptoms (as well as their underlying mechanisms) that are uncomfortable, painful, or troublesome to those with the diagnosis. (Herbert and Anderson, 2008, p. 431)

The second paragraph of the above quotation begins to offer one possible answer to the question I posed above – the “why” concerning interventions. The authors suggest that the target for interventions should be symptoms that are “uncomfortable, painful or troublesome to those with the diagnosis”. Their suggestion is that there may well be appropriate biological treatments for autistic people, but that the treatment targets may be markedly different from the behavioural manifestations of autism. They also hint that the priorities of autistic people may be different from those of people around them.

Herbert and Anderson therefore offer a critique of the genes-brain-behaviour model, arguing that if it is incomplete it is bound to fail, citing “brain-body cross-talk” and the accumulating literature on the substantial prevalence of gastro-intestinal and immune dysregulation (Herbert and Anderson, 2008, pp. 436–440).

It is important to note that chronicity may masquerade as incurability … If … chronic somatic and systemic features are core components of autism pathophysiology rather than secondary accompaniments, then their treatment and reversal may lead to reversal at the level of brain and behaviour as well. (Herbert and Anderson, 2008, p. 448)
Thus, they suggest that the implication of heterogeneity in the symptoms and manifestations of autism is that there “may be heterogeneity in reversibility” (Herbert and Anderson, 2008, p. 454).

They therefore spell out the implications for the autism research agenda as follows (2008, p. 456):

1. Research should aim for linkage to underlying dysregulated biology and cellular signallng pathways.

2. It should take an expanded temporal approach, viewing autism less as an inborn defect with genetic and environment determinants and more as an “ongoing mutually reinforcing physiological and signaling gridlock that may look incurable but that actually may be approached as a puzzle (as opposed to a mystery) to be untangled and addressed stepwise and systematically”.

3. It then follows that “change is possible in autism … we will be most successful at optimizing opportunities and outcomes if we move beyond exclusively considering just genes, brain and behaviour to inclusively considering all levels and interactions in the biological hierarchy”.

4. “An analytic approach to identifying treatment targets, however mundane or seemingly removed from the ‘autism’ as behaviourally defined, may improve quality of life and reduce the aspect of autism that involves suffering. Moreover, an expanded, more inclusive modelling of autism will help us to articulate precisely what aspects of autism involve suffering for the affected individual, which will enable practitioners to more effectively address the concerns of those members of the autism community who feel that their autism gives them many strengths and do
not wish to be subjected to treatments they feel are aimed at making them neurotypically ‘normal’.” (Herbert and Anderson, 2008, p. 456-457)

This is important for my research question since it is a suggestion that the goal of tackling autism as currently defined should yield to exploring what autistic people themselves are identifying as problematic. I will pick up on this point at several stages in my thesis: later in this chapter and then particularly in Chapters 5 and 6. While adopting the language of “cure”, “incurable” and “recovery” within a medical view of autism, the Herbert and Anderson agenda suggests that treatments offered to autistic people should focus on particular areas of discomfort or distress, rather than autism as a totality. The general goal of aiming to cure and/or prevent autism as an overall entity yields to something more specific, oriented towards the diverse circumstances of different individuals rather than to all autistic people.

In contrast, the research to date around contrasting interventions with regard to autism has been rather limited and inconclusive.

1.3. Interventions: the rationale and evidence for them

I outlined above the way that, prior to neurobiological and genetic discoveries, autism was thought to be caused by disruption of the interpersonal norms that govern most mother-infant relations and that the consequent intervention recommended by Bettelheim was that children displaying autistic behaviours should be removed from their mothers. In contrast, subsequent investigations have painted a picture of the organic nature of ASD – a developmental neurological disorder which thereby throws
out for scientists the tantalising lure of potential interventions that might alter an individual’s organic developmental trajectory, even while ASD is described as incurable and lifelong.

Because organic interventions have not (yet) come on stream, tailored education has been the most commonly recommended approach to autism, based on applying the emerging understanding around symptoms, in order to build strategies for either compensating for, or ameliorating, underlying deficits (see Feinstein (2010, Chapter 5), NICE (2013, p. 23) and Jordan, Jones and Murray (1998)). A range of specialist and distinct teaching programmes have been devised, of which Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) is probably the most globally applied. However, while TEACCH is based on theories about cognitive deficits and a response to autistic subjectivities, there is a relative paucity of empirical evidence about its efficacy, particularly in terms of outcomes.

In parallel, applied intensive behavioural approaches have been developed in the field of autism education that have originated in pedagogical science more broadly rather than in specific knowledge of autism. The science of applied behaviour analysis (ABA) has been tailored to children and young people with autism as a specific group, and to such an extent that in some quarters “ABA” is defined as an autism-specific teaching intervention, even though its reach, practice and history are far broader.\(^{16}\) A further confusion is that “ABA” is often used coterminously with “EIBI” – early intensive behavioural intervention – because the first major study using ABA in relation to autism was a particular pre-school intervention for very young autistic

\(^{16}\) See Schreibman (2005, p. 279 n. 9).
children. The Lovaas experiment (Lovaas, 1987; McEachin, Smith and Lovaas (1993) proved both seminal and controversial in several ways. It was evaluated via a comparison control study and its results were startling (47% of the children made such good progress in IQ, language acquisition and social interaction that they were on these measures deemed “indistinguishable from their peers” over medium-term follow-up), but the methods were unusual, involving intensive home-based intervention for 40 hours a week of a structured behavioural kind.

Lovaas’ work and the follow-up studies it spawned were the first to try to adopt an experimental design with a view to drawing conclusions about efficacy based on outcomes. While subjected to extensive critiques, both about methodology and philosophy, it remains a key reference point and I will be exploring the ethical issues surrounding it in depth in Chapter 5. Experimental scientists have set up replication trials in other groups of children, and have also introduced and evaluated contrasting approaches to EIBI incorporating additional principles (e.g. the Early Start Denver Model). Academics have drawn together in systematic reviews the key conclusions that can be generalised across the field, and on this basis identify new research and practice questions that need still to be addressed (see for example Howlin, Charman and Magiati (2009); Rogers and Vismara (2008)). However, there remains considerable scepticism in some quarters about how conclusive such studies are, particularly regarding whether they are sufficiently robust to generate broad practice recommendations.

A similar picture emerges with regard to pharmacological interventions. Systematic reviews of pharmacological interventions for autism are published on a regular basis,
for example from Bryson, Rogers and Fombonne (2003) and des Portes, Hagerman and Hendren (2003) through to more recent reviews such as (NICE, 2012 and 2013). According to the NICE recommendations, there are no drug treatments currently available that have been found to be effective in treating core autism symptoms. But considerable research efforts are underway which might ultimately lead to new autism treatments (see Steckler, Spooren and Murphy (2014)). Medication is also prescribed for autistic people for additional difficulties they may have. For example, risperidone is frequently cited as having a beneficial impact on irritability/challenging behaviour (see NICE (2013, p. 477)).

Overall, the state of intervention science remains patchy at best. One of the reasons why the field of interventions remains so inconclusive is that there are substantial methodological challenges that present in the conduct of interventions studies, which make it extremely difficult to reach a firm verdict on the efficacy of any single intervention. The heterogeneity of autism’s presentation adds to the challenges of undertaking robust intervention trials, even when attempts are made to match subjects according to abilities and characteristics against a control group. There is a lack of consistency in outcome indicators (whether the impact is on core features of autism or linked outcomes such as speech and language). There are significant challenges in marrying the requirements of rigour (e.g. double-blinding) with interventions – particularly psychosocial and educational – that take place in the real world over time.

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17 Thus Declan Murphy often uses a blank slide to illustrate what is currently known about autism treatments (for example Murphy (2014)).
18 See NICE (2013, pp. 30–32) with regard to psychosocial interventions in particular, and note too the overall absence of recommended treatments emerging from NICE’s large-scale reviews (2013; 2012) of all randomised intervention trials with regard to autism.
and in an array of contexts (confounding variables, treatment fidelity). Few have yet been replicated or subjected to long-term follow-up studies.

This foggy picture is in turn a reflection of wider realities such as the relative lack of research funding oriented to interventions, as well as the lack of strategic overview and coordination of the autism research effort as a whole (see Pellicano, Dinsmore and Charman 2013). Further, there are critics who argue that the emphasis on positivist research adopting methodology based on randomised control trials (RCTs) as the sole arbiter of judgement for an intervention misses out on valuable experiential knowledge of interventions. Qualitative research, first- and second-hand accounts of how individuals learn and develop, and critical sociological analysis, it is argued, are all essential for a rich understanding of how we might evaluate interventions (Milton, 2013).

Against this background of an “evidence gap”, a plethora of unevaluated interventions have grown up, spanning therapies linked with the senses, the arts, animals, diets. The Research Autism Interventions website lists 1,195 such interventions alphabetically, and also offers a grading system for some of them based on the evidence that does currently exist (Research Autism, 2014a).

Mercifully, my research question does not require me to judge on the scientific accuracy of the intervention literature, nor, therefore, on the relative efficacy of one intervention over another. Rather, I will be seeking to highlight the ethical and conceptual issues that are implicated in and across interventions – both those that have been researched and those that are practised despite having a poor evidence base.
My broad interpretation of what we can conclude from the intervention literature, incorporating first-person accounts and the views of acknowledged experts in the science, is this:

- Some autistic people do well and this is not always attributable to any specific intervention.
- Some autistic people do well and this is attributed at least in part to deliberate intervention.
- Some autistic people don’t do well, regardless of intervention.

What is meant by “doing well” is of course unclear, and how we evaluate outcomes is at the heart of much of the work of the thesis, as I hope I will successfully demonstrate throughout what follows.

1.4. Conclusion to Response Number 1 (autism within clinical and medical science)

The account of how knowledge of autism has evolved has so far drawn a clear distinction between emotional/relational interpretations and organic/biological. We have seen how scientific investigation has served to distance the outputs of empirical discovery from the damagingly speculative hypothesis postulated by Bettelheim.

The quest for organic understanding of autism has gained momentum over the past decade due to an expansion of funding for medical/scientific research into autism. What can be said about the underlying purpose of this direction of enquiry? In other
words, why is there such an intense endeavour to seek out biomarkers? And how will the knowledge be used?

1.4.1. The “why” question

The literature is awash with examples of justifications for the medical research effort. To illustrate this, I have picked out just three quotations which reveal the common attitudes, and the italics in each case are mine:

- Morris et al. (2008) put forward the hypothesis that maternal autoimmunity is a contributing factor to aetiology in up to 40% of pregnancies leading to autism. They anticipate screening leading to immunomodulatory therapies that “may provide a practical approach to the prevention of this disabling and increasingly prevalent disease” (2008, p. 234).

- Evers and Hollander write: “if excitotoxicity contributes to the pathology of at least a subset of patients with autism spectrum disorders, then glutamatergic drugs may have some utility among this population” (2008, p. 139). There are “possible future implications for prevention, diagnosis and treatment of at least a subset of children with autism” (2008, pp. 139–141).

- Keller, Panteri and Biamonte (2008), in exploring how male and female sex steroids and Reelin interact during cerebellar development, and how they impinge on the regulation of Purkinje cell loss, suggest that this line of enquiry “might allow for new therapeutic targets” (2008, p. 223).

In the above, I have shown graded examples of how prevention/cure is elucidated amongst scientific writers: a desire to attack autism wholesale because it is viewed as
a disabling disease; a more qualified target of prevention for “at least a subset”; and a more modulated/non-specific reference to “therapeutic targets”. Similarly, in an overview of the quest for biomarkers, a general belief in therapeutic discoveries is held to be the justification for the substantial research effort (Walsh et al., 2011).

It should also be acknowledged that sometimes the purpose of investigations falls short of any kind of articulated explanation beyond a “knowledge for knowledge’s sake” perspective. There is an implicit and sometimes explicit assertion that the value of all the research is to increase our understanding of the range of processes at work in relation to autism, full stop. Whether or not the work will impact beneficially on people’s lives is often unstated, suggesting that the potential benefits are somehow self-evident. And yet – as my thesis will make clear – there is actually no consensus about what response autism should elicit, and how or if the scientific knowledge that is accumulating (though still in its infancy) should be used.

Nonetheless, behind all these presentations of an answer to the “why” question, there lies a shared belief that autism entails and predicts difficulties that are best avoided or ameliorated. Recent long-term follow-up studies support this idea of “the bad thing” that is autism,\(^\text{19}\) insofar as, overall, set against both socio-economic indicators and medical symptoms, long-term prognosis paints a gloomy picture (Howlin et al., 2004; Howlin et al., 2013; Howlin et al., 2014; Seltzer, 2011).

\(^{19}\) I am here echoing Scully’s use of the phrase “the Bad Thing” in relation to disability (2008).
1.4.2. The “what” question(s)

Although the above reflect the predominant attitude towards autism as pathology requiring treatment, it should be noted that alternative conceptualisations of the scientific project are emerging. The idea of autism as a distinct nosological entity remains intact within these alternative perspectives, but the emphasis on autism as pathology is starting to be questioned. There has in some quarters been a move away from describing it as a disease. Contemporary literature and scientists vary in their descriptions from “disease” to “disorder” to “condition”. Similarly, while some still refer to the “pathology” implicit in altered brain structure and development, others are referring merely to contrasts and “alterations”. Further, as discussed above (p.25) in relation to cognitive models, some enquiry focuses on areas of autistic strengths. Commentators also point out that the same qualities can be seen both as disability and as asset, depending on context and viewpoint. For example Baron-Cohen refers to “strong persistent interests, attention to detail, unusual memory, fascination with systems and patterns, and ability to concentrate for long periods that may be conducive to creativity and originality” (Baron-Cohen, 2000a).

What this highlights, and why it reinforces the observations I have made so far, is that the more the organic features linked to autism are examined, the more complicated the picture becomes, both in asserting what autism is, and what responses it should elicit.

Regarding “what autism is”, Verhoeff (2012) suggests that the scientific community has attempted to deal with such complications in two contrasting ways – “splitting” and “lumping”. Alongside the multiple and interacting processes at work, and the
presence of “ubiquitous heterogeneity” among the autistic population, there is increasing talk of “subsets” – or “splitting”. Notably, some prominent scientists have suggested that the time has come to abandon altogether a notion of a single neurological condition (Waterhouse and Gillberg, 2014).

In contrast, “lumping” insists on a unifying whole, notwithstanding diversity in presentation. DSM-5’s attempt to unite such a broad range of presenting behaviours within a “single all-encompassing autism category” is an example of this. Verhoeff’s analysis requires us to see autism not simply in terms of a distinct biological entity, but rather to incorporate social, historical and cultural contextual issues which I will be discussing below (Section 4.1).

I have suggested in this section that how autism is viewed and responded to within science is thus a “work in progress”. I introduced above the fact that within clinical science, autism is conceived as a problem requiring treatments targeted at affected individuals. However, the clinical and therapeutic intervention research that exists is far less clear in terms of its overall goals, let alone the conclusions that can be drawn.

It is now time to take a look at how autism is viewed and experienced – and the responses it has elicited – beyond the confines of the laboratory and scientific community. I hope to demonstrate below that it is only by attending to the experiences of people’s lives, taking into account social, cultural and institutional responses to autism, that we can more fully understand what issues are at stake when formulating views about the ethics of cure and prevention within the context of our
contemporary world. I will show that answers to the question “what is autism?” are as many-layered from beyond the scientific community as they have been from within it.

2. Parents and professionals/practitioners

First-person accounts of being the parent of an autistic child abound (see for example Collins (2004); Gilman (2011); Claiborne Park (1967); Moore (2012); Cohen (2007); Rankin (2000)). Rather than offer a review (but see Osteen (2008)), my purpose in this section is to focus on some key themes that I feel are of significance in the pursuit of my research question. As with the scientific and medical discourse covered above, I have found that understanding and explaining the standpoints of parents and professionals requires a historical perspective.

The first thing to point out is that the relationship between parents and professionals has been a mixture of friction, partnership and overlap. With regard to overlap, it is notable that parents have contributed in dual roles as parents and academics/professionals in influencing what is known or understood about autism over decades, in areas as diverse as clinical science (Lorna Wing), anthropology (Grinker), history (Adam Feinstein), culture (Stuart Murray, Osteen) and sociology (Nadesan and Eyal).

With regard to friction, Langan suggests that once autism became widely recognised, parents’ distinctive contribution was in “contesting expert theories and professional practices” (2011, p. 193) and that there were inevitable tensions of power imbalance. As we see from Response Number 1 above, the emergence of autism as an entity
originated in the field of psychiatry and extended into psychology. It was viewed as a pathology, with views on causality linked closely with views as to remedy. The impact of Bettelheim’s view on autism and his recommendation of “parentectomy” has received extensive attention in the literature, not just in terms of its empirical vacuity but also concerning the impact it had on parents and in particular the emergence of parent advocacy (see Feinstein (2010) and Langan (2011)).

It should be noted that the phenomenon of parent-blaming did not end when Bettelheim became discredited (see above pp.18-20). More recent versions of a similar thesis led to “holding therapy” (Welch, 1983 and 1989) – a kind of enforced re-enactment of bonding to compensate for the bonding that, it was suggested, had not taken place as it should have done in infancy. The fact that neither response was empirically supported, and both were based on inaccurate theories of causality, did not stop these ideas having potency.

Thus although parents are cited as rejecting the blame culture associated with Bettelheim, it is also of note that many parents were persuaded by Martha Welch, despite the seeming “blame” her theory attributed to them, to the extent of undertaking enforced holding, however counter-intuitive given the often violent resistance of their children (Maurice, 1993). The message was that autism is something that should be remedied, and that even if the remedy is aversive to the children, this is a price worth paying. It reveals the complex sentiments at play in relation to autism – parents feeling guilty, parents wanting to find a child that might have been there, and could still be there, once the autism is removed, and parents

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20 Holding therapy is described as “sensory rape” by Clare Sainsbury (see Feinstein (2010, p. 161)).
seeing autism as so “bad” that it is worth putting a child through some very uncomfortable procedures in order to eliminate it.

The appeal of psychoanalytic approaches to autism lay precisely in this relationship to an idea of cure … Appropriate therapy could, it appeared, “bring back” the child who had been “lost”. … For some, accepting that they were to blame was a price worth paying if it meant that their child could be “rescued” from autism. (Murray, 2012, pp. 57–8)

These ideas are expanded upon in a number of sources (see for example Murray (2008, pp. 169–203), Feinstein (2010) and Eyal et al. (2010)). Yet these writers also explore the counterpoint development of the role of parents as advocates and co-experts, in alliance with professionals, and Murray sums this up as follows:

Not all parents accepted the view of themselves as brutal suppressors of their child’s development however, and not all of those with autism were prepared to allow their endless objectification. One consequence of the traumatic history of autism in the 1960s and 1970s, and possibly the only beneficial one, was the rise of the advocacy movements that began to demand better care policies, better education, and greater understanding of the condition. Often parent led in their initial stages, such movements changed the ways in which autism was discussed, and paved the way for the kinds of disability rights campaigns that would follow in later decades. It was an emergence from a long dark tunnel. (2012, p. 59)

The role of parent advocacy is notable in terms of the breadth of its focus and its impact (see for example Eyal et al. (2010) and Murray (2012)). Within the USA, Bernard Rimland’s work (1964) asserting the biological nature of autism and refuting the psychodynamic, and the formation of the National Society of Autistic Children (later to become the Autism Society of America (ASA)), heralded a parental “fight back” (Feinstein, 2010, Chapter 6) which had its parallel within the UK in the parent-founded National Autistic Society (NAS). It was only then that the first autism-

An alternative attitude is cited by Grinker (2009, pp. 284-285) in relation to mothers in South Korea and elsewhere who would prefer to avoid the implication that they carry defective genes, and therefore are willing to accept that their child suffers from “Reactive Attachment Disorder".

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21 An alternative attitude is cited by Grinker (2009, pp. 284-285) in relation to mothers in South Korea and elsewhere who would prefer to avoid the implication that they carry defective genes, and therefore are willing to accept that their child suffers from “Reactive Attachment Disorder".
specific services were created, in schools and, later, adult provisions for autistic people.

Gradually, in response, the standpoint of some of the established professions moved from one of oblivion, judgement or obstruction, to one of support and partnership with parents and voluntary organisations. Beyond the early and unhelpful response from (at least some members of) the psychiatric and social-work professions (documented by Clara Claiborne Park (1967) and others), there grew up a more positive response focused initially on special education.

Tailored approaches to teaching autistic children were pioneered by individual practitioners such as Sybil Elgar in the UK (see Feinstein (2010, pp. 86–90)), and in the USA by Schopler (founder of TEACCH), and by Lovaas’ application of behaviour-analytic principles to pre-school children with autism. (See Feinstein (2010, Chapter 5); Eyal et al. (2010, Chapters 7 and 8), pp 44-45 above and further discussion in chapter 5 below.) Despite their differences, what both approaches achieved was a belief that – while autism was itself incurable and lifelong – there might still be helpful interventions to support the individual and their family, and in particular – given the developmental nature of the condition – tailored education was recommended, based on applying the emerging understanding around symptoms, in order to build strategies for either compensating for, or ameliorating, underlying deficits. The lack of interest from the educational mainstream gradually yielded, as a result of the schools set up by parents and of the ongoing pressure that parents exerted on public agencies towards the end of the twentieth century, to the idea that autism demanded understanding, knowledge and designated professional specialism.
Recognition of the need for autism-specific teaching approaches gradually spilled over into the maintained sector and official guidance. (See NICE (2013, pp. 23–24).)

The emphasis on the crucial nature of tailored and individualised education, delivered by people who understand and have skills working with people with ASD, continues to this day in a whole raft of clinical, professional, regulatory guidance, textbooks, teaching manuals and so on. However, there remains an awareness among some professionals and families of how limited the application of this guidance still is in practice, and how much remains to be done (as illustrated, within the UK, by a series of reports and campaigns from organisations such as Autism in Mind (AIM), Ambitious about Autism and the National Autistic Society).

Thus, at a broader structural level, in terms of resourcing and availability of expertise, a sense of parental dismay at the inadequacy of the status quo has persisted. There remains an underlying sense of indignation about how society currently responds to autism, both in terms of the quantity and quality of support – something that the respective pieces of legislation in the USA (United States Congress, 2006) and the UK (Great Britain, 2009) in their contrasting ways have acknowledged. This fact of “unmet need” and a seemingly hostile wider environment is of direct relevance to my thesis, as will become clear throughout.

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22 Within the UK the main evidence of this recognition lies in the official status of the Autism Education Trust (Autism Education Trust, n.d.) and in the long list of publications from mainstream publishers such as the National Autistic Society and Jessica Kingsley.

23 See for example AIM (n.d.), Barnard (2002) and Ambitious About Autism’s Finished at School campaign (Ambitious About Autism, n.d.).

24 Murray (2012, p. 66) also points out the contrast in name between the Combating Autism Act in the US and the Autism Act in the UK, which perhaps serves as a shorthand for the contrasting views on autism expressed above. While “combating autism” has an implicitly negative account of autism within its title, the UK Act’s title is neutral.
First, as I have indicated, parents have often had to withstand the power of charlatan “experts” and practitioners on the one hand, or oblivion/indifference on the other hand, in order to shape a more accurate knowledge of the nature of their children’s real needs, and then go on to (try to) meet these needs themselves. Thus Eyal et al. refer to the changing and emerging roles of parents in the post-Bettelheim world, both as advocates and establishers of national pressure groups and also as direct therapists for their children. The all-embracing nature of the role some parents feel impelled to take on is captured by reference to “the parent-activist-therapist-researcher as a new type of expert” (Eyal et al., 2010, p. 172) and “autism parenting as a vocation” (Eyal et al., 2010, p. 183).

This is significant in terms of how fervent many parents have been in their activism. The role of parents of autistic children as “the two-fisted street-fighters of the disability movement” (Ladyman, 2002) gives a hint of both the energy and drive that at least a subset of parents have brought in order to improve the support offered to autistic people and their families, and also perhaps to the dangers of zealotry which some aspects of parental advocacy have featured.

Second, there is an important loop-back effect in terms of what society fails to offer autistic people and their families, and the degree of desperation and the language of advocacy adopted to try to push for more resources. In calling for autistic people and their families to be more generously supported, some parent advocates and voluntary organisations have used emotive language about the problems associated with autism in order to highlight the scale of unmet need. There would surely be less impetus for
adverse comparisons with the levels of support that cancer patients receive, or references to autism as a national emergency (Wright, 2013), in an environment in which autistic people and their families who needed support were surrounded as a matter of routine with generously provided support services and a broader climate of acceptance. In the absence of this, failure to meet the needs of autistic people and their families is often experienced – and portrayed – in stark and desperate ways (see Klar-Wolfond (2008) for several illustrations of this).

Such experiences and perceptions – in the context of a clinical establishment that can offer nothing conclusive in the way of interventions – then fuel the recourse not just to extreme language but also to passionately held views on “what needs to be done about autism”. While for some, indignation and activism are born from a sense that autistic people have much greater potential which could be realised if greater and more appropriate provision were available – but with their autism as it were “intact” – for others the goal of a “cure” or “recovery” from autism holds particular power and hope, because their experience of autism is felt to be almost overwhelmingly negative and/or because of a conviction that their children’s autism was caused by a toxic external agent and/or simply because the response from the “establishment” seems so ineffectual.

Such activism has taken different directions in terms of what is felt to be the right response to autism, with this linked closely to views about autism itself. On one hand we see parents active in pioneering new services and support systems, but without

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25 This was the topic of Bob Wright’s input at the inaugural annual lecture “Are We Ambitious Enough About Autism?” in 2008 (see Jardine (2008)). Equivalences between cancer and autism are often adopted elsewhere (see for example Chew (2013)).
articulating any aspirations towards cure or prevention. Thus, a feature of the educational approaches of the early schools was that these schools were not oriented towards eliminating autism but, rather, were focused on maximising potential taking into account the key impairments of autism as perceived at the time (for example communication, social behaviour and, for the more intellectually disabled, self-help skills). Likewise, aside from specialist services, the bulk of parental and charitable voluntary activity within autism during the 1970s and 1980s was focused on the provision of information and advice to families; the lifelong nature of autism was taken as a given.

In contrast, some aspects of parent and practitioner advocacy have been consistently characterised by efforts to disseminate and influence the development of specific new interventions and “treatments” for autism, alongside a desire to influence the path of research. In several of these cases the push for interventions is closely linked to beliefs about particular biomedical causal factors and the possibility of recovery and cure (see for example Eyal et al.’s discussion of the newer biomedical charities in the US (2010, Chapter 11), Offit (2008) and Langan’s account of “the new parent movement” of the 1990s (2011, pp. 197–200)). Thus, outside the orthodox medical, institutional and academic fields, there has for several years been a parallel movement exploring additional interventions. Examples include the recommendation to use dimethylglycine (DMG) (a dietary supplement), which seemed to lead to a reduction in autism symptoms. The mass publicisation of secretin (late 1990s) was another example.

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²⁶ For a fuller account of these developments, see Feinstein (2010).
Gradually, a composite of theories and treatments came together and was taken up by a group of (non-mainstream) medical practitioners, supported by families, and a movement entitled Defeat Autism Now! (DAN) (Defeat Autism Now!, n.d.). From this there has come the DAN Protocol – a list of treatments – and some medical professionals in the UK are willing to offer private treatment according to its recommendations. Chelation falls within the category of biomedical interventions – the removal of heavy metals from the blood of autistic individuals. It became notorious when a child died in 2005 while undergoing chelation therapy.

There is an extensive literature commenting on the biomedical “movement” – not to mention a proliferation of “grey” literature, protocols, internet-based studies and articles in non-peer-reviewed journals. Of note about all these interventions is the concept of autism as representing biological damage to a person who, “beneath” their autism, or in the event of taking away their autism, would be “normal” (Fitzpatrick, 2009b; Murray, 2012). As the title “Defeat Autism Now!” reveals, autism is conceptualised as an enemy to be wrestled with. Similarly, the title of the US foundation “Cure Autism Now” (CAN) suggests the notion of autism as a disease, with “cure” as an unequivocally positive objective. CAN’s 2007 merger with Autism Speaks (US) involved a carry-over of the “cure quest” into the largest funding charity for autism research in the world.

In other cases, the promotion of specific interventions – usually educational, psychological or sensory in nature – has been linked to observations on the basis of their perceived efficacy, regardless of theories about biological cause. Here, as discussed above (pp. 46-48), the evidence of efficacy is of variable quality. What is of
interest, still, is that the goals and outcomes of these approaches vary: while an approach such as TEACCH has been upheld for maximising potential “within autism”, others (some applications of Lovaas/ABA and Son-Rise (discussed further in Chapter 5 together with various biomedical interventions) have been articulated as routes to “recovery” from autism.

I will be saying much more about the ethical content of these contrasts in Chapters 4, 5 and 6. In this section, I have merely set the scene for the identification and analysis of the ethical questions that parental and professional views give rise to. But there is a crucial group of stakeholders whose perspectives are key to the attitudinal and experiential context that gave birth to my original research question, and which in turn have influenced how parents and professionals reflect on and develop their own stance. I now turn to the lives and experiences of autistic people themselves.

3. Autistic people

The reason I have included this section after, rather than before, that concerning parents and professionals is that, in terms of history, it was the parental and professional voices that dominated and shaped the landscape of “the autism movement” in the bulk of the second half of the twentieth century. Nonetheless, although the emergence of “self-advocacy” – autistic people speaking or writing for themselves – followed these earlier developments, I consider it to be the foremost important development in driving the work of my thesis.
Temple Grandin (Grandin and Scariano, 1996; Grandin, 2006) is often held up as one of the most successful and possibly the first internationally famous individual with autism, following her writings, lectures and most recently the eponymous feature film. Her insistence, based on willingness to tell of her own experiences, that autistic people are capable of achieving a lot if they receive the right kind of interventions and understanding from an early age has illuminated understanding of the condition for outsiders, for example around autistic strengths including visual thinking, and around sensory issues and difficulties in social imagination.

A proliferation of first-person accounts has since been offered, via both published and internet material, ranging from academic papers through to art, film and poetry, to opinions and blogs, to autobiography, to treatise, to specialist advice on particular subjects. I cannot claim to have read the whole canon (a comprehensive list of all the literature is included in the bibliography of autistic authors compiled by Amanda Baggs (2013)). In addition to those I will be referring to directly in the rest of the thesis, I have been influenced by the first-person writings of Clare Sainsbury (2000), John Elder Robison (2007), Gerland (1997), Nazeer (2006), Williams (1998), Lawson (1998), Tammet (2006), Healey (2008), Higashida (2013). Informative and critical analysis of some of these works is offered elsewhere (e.g. by Murray (2008) and Osteen (2008)). For the purposes of this introduction, the main observation of relevance is that – notwithstanding what one might call the unifying features of a diagnosis of autism – these views express a diversity of standpoints on attitudes to autism itself. We find individuals who lament their autism, and those who assert the value of their way of being (Baggs, 2007) and this is seemingly distinct from their

27 See for example Ros Blackburn quoted in Feinstein (2010, p. 290).
“levels of functioning” in different domains (though all of those I have read, by
definition, share the ability to express themselves in the written or spoken word).
There is not a shared perspective on whether autism is an “assert or a curse”, either
for them or for those around them, and in particular we find several expressions of
ambivalence in which both positives and negatives are experienced and described by
individuals – e.g. Gerland and Higashida.

Yet most share a desire for greater understanding, a desire to be heard and included,
to have their strengths and dogged efforts (or in some cases defiant refusal) to
acclimatise to a NT-dominated world recognised, and for better and more appropriate
support – all of which amount to a more autism-friendly environment. Thus, what
much of this discourse explores, either implicitly or explicitly, is the question about
how much the difficulties associated with autism are integral to the condition, and
how much they are externally imposed by prevailing social attitudes, norms and
institutions – and how much they are difficulties at all. There are strong resonances
here with the wider literature on the medical vs social models of disability, the latter
of which consciously inspired the UK-based Autism Rights Movement (now renamed
Autistic UK).

3.1. The social model of disability and the neurodiversity movement

The extensive discourse around the social model of disability, from its political roots
in the Union of the Physically Impaired Against Segregation (UPIAS) to the academic
domain of disability studies, is rich and broad, and I cannot do justice to it here (but
see for example Shakespeare (2006), Thomas (2007) and Swain et al. (2004)). The
relevance of the distinction between social and medical approaches to all kinds of difference has also been covered, though less extensively, within the field of bioethics (e.g. Glover (2006), Buchanan et al. (2000), Scully (2008)). These themes will be taken up again in Chapters 4, 5 and 6, so I wish to make just a few introductory observations at this stage.

Contrasts between the medical and social models of disability occupy a large and complex area of enquiry – each model has been subjected to contrasts of analysis, interpretation and emphasis. For example, subcategories have been created beyond a crude binary divide between social and medical models. Scully (2008, pp. 22–30) separates the medical model, which she refers to as “Disability as Individual Trouble”, into two domains – Moral and Medical on the one hand, and Genetic on the other. And instead of “the social model” she refers to “Disability as Social Relation”, within which there are two subgroups: the Strong Social Model and alternative Social-Relational Approaches. These latter echo the demarcation of the social model as between the radical and interactive model outlined by Wasserman, Bickenbach and Wachbroit (2005, pp. 12–15).

Whilst these contrasting emphases are interesting and carry implications in terms of what interventions are most appropriate, my purpose at this point is more general and does not require delving into the contrasts. Combining both the non-individual-based subgroups into the social model, there are important common features to stress between this approach to disability as a whole, and the neurodiversity paradigm, which relates in particular to neurological differences, and is the philosophical
foundation of the neurodiversity movement to which many autistic self-advocates consciously or implicitly belong.

The neurodiversity paradigm holds neurodiversity as natural, rejects the idea that there is one “right” or “normal” kind of brain and recognises similar dynamics of social power inequalities to those that operate in other areas of human diversity (e.g. race or gender) (Walker, 2014). It therefore rejects the “pathology paradigm” (equivalent to the medical model of disability), which views divergent neurological functioning as meaning “there is Something Wrong With You” (Walker, 2013). Although the neurodiversity paradigm and resultant movement cover all forms of neurodivergence, the movement is strongly equated in many people’s minds with autism self-advocacy in particular.

Both the neurodiversity paradigm and the broader social model of disability generate similar questions regarding autism. For example, concerning the interrelationship between the individual and their wider environment, does the key source of any difficulties experienced by autistic people lie within the individuals or as a result of the wider social and attitudinal environment around them? Second, who is to judge on the quality of life and experiences of autistic people – “typical” outsiders? Or autistic people themselves? Key issues here are the extent to which the pleasures and positives of being autistic are subjective and not understood by outsiders (see for example Something About Us (2008) and Murray (2008, pp. 49–50)) compared with the difficulties of autism as perceived and focused upon by non-autistic onlookers, including academic analysts. Third, there is a question of minority status, and the evolution of particular cultures. Thus, some commentators have drawn parallels
between autism and the deaf movement, in the sense of the emergence of a distinct autistic culture (Saner, 2007; Sinclair, 2005).

All these points lie at the heart of the social model and converge to generate strong political movement to bring about change – a movement about which there is ample discussion in the literature already concerning disability. The disability rights movement’s opposition to the way disabled people are marginalised, not only from and by society in general but also from decisions that affect them directly, has led to calls for greater autonomy, to shape not only how disabled people live their own lives but also to influence the direction of practices, research and policies that affect them, through to claiming an equal stake in what society offers and notions of what society is. The impetus for greater power and participation is captured around the phrase “nothing about us, without us”, a key message of the disability rights movement in general and a reflection of the reason why autistics have increasingly sought to have a louder and independent voice. All these trends are reflected in the neurodiversity movement in general, and, hence, in the messages of autistic advocates.

Often critical of parent- and professional-dominated organisations, and of academics who achieve expert status and speak as if they know more about autism than autistic people themselves, groups in the USA and the UK such as Aspies for Freedom, the Autistic Self Advocacy Network (ASAN) and Autistic UK are now requiring attention and involvement in the shaping of developments such as the UK National Autism Strategy and the US Interagency Autism Coordinating Committee. Some

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28 The Combating Autism Act (USA) and the Autism Act (UK) have both established forums in which individuals with autism are expected to play a part.
autistic activists have also sought greater influence within established and formerly parent-led organisations such as the National Autistic Society, and increasingly voluntary and public agencies are being called upon to recognise that autistic people should be represented within their governing structures.

It is probably too early to say whether or not such moves by the “establishment” to involve autistic people are tokenistic, or genuinely reflective of an ongoing move to accommodate neurodiversity in these wider forums. What is clear, though, is that the self-advocacy movement has been key in raising important ethical questions – questions about how autistic people are to be viewed and what is the right way for society to respond to autism. Particular concern has been expressed by self-advocates about the implications of ongoing scientific research and findings in relation to autism and how these spill over into practice towards autistic people.

3.2. Ethics in research and practice with respect to autism

This section explores the nature of the growing concern, among autistics primarily, about what they perceive as imbalance and bias in how research into autism is conducted and interpreted.

In a broad overview of the issues, following on from the UK-based conference on Autism, Ethics and Society in 2010 (University College London, 2010), Pellicano and Stears (2011) offer what they describe as “the first major analysis” of the unease that is felt by autism activists concerning the implications of recent scientific developments, in the context of contrasting responses to autism and competing claims.
on finite research funding. The authors’ recommendations relate to concrete changes in mechanisms by which research priorities are set, in order to enable the debate to continue in a way that recognises the great potential impact on lives resulting from scientific discoveries. Attitudinal research, participatory research, and formal representation of people with autism on influential committees and advisory groups are proposed, and more proactive engagement from scientists: “although scientists operate in a well-established professional environment, and are keen to continue to operate by its rules, they must nonetheless also see themselves as agents of influence and not simply as imprisoned by the inherited norms of their profession” (Pellicano and Stears, 2011, p. 9).

The ethical, legal and social implications (ELSI) of autism in research were also the subject of two workshops in the USA, the first (26 September 2011) mandated by Congress (Office of Autism Research Coordination, 2011) and the second (December 2011) hosted jointly by ASAN and Harvard Law School and funded by the Administration of Developmental Disabilities (ASAN, 2011).

From the first workshop, with participant membership reflecting a combination of autism scientists, ethicists, historians, and parents – with just one self-advocate – the following recommendations and observations were made by several contributors:

- Integrating community values into the formulation and conduct of research should become a higher priority, and work needs to be done to devise new methods for this and for engaging in dialogue between stakeholders and the research community.
• Scientists must do more to recognise that their work takes place in a social and ideological context and that by asking certain questions and not others, their work is not value-neutral, either in its conception or its implications.

• The communication of scientific goals and findings is fraught with complications, including possible biases.

• The balance of research funding between cause and intervention needs to shift.

The second workshop (ASAN, 2011), whose speakers comprised autistic adults and traditional researchers in equal numbers, echoed and extended some of these themes:

• Citations of “ableism as systematic prejudice” (Zoe Gross) leading to the phenomenon of “pseudospeciation”, which in turn leads to dehumanisation of autistic people.

• Citations of the consequence of this prejudice feeding into bias in research, with illustrations including (i) how autism is described and how data are interpreted; (ii) imbalances in research emphasis leading to a focus on causes and young children, rather than on support services and adults; (iii) imbalance between user-led (community-based participation research (CPBR)) and traditional research methods; (iv) the absence of accounts or exploration of negative consequences in relation to (behavioural) interventions.

• The ethical issues raised in relation to prenatal testing.

A series of specific measures and recommendations arose from this second workshop, reflecting the calls made by participants across a range of issues. These included the need for:
A switch from deficit language to neutral language (for example “difference” rather than “disorder”);

A comprehensive set of ethics for intervention, including the proposal that no interventions arising from research should be copyrighted;

New outcome measures to include quality of life and well-being;

Training of genetic counsellors in the social model of disability;

Wider use of the legal routes within the USA by which aversives and physical restraint in some institutional settings can be challenged.

In these workshops there was a broad recognition of a power imbalance between autistics and the research community, both in the area of influencing what research takes place and also in deconstructing how data are interpreted within existing studies.

A key example of loaded interpretation relates back to the fundamental point of the neurodiversity paradigm – that difference is not the same thing as pathology. The possibility that qualities possessed by autistics are not deficits but actually just differences or even assets, and that this has been overlooked by mainstream science – and also ethics – was reiterated at the ASAN symposium. One of several illustrations of the one-sided way researchers interpret contrasts in behaviour between autistics and NTs concerned the impact of being observed when making charitable donations (Izuma et al., 2011). The fact that having an observer present did not alter the way autistics gave to charity was interpreted as a deficit by the authors. Another interpretation could be that the autistics were more consistent, trustworthy and less vulnerable to extraneous agendas. The susceptibility of NTs to the influence of being
observed was felt by an autistic commentator to be much more of a problem than the consistency of the autistics even though it was NTs’ susceptibility that was deemed socially appropriate by the researcher. Yet reframing the qualities under investigation might just as appropriately lead us to feel that social conformity is a more detrimental quality than independence from social influence, and that autistics show less weakness in this area. The ethical implications of this observation relate to what qualities count as virtues and they are explored in the context of virtue ethics more thoroughly in Chapter 6. There are significant implications regarding how we appraise difference vs deficit, when evaluating outcomes from autism interventions and treatments.

3.2.1. Interventions and clinical practice

There are therefore several concerns raised by autistic advocates about the nature and practice of interventions.

One concern is that commercial and professional agendas might influence not only the way research is conducted but also how the research findings are then interpreted in order to promote particular interventions. If an organisation or professional body stands to gain from presenting results in a particular way, this opens up the possibility of drift between what the data really say and how they are used, interpreted and “marketed”. The danger that this can lead to unethical behaviour on the part of those allied to particular interventions is something about which the autistic scientist Michelle Dawson has been vocal.

29 Interestingly, a study that is still ongoing has responded to this observation, and the wording of the title alters the power balance of the enquiry in favour of autistic subjects: “Social conformity: Why do humans and monkeys make weak decisions under social influence?” (IOE, n.d.).
Her critique of “ABA autism” (2004) includes an assertion that the studies purporting to justify one particular intervention (Lovaas) were flawed, and that the data do not justify the claims of efficacy made by some practitioners and academics. Her further objection was that the approach involves the use of aversives, which are contrary to the rights of the autistic children being subjected to the intervention, and as such the practitioners were attacking their personhood. (See also Waltz (2007).)

Thus, the ethics of intervention relate not only to the claims made on the basis of research, but also the practices involved, and – finally – the very goals of the intervention. Dawson and several others strongly contest the idea that the reduction of autism symptoms – so that autistic children become “indistinguishable from their peers” – should be seen as a positive outcome.

Dawson has also questioned the purpose of, and basis on which claims of effectiveness have been made for, research into the impact of oxytocin on autistic people (2010). The study measured the social interaction and responsiveness to social cues of people with autism before and after being administered oxytocin, and found that oxytocin induced “more appropriate social behaviour and affect” (Andari et al., 2010). But what is “appropriate” and by whose standards? By observing that the allegedly positive improvements towards more NT behaviour entailed a greater propensity for “selfishness and hypocrisy”, Dawson questioned the criteria by which “positive” and “negative” outcomes are judged. This echoes the example offered above in relation to contrasts between autistics and NTs in the studies of charitable
giving – where the researchers were perceived as biased in equating “normal” with “preferable/superior”. I will develop these observations in chapter 6.

The examples of potential bias of interpretation link with the objection that many have made to viewing a reduction of autistic symptoms as synonymous with a positive outcome. The further possibility, that some interventions might require discomfort in order to achieve “normality”, is particularly questioned. (These ideas will be covered in much greater depth in Chapter 5 below.)

3.3. Conclusion / overview

We see a picture of an academic and institutional establishment only slowly recognising that the voices of autistic people themselves, and not just their parents, need to be heard. For some, including some parents and professionals, the autistic voice has also contributed to a reframing of how we should regard the very nature of autism, whether this is based on a deep mistrust of the medical model of disability in general or an approach based on experience of knowing autistic people (see Langan (2011, pp. 200–203)).

The self-advocacy movement has been particularly effective at questioning the extent to which autism is viewed solely as pathological and urging a shift towards difference rather than disorder, and towards recognition of autistic strengths. Some practices that might have seemed morally innocuous at one point in time are now more likely to be scrutinised in terms of their ethics. Yet for others, the analysis and messaging offered by self-advocates are felt to sum up, if at all, the views of only a section of those with
a diagnosis of autism. Parents of autistic people whose impairments present in more severe ways – including those with severe learning disabilities – have suggested that the above perspectives do not reflect the reality of their children’s lives nor of their needs and priorities. Indeed, there is for some a real clash of perspective between those autistic people who self-advocate in sophisticated and articulate ways, and those whose impairments are felt to be profound and debilitating and who, it is argued, are at risk of being ignored if the self-advocates become the sole depiction of autism in the priorities of science and society.

These tensions are serious, sometimes agonizing. Online discussions can quickly become acrimonious. At their worst, they lead to balkanization. … Some parents of severely afflicted autistic children find it hard to sympathize. They tend to depict the self-advocates as fellow travelers, incidental tourists whose claims for association with autism are self-made, dubious and injurious to the more serious campaign. (Eyal et al., 2010, pp. 230–231)

It would be wrong to imply that all parents share this view, just as it would be wrong to infer that all articulate autistics consider that acceptance on its own is sufficient to make life easier or better. But this view of the “balkanization” and of the “sometimes agonizing” disagreement within the autism movement describes well the tensions to which I referred in my introduction – the treatment vs acceptance debate – and the distress and polarisation that such opposition can cause. It also reveals the possibility that the significant differences between those autistic people who have severe learning difficulties, and those whose intellectual functioning is on a par with or greater than that of many NTs, may have ethical relevance.

Thus, the historical perspective that I have taken helps, I hope, to explain the origins and evolution of differences of emphasis, and in particular the challenges thrown up by the heterogeneity of contemporary notions – and experiences – of autism. Amongst
other things, the evolution of ideas around autism has given rise to a battle for brand ownership, which pitches those who hold on to Kanner’s autism as the “true autism” – in effect, the autism that was first to be identified – from “newer” brands of autism that do not entail learning disability and whose spokespeople claim representational rights. Who is more legitimately autistic? Which “type” of autism presents with greater needs? “A competition for oxygen” is how one colleague (herself a sibling of an autistic man) has described the resulting tension (Anon, 2013, pers. comm.).

The moral significance of this “battle for the brand” lies in the widely different conclusions it can lead to about what constitutes an appropriate intervention. At its most extreme, separating out the “high” and the “low” functioning is an argument used to justify prevention in the latter cases but not in the former. The argument is illustrated very clearly in Feinstein’s account of his conversation with Dr Sally Ozonoff (from the Medical Investigation of Neurodevelopmental Disorders (MIND) Institute, California):

Sally Ozonoff agrees to a certain extent with those who claim their autism is a valuable difference, not a disability: “A lot of them are incredibly interesting and fun people to be around. But if you can’t tell who those 30%–40% – let’s say – will be, and yet you can prevent someone from having something really difficult … I’m not taking about curing autism but preventing them from having the really disabling versions. It is very hard to predict even as late as 3 whether a child will have the kind of autism which will be valued as an important contribution to society, or whether it will be the kind that makes life very hard and is a disability.” (Feinstein, 2010, p. 272)

With thanks to Saskia Baron (2013) for introducing me to this phrase in her presentation.

There is a linked concern that scientific enquiry is increasingly focused on the more “high functioning” and that this will lead to marginalisation of those with learning disabilities. This is at least in part because it is only the more able autistic people who attain the necessary levels of comprehension and/or tolerance for certain psychological experiments or brain-imaging procedures. If autism is actually comprised of distinct subgroups, then such investigations can at best only claim to draw conclusions about the more able subgroup studied. Against this, one is reminded of Minshew et al. whose research identified neurological differences amongst those with intellectual disability (ID) from those with high-functioning autism (HFA) (see above p. 37).
The possibility that prevention and other interventions might be appropriate or not according to the “type” of autism someone has or might have is of central significance to my thesis. It suggests an ethical position that permits or even requires one to differentiate autism interventions according to prognosis or presenting ability.

Ozonoff further equates such differentiation according to the potential contribution to society a person might make. I will be revisiting these propositions later in the thesis, with particular scrutiny offered in Chapter 6. I introduce the ideas here in order to illustrate how the moral debates have arisen in the context of what seems like a head-on clash between the “medical model” – held by many clinicians and many parents – and the neurodiversity movement.

I am nearly ready to explore the ethical literature around all these issues, but my final task in this chapter is to pull together some of the strands of what I have said so far.

4. What can be learned from the range of responses to autism?

Although I have written about the frictions between different sections of the autism community, it would be inaccurate to imply that the clash can be drawn up simply along the lines of parents vs autistics, parents vs professionals or “high functioning” vs “Kanner’s autism”. Rather, these are fault lines that reveal contrasting views and experiences of significant sections of the stakeholder communities but cannot be generalised to speak for all. Furthermore, Langan argues that the past decade has featured an “evolving dialogue” – “the emergence of a less confrontational and more collaborative relationship between parents and professionals – and also between
parents and people with autism” (Langan, 2011, p. 203). She attributes this in part to the decline in influence of the “biomedical movement”. While I feel this last observation may be premature, I share with her a belief in the significance of what she bases her argument on – an emerging literature from both parents and autistic people questioning the crude medical model and sharing an appreciation of wider social forces. What I wish to do now is briefly illustrate this and suggest that it demonstrates, in essence, a shared endeavour amongst some of the stakeholders referred to in Responses Numbers 2 and 3 above to question the primacy given to biological and psychological accounts of autism (Response Number 1).

4.1. Deconstructing the essence of autism

Within the outline of Response Number 1, I demonstrated the significant challenge in pinning down the essential essence of autism from within medical science. Yet it has also been the case that, in recognising that knowledge seems to raise more questions than it answers, the clinical/scientific research community has been undeterred and has, rather, redoubled its efforts. Thus Eric London, a leading parent advocate for scientific research, ten years on from his initial work to establish the National Alliance for Autism Research (NAAR), said of the current level of knowledge about autism: “We really don’t know what we’re talking about” (London, 2011). However, rather than downing tools, he followed this remark with a call to arms to intensify the research effort.

The challenge to identify autism’s essence has also received attention within wider socio-cultural academic analysis of autism – incorporating sociology, history and...
philosophy. Langan makes the point that parents have been key contributors in these areas, and I would add that autistics themselves have been significant in addressing autism as a cultural phenomenon – one that has (at least in part) a non-biological entity and significance. What follows is a brief overview of these contributions.

There are several critical historical accounts of autism taking on board cultural and social perspectives (including Nadesan (2005), Osteen (2008), Timimi, Gardner and McCabe (2011), Murray (2008; 2012), Eyal et al. (2010) and Silverman (2011)). What they share is an appreciation that laboratory-based knowledge about autism is not generated in a social or cultural vacuum, and that institutional factors are relevant – something that I have already illustrated in discussion about the institutional impact on prevalence statistics (see above p. 23).

The way autism is perceived and portrayed in wider socio-cultural discourse sharply contrasts with the medical discourse of scientists outlined above in Section 1. For example, the contributors to Osteen’s anthology (2008) offer analyses of autism in biography and popular culture, as well as the “construction” of autism in clinical practice. Murray (2008) explores the role of metaphor in how autism is constructed in the wider public imagination, and also what this reflects about (perhaps unconscious) attitudes on the part of the scientific and clinical community.

One of the most radical standpoints is offered by those who question the very idea that “autism” should be subjected to medical categorisation at all, let alone then pursued as an entity for treatment or prevention. Thus Nadesan (2005) (parent) argues that autism is primarily socially constructed, a twentieth-century phenomenon.
emerging from the increased surveillance of childhood. She observes that “classificatory systems engender practices and institutions having the effect of producing what was classified” (2005, p. 24), and concludes: “Autism is produced through the nosological clustering of symptoms – symptoms no doubt stemming from diverse etiologies – and through the clinical practices or remediation. It is ‘produced’ through historically unique institutional and representational practices” (2005, p. 215).

Within the UK, autistic intellectuals have also offered new ways of viewing autism that move away from a strict biological and bodily phenomenon, including questioning what is apparently “known”. Starr suggests that by virtue of the social communication terrain in which autism sits, and how it has been defined, it cannot be located – let alone defined – as simply internal to an individual, devoid of social context. “Robinson Crusoe couldn’t have been autistic until he met Man Friday” is how he put it. To explore autism as if it were biologically located and operating within a single body is to miss out on crucial influences and components of autism as a concept (Starr, 2009–14, pers. comm.). Thus Starr is saying that the conceptualisation of autism is at least in part a function of prevailing social norms and expectations, which exist external to a person.

Arnold (2006–14, pers. comm.), citing Merleau-Ponty and Foucault, suggests that the very selection of specific criteria as constituting the entity “autism” is bound up in prevailing structures of knowledge and power which are applied, though obliviously, by many professionals and scientists. Echoing the social model of disability, he places less emphasis on any integral components of autism and, instead, gives greater focus

32 Several conversations held during 2009–2014, summarised here with his permission.
to how external structures and influences operate to make life hard for certain kinds of people (including those diagnosed autistic).

Perhaps most radical of all, Timimi, Gardner and McCabe (2011) (co-authors comprising a child psychiatrist and two adults diagnosed with Asperger Syndrome) wish to entirely debunk the idea of autism as a biological entity. In a meticulous analysis of the scientific evidence, as well as of the wider institutional, social and politico-economic forces surrounding autism, they suggest that “current theory and practice around ASD has more to do with socio-cultural processes than scientific progress” (2011, p.13). Their painstaking critique takes us through an analysis of how notions of “normal” childhood have evolved within the specific requirements of the industrialised world; the emergence and evolution of concepts of autism into the wide spectrum condition as set out and modified by successive DSMs as crucially located within the twentieth-century phenomenon of “the cult of child development”; and how this all fits into a wider political, economic and cultural climate in which certain notions of a good life are dominant, such that deviations from this lead to pathological labelling and social exclusion. They draw on a wide literature, adopting an overtly Marxist perspective and citing Foucault, Gramsci, Althusser and many more.

Their criticism is not purely socio-cultural however. They then dissect the current scientific orthodoxies in terms of genetics and the idea of the spectrum, challenging the interpretations to data offered in high-profile genetic studies in forensic detail. As a result, with regard to a wider phenotype, they suggest:

So, on the basis of a few twin and family studies we are now told that there is good evidence for an autism phenotype and that previous diagnostic classifications must be
re-evaluated. This seems a rather skewed form of reasoning – a bit like arguing that because one member of a family had bronchitis and others had colds that there was a bronchitis phenotype. (Timimi, Gardner and McCabe, 2011, p. 118)

And:

The evidence on the genetics of autism is weak, based on poor material to support the genetic hypotheses for autism and ASDs. It is not even clear what help finding “autism genes” would provide to those thus labeled.

… As a result we have the absurd situation where someone with severe learning difficulties, very little language, suffering with epilepsy and requiring full-time care can receive the same “neurodevelopmental” diagnosis as someone who has an above-average IQ and is holding down a prestigious post at a top university.

The notion that we have established autism as a genetic, neuro-developmental disorder is simply false. (2011, pp. 137–138, my italics)

They hold the breadth of the spectrum, or the heterogeneity of autism symptoms, as a significant problem:

It is obviously absurd to have a spectrum stretching from speechless residents of day centres who have little voluntary control over the most basic bodily functions to Einstein, but that is precisely the position we now appear to have reached. (2011, p. 178, my italics)

The fact that mainstream scientists are talking about multiple causative pathways as well as multiple manifestations is referred to as an example of this “absurdity”.

As a result of their analysis, they recommend a critical appraisal of the institutions surrounding autism – the institutions and values at the heart of modern industrialised, capitalist society. For example, with respect to education for children on the spectrum (aside from the most profoundly disabled):

If the problem here is not these individuals’ innate abilities, but a mismatch between them and their schools, is it the kids or their schooling environments that we should
be changing, or indeed, need we get so concerned about changing anything at all? (2011, p. 187)

And with respect to the possibility of both antenatal and postnatal interventions in relation to autism, they question the validity of this because they locate the issue of choice and decision-making within the economic and cultural values of a flawed system: “the process of having a child can ... be viewed through the prism of a narcissistic consumer value system” (2011, p. 227). Further, it feeds into wider economic considerations around dependency and productivity – “bad children can be seen as a risk and sad children as a poor investment” (2011, p. 238).

And finally, as an example of the tendency of dominant culture to pathologise the “different”, they point out how laden these judgements can be seen to be:

one may reasonably wonder why watching *EastEnders* every day and spending over ten hours a week gambling online is not considered pathological, while checking and collecting outdated bus timetables and spending over ten hours a week exploring obscure websites about defunct programming languages is somehow a sign of a genetic disorder or difference. Both are equally dysfunctional in terms of wasting time, whereas the former activity may expose the addict to greater financial risk, the latter is in itself harmless, but rendered more pathological, because of its uncommon nature. (2011, p. 261)

These points raise important questions about how we evaluate a worthwhile life and about which human qualities are met with respect, approval or disapproval. As suggested previously (see pp.71-74) these are important points concerning “the good life” and “virtues” which are fundamental in an assessment of the ethical case for seeking to prevent/cure autism. Indeed, all that I have said about the social construction of autism points to a complex range of standpoints by which attempts to cure and prevent it should be appraised. These points will all be developed in subsequent chapters and take centre stage in Chapter 6.
I have pointed out that many of these criticisms come from stakeholders who have a close connection with the condition with which they, or their loved ones, have been diagnosed. I should stress though that this wider analysis is of broader relevance, and the critical approach to scientific orthodoxy extends more broadly. Amongst others who argue that there is no unifying, underpinning biological fact of autism at all, Verhoeff (2012) concludes that “despite the widely experienced sense of a distinct and unique syndrome, there is no transhistorical essence or ‘true’ autism core to be revealed in nature”, and he too emphasises how it is made up from the external influences coming from outside a person: “there is a remarkably persistent desire to locate suffering, disruption and the requirement for care as a natural phenomenon, rather than implicated in the demands of a social world” (2012, p. 429).

Moreover, it is important to stress that Verhoeff, Nadesan, and Timimi, Gardner and McCabe are not alone in asserting the role of wider social, cultural and institutional forces in shaping the nature of emerging knowledge about autism, even amongst those who hold on to the possibility that autism has a persistent organic essence. A key example is the point referred to above (p.23) about how the rise in prevalence should be explained. Grinker (2009) argues that the availability of services is a key determinant of whether people will seek and obtain a diagnosis. Similarly, and echoing Nadesan and Timimi, Eyal et al. locate the identification of ASD within developments in our approach to childhood and its surveillance. They too point to the possibility that the rise in rates of diagnosis says as much about institutional factors as it does about the underlying prevalence of autism as a biological entity. They pay particular attention to the role of de-institutionalisation in the 1960s, which they say
led to “diagnostic substitution from mental retardation” (2010, p. 7). Their work examines a process by which, as classifications have evolved, “autism” is no longer the same thing as it used to be. But unlike Timimi, Gardner and McCabe, they do not think these wider forces, nor the problematic issue of heterogeneity and change within the diagnosis, require “a denial of the reality of autism” (2010, p. 9). Rather, they point out that positivist science on its own cannot easily handle the fluidity of what autism is:

> a sociological explanation can coexist quite comfortably with such diversity. But the scientists, the medical researchers advancing naturalist explanations, cannot. If you conscientiously seek a naturalist explanation for autism and the autism epidemic, you must be deeply troubled by such mess. … the logic of naturalistic explanation of necessity pushes it in the direction of deeply distrusting the reality of the autism spectrum and dissolving its unity. (2010, pp. 11–13)

This is similar to the position arrived at by Hacking (1999) in his deliberations as to whether autism can be both a “natural kind” and an “interactive kind”. The latter feature of autism refers to the way reactions to autism have a looping effect which then alters the concept of autism (illustrated in terms of the impact of Bettelheim’s early influence, and the subsequent impact of autistic self-narrative in forging a more positive autistic identity). In contrast, the “natural kind” concept allows for some persistent essential essence that is independent of context and unchanging over time.

4.2. What to take away from this confusion?

The fact that there is so little that can be said about autism *in general* that doesn’t require immediate clarification, qualification and caveats means that any answer to the question about the morality of seeking to prevent and/or cure autism is necessarily
multi-layered. The discussion so far suggests that a crude perspective on autism, either as something that is bad and should be eliminated, or as something that is good that should be celebrated, does not do justice to the complexity of human experience, of lives being lived and challenges being posed, for the autistic person, their families, and the wider society around them. We may also wonder, therefore, about the extent to which developments in the science, and explorations as to causality and treatments, are informed by these complexities.

For the purpose of my research question, the breadth of the spectrum, the fact that it is “not a monolith” (Happe, 2011), and that there is widespread disagreement about what scientific endeavour may yield, let alone what we might do with any knowledge that does emerge – all make the conceptualisation of “prevention” and “cure” challenging. Whether, in seeing autism, we see “it” (a single thing) or a collection of disparate people with disparate traits, remains a moot point, in terms of the widely differing needs, experiences and presentations of autism – including those autistic people who are intellectually able, vocal and articulate, and those with profound intellectual impairments and extremely unusual behaviours, some of which denote to the onlooker extreme distress.

The basic problem I need to address straightaway, then, is this: is it possible to explore the ethical issues around seeking cure and/or prevention, if I can’t say exactly what autism is? If Eric London is right that “We really don’t know what we’re talking about” (see above, p. 78), how can anyone say that autism should – or should not – be prevented or cured, let alone why, or how this is to be done? I could shut up shop here and now, arguing that it is not possible to take the enquiry further, because any
conclusion will depend on a questionable definition about an abstract thing whose existence is disputed.

While intellectually tempting, that would be irresponsible. Regardless of the ambiguities identified, the fact remains that in the “real world” attitudes towards autism, and towards its cure and prevention, and a tenacious drive to further these goals, exist and have significant consequences. Many hold on to the idea that there is validity and purpose in a unifying umbrella of symptoms, and as such autism persists as a condition with which people are diagnosed every day.

Autism does not have to have biological validity to be an influential category. The fact that autism singular or plural remains a working definition for categorising groups of people is incontestable. Even if autism is no more than a social construct, we should not underestimate the power of social constructs. It confers a status that can open doors for particular types of support and state funding that impact on people’s well-being and safety, as well as labelling them in a way that can be either stigmatising and excluding, or illuminating and liberating (this will be discussed in more detail in Chapters 4, 5 and 6). In other words, “autism” impacts on real lives, however it is defined and however intangible its essence may be. The power of the construct was expressed by one parent as follows: “If we tried to define a table, we’d all end up with a different definition. And yet we all know what a table is. The same with autism – we know it when we see it, even if we can’t define it.” (Stanton, 2011)

Notwithstanding the questions about whether “autism” will remain as a single entity in the future, and acknowledging all the caveats posed by several commentators, a lot
is happening in the world and to real people on the basis of decisions made and experiences of those labelled autistic and their families. Chief amongst this is the experience of having a condition that is often headlined in popular media in terms of its “incurability” and/or the tantalising potential for developing new treatments and cures.

So I will press on, not least because, having reviewed the current state of knowledge in terms of responses to autism, I have referred to several issues that have ethical implications. The questions to which the issues give rise include, in summary:

- Does the heterogeneity of autism permit a differential approach towards prevention and cure, depending on what “type” of autism is being addressed?
- In particular, is the broad contrast between autistic people who are intellectually able and those with severe learning disabilities a relevant one in terms of differentiating the goals of interventions?
- Are there integral autistic attributes and qualities – including particular virtues and strengths – that are relevant in evaluating the morality of seeking prevention and/or cure?
- Are there broader socio-cultural factors that an ethical analysis needs to consider?
- Whose perspective on autism is most relevant in determining what are ethical intervention targets?
Against this background, it is now time to explore the work that has been done so far in the field of academic ethics in tackling this array of issues. What will become apparent from the following review, however, is that as yet academic ethics has tackled very few of them. As indicated in the introduction, my hope has been to fill some of the gaps, and in pursuit of this, the next chapter will also offer a framework within which some of the key ethical issues can be further examined.
Chapter 3 The response to autism within (academic) ethics – towards building a new ethical framework

Introduction

In the previous chapter I demonstrated the breadth of ways of viewing autism, including questions about whether it is reducible to an “essence”, and in so doing started to point out the areas of ethical implication that arise from the range of perspectives. The overlap between these two endeavours is encapsulated in the following quotation from Anderson and Cushing (parents and philosophers) in their introduction to an anthology of essays in *The Philosophy of Autism*: “it is practically impossible to separate discussion of what, if anything, constitutes the ‘essence’ of autism from discussion of related normative issues.” (2013, p. 10)

They reflect that, in exploring autism’s essence, there is a danger of circularity in looking for biological markers based on presenting behaviours that have been subjected to external categorisation: “The issue of what exactly autism is is inextricably bound up with the epistemological question of how to tell that a person is autistic. When a diagnosis is made, what are the signs that justify that diagnosis? And why is it that they are the signs that justify a diagnosis of autism?” (2013, p. 4). They also stress the extent to which cognitive models of autism (chapter 2 section 1.1.5) are rooted in the philosophy of mind (2013, p. 8), suggesting once again that issues of natural science cannot be separated from philosophy.33

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33 It is a critical response to the cognitive models, the philosophy of mind and in particular the works of Simon Baron-Cohen that occupies the bulk of the essays in their anthology, and addresses the “related normative issues” to which discussing autism gives rise.
I suggested above that if it is hard enough agreeing precisely what autism is in conceptual terms, it is very hard to establish what it means in practical terms to prevent or cure autism. Given the multiplicity of biological pathways under investigation, might there be multiple candidate mechanisms through which to intervene in autism? And if so, will the ethical implications of diverse interventions be the same in each case, or will different considerations apply according to the type of intervention? Can overall quests such as “cure” and “prevention” be supported or rejected in the absence of knowing more about the specifics?

I therefore plan to do two things in this chapter. The first is to discuss the published literature around autism and ethics, and the second is to introduce a framework by which concrete scenarios can be explored in more detail.

1. **Review of literature on ethics and autism**

My first task is to review the published literature in relation to autism and academic ethics. In so doing, I will be confining myself to literature on the ethics of autism itself, rather than the much larger literature on ethical issues that are of general relevance to autism. I will be incorporating the latter, wider literature in subsequent chapters. Meanwhile, within the more focused review of this chapter, I will propose that what academic ethics has so far explored in relation to autism offers an inadequate response to many of the issues raised, being preoccupied chiefly with whether or not autistic people have moral agency and a linked exploration of their capacity for empathy. I will suggest further that these discussions do not provide

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34 For details of the literature search, please see Appendix 1.
sufficient basis on which to explore questions about the ethics of cure and/or prevention of autism, although the work that does exist on these latter issues provides some guidance as to the further questions that need to be explored.

1.1. Membership of the moral community and empathy

The nature of autism has raised the question in some people’s minds about the personhood and capacity for moral agency of autistic people.

A comparison between psychopathy and autism was offered by Jeanette Kennett (2002) in her exploration of the way both conditions carry with them a presumed absence of empathy. The reason this is such a key question is due to the importance given to empathy in conferring moral agency on people (Hume, 1948). The claim that autistic subjects have difficulties – or an absence – of social reciprocity, including empathy, might be taken to imply a claim that autistic people lack the capacity for moral agency.

Kennett stressed the ability of autistic people to recognise the interests of others as reason-giving, in contrast to the psychopath’s indifference to those interests:

Autistic people, though lacking empathy, do seem capable of deep moral concerns. They are capable, as psychopaths are not, of the subjective realization that other people’s interests are reason-giving in the same ways as one’s own, though they may have great difficulty in discerning what those interests are. (2002, p. 354)

Another way of describing this facility is offered by Goldman, who uses the term “the concern mechanism” (2006, p. 293).
Barnbaum’s approach is somewhat different (2008). Like Kennett she explores the relative compatibility of contrasting schools of moral philosophy with autism, but she questions Kennett’s assertion that autism is compatible with a Kantian approach, suggesting (2008, pp. 126–129) that the various formulations of the categorical imperative all pose problems for the person with autism, of which the third is the most obviously challenging:

> can the autistic individual treat others as ends in themselves, rather than merely as means to some other end? It is questionable whether a person whose ability to ascribe intentionality to others is compromised is able to conceive of persons as objective ends. (2008, p. 129)

She then interrogates a range of alternative models for conferring moral agency. She finds that autism – based on her exclusive emphasis on the absence of theory of mind – does not sit comfortably within any of them. She perceives absence of theory of mind to be a disqualifying criterion, and on that basis proposes that, in the event of genetic technologies becoming available that will allow parents to avoid having children with autism, parents should indeed use these technologies (2008, p. 163). This is following an exploration – and ultimate rejection – of a range of arguments that might be put forward to claim that it is morally unacceptable to use genetic technologies to prevent the birth of persons with autism – arguments based on parental autonomy, social construction of disability and comparisons with the deaf community.

Her conclusion that parents are morally obliged to avoid having an autistic child is based on “the right to an open future”, first articulated by Joel Feinberg (1980) as a
means of understanding autonomy rights that are held in trust for persons who do not yet have autonomy, but who one day will be autonomous agents.

In contrast, rather than basing their views solely on a theoretical cognitive framework of autism, Krahn and Fenton (2009) have sought to look at empathy and autism in terms of empirical evidence. Focusing on individuals with so-called high-functioning autism (HFA), Krahn and Fenton have explored the “multi-dimensional” nature of empathy, which has been defined and examined in a range of ways and which they critically examine in order to be precise about what aspect of empathy might be compromised for individuals with autism. They focus on the distinction between affective and cognitive empathetic capacity. “Affective empathy” relates to the capacity to experience a felt response to the expressions of others, while “cognitive empathy” requires the ability to appreciate what another is experiencing, inferring and attributing mental states to self and other. Cognitive empathy is the element of empathy that equates with theory of mind.

Drawing on experimental studies, Krahn and Fenton say there is evidence that the capacity for affective empathy among people with HFA is intact. Disqualifying HFAs from the moral community would then rely on cognitive empathy being a necessary condition for moral agency – a notion they then question. First, they offer examples of rule- and duty-based moral learning, which they argue are highly compatible with autism and which play a not insignificant part in all notions of moral behaviour. Second, they offer examples of the capacity within neurotypicals (NTs) to “switch off” – for example when ignoring homeless beggars on the street.
Do the relevant individuals that pass them without notice, and we include ourselves here, suffer from an empathy deficit? ... Even if such a deficit is properly ascribed (to HFAs), it is not clearly relevant to the question of whether they qualify as moral agents ... unless we would be inclined to extend the same doubts to include those described as neurologically typical who similarly ignore, if not rebut, the homeless. (2009, p. 157)

They conclude that it is not appropriate to elevate the capacity for empathy as the qualifier for moral agency. “As such, it is our hope to force an approach to moral agency that views it as graduated and layered rather than as an ‘all or nothing’ set of capacities” (2009, p. 158).

As such, they are suggesting that we should interrogate not HFAs’ capacity for moral agency but – rather – any criteria that might inadvertently exclude them.

The notion that autistic people have “zero degrees of empathy” has since been taken up by Baron-Cohen (2011), who cites brain-imaging studies that reveal abnormalities in “the parts of the brain where empathy resides” (2011, pp. 69–71). Echoing Krahn and Fenton, he sees the distinction between cognitive and affective empathy as important. He suggests that the apparently insensitive behaviour of people with autism is not intentional, and further that this absence of the cognitive element of empathy is a relevant distinction that renders autism morally different from psychopathy, where the cognitive element is intact (such that inflicting hurt may be part of the satisfaction derived).

While he holds on to a central message that empathy is of crucial significance in moral behaviour, he seeks to draw a distinction that would locate autistic people within the moral community rather than outside it. Thus, in contrast to other conditions that also display similar neurological abnormalities and likewise
experience “zero degrees” of empathy (psychopaths, narcissists and those with
borderline personality disorder), he suggests that autistic people’s lack of (cognitive)
empathy is not all negative, since it brings with it a systematising faculty. This faculty
is associated with remarkable talents and abilities to perceive patterns, such that it has
positively contributed to human, societal and cultural development (2011, p. 81).
Further, he suggests that the ability to “systematize to an extreme degree” often
generates a strict adherence to rules and laws, which actively prevents the conduct of
immoral acts (2011, p. 84). In its reference to the importance of intentionality, and its
focus on rules and laws, his interpretation is reminiscent of Kennett’s suggestion that
high-functioning autism tends towards a deontological account of moral agency.

What these perspectives share is a sense that, notwithstanding difficulties with
empathy, autistic people are not outside the moral community in the way that those
capable of deliberate acts of cruelty are. Both Krahn and Fenton and Baron-Cohen
make strong claims for the moral status of people with autism despite possible
impairments in cognitive empathy/theory of mind. As such they distance themselves
from Barnbaum’s perspective. Yet there are more radical challenges both to
Barnbaum and to the positions on empathy that Krahn and Fenton and Baron-Cohen
hold and I will outline these below.

1.1.1. Challenging the empathy theories
When making such a strong assertion about a group of people as to judge them
members of or outside the moral community, as Barnbaum does, or incapable of
(cognitive) empathy, as several do, it is, at the very least, important to ground this in a
robust account of the condition in question and good evidence. Yet as we saw above,
theory of mind has been criticised and supplemented with new models to explain some core features within the condition. Experimental psychology and developmental observation have both shown that theory of mind can be and is often acquired by people with autism, albeit at a later age than neurotypical children. Further, it is not the distinguishing feature between autistic people and NTs – as Barnbaum herself explicitly states:

“Not every person with autism lacks theory of mind, and not every person who lacks theory of mind has autism” … Some high-functioning persons with autism, including those with Asperger’s syndrome, do have a theory of mind. (Barnbaum 2008, p 64, citing Ponnet et al., 2005).

Barnbaum acknowledges that people with autism can acquire theory of mind, but they might just do it later, and to a less subtle level than the average neurotypical person. For example, in her later discussion of autistic integrity (2008, pp. 204–207), she says that many adults with autism learn how to compensate for deficits in theory of mind, and have a full and engaging life, including learning how to “recognize others in the fullest sense” (citing Frith and Happe, 1999). Barnbaum therefore rests a very controversial and uncompromising conclusion about the moral status of autistic people on an at best only partially accurate – and certainly not sufficient – account of their condition.

Those who question the emphasis on theory of mind/cognitive empathy have made a number of relevant points. First, measures of empathy are sensitive to the instruments used; for example, Rogers et al. (2007) found no evidence to indicate reduced empathy among autistic subjects, based on an empathy questionnaire. Second, it seems reasonable to question why cognitive empathy is given so much attention, if –
as the above have indicated – affective empathy is intact. Indeed, supporting the assertion of Smith (2009), data may even suggest that autistic people can have greater degrees of affective empathy than NTs: autistics showed higher levels of personal distress linked with observed acts of cruelty. This is reflected in first-person accounts, for example the following extract from a blog:

Understand I have too much empathy, I feel too much when I see others distress and pain, so I shut down sometimes. When I want to comfort [sic] you I normally don’t know how, believe I am more worried for you than you can think. (Lile, 2011)

Perhaps what is really happening here is that difficulties in social skills mask a strong capacity for affective empathy. There are sufficient examples, both in the literature and in day-to-day observations and experiences around people with autism, to justify Happe’s observation that “people with autism do care, even if they are not very good at mind-reading” (Happe, 2011). Yet it is important that we do differentiate between a skill deficit in “human sensitivity” as it relates to the ability to pick up social signals from another person in front of you, and a cognitive impairment that makes it impossible to recognise other persons as persons in general. Theory of mind difficulty affects skills/capacities in relation to the former, but this doesn’t mean it affects Goldman’s “concern mechanism” – the ability to see that other people’s interests are reason-giving.

How much does this matter in real life? If in any case – as all but Barnbaum have argued – an impaired capacity for theory of mind/cognitive empathy is not a “deal breaker” in terms of moral behaviour, nor acts of kindness, then should we put this area of discussion to bed? My response to this question is that it is important not only to reiterate the limitations of Barnbaum’s position, but also to note how symptomatic
it is of an imbalance of perspective, and one that is unconsciously biased towards the “norm”.

Echoing the concerns expressed by autistic commentators on a perceived bias in research, (see above pp. 69-73), it can be argued that the greater interest shown by NTs in cognitive empathy deficiencies, rather than affective empathy strengths, is an example of NT bias in the study of autism-autistic people, and that it serves to bolster a sense of NT superiority that is unjustified. Out of cognitive and affective empathy, which, really, is more morally important? For example, cognitive empathy can be seen as a double-edged sword if it tips over into an ability to be sycophantic, yet it seems to get unquestioning endorsement from at least some ethicists – to the extent of indicating a need for young autistic people to undergo “moral education” to enable them to become “socially skilled empathic liars” (Jaarsma, Gelhaus and Welin, 2012, p. 271); see also Chapter 6 Section 1.3).

The point that Krahn and Fenton make is that NTs, not just psychopaths, are able to mentalise yet still they lie, cheat, steal, behave cruelly. They may have a capacity to empathise, but they don’t always use it, or indeed they misuse it. Not everyone who isn’t autistic exercises their ability to empathise in such a way that it stops them from transgressions such as this, yet this does not appear to disqualify them from starting-point membership of the moral community.

Extending the point that discussions of empathy have been based too heavily on NT misunderstanding of autistics’ way of thinking and behaving, without checking on their own biases based on norms, Milton (2012) has suggested that in actuality there is
a “double empathy” problem. NTs and autistics have a mutual and shared problem of communication and understanding, rather as two people who do not speak each other’s language might have. Similarly, Chown reminds us that “lack of empathy is not a one-way street” (2013, p. 1).

Anna Stubblefield’s passionate rejection of Barnbaum’s position is revealing in this regard (2013). First of all, she covers in detail some of the points I make above (which I wrote prior to reading her chapter) concerning the limitations of basing autistic people’s moral status on theory of mind. Second, and as a result, she makes some forceful claims about the implications of Barnbaum’s conclusions:

To call into question autistic humanity is to call into question the human rights of people labeled with autism, and that is neither accurate nor morally acceptable. (2013, p. 146)

Denying moral agency and hence full personhood status to people labeled with autism on the basis of their supposed lack of empathy and moral understanding is an insidious form of blaming the victim. (2013, p. 157)

Third, Stubblefield highlights the danger of bias and double standards against autistic individuals, and the linked danger of seeing them as “other” rather than as “within” society because they constitute a minority set against an NT majority. Chown (2013) makes a similar point:

I argue that it is not just ethnic minorities and women who have had to battle against mismeasurement since autistic people face the very same issue. However, the struggle to convince society that it is guilty of mismeasuring those of us who are autistic is likely to be very much harder to win because, unlike ethnic minorities and women (and I do not underestimate the difficulties they have faced), there are only one in a hundred of us.
Referring to those NTs with poor empathy skills who nonetheless acquire positions of social power, Stubblefield says: “This indicates that what really matters in our society is people’s normality rather than their empathy skills per se, a stance we should question” (2013, p. 160).

This chimes with Milton’s analysis when, drawing on “micro-sociological analysis of autism” in order to highlight issues around social interactions involving autistic people, he challenges the “hegemonic view of what constitutes normalcy” (Milton, 2013).

And Stubblefield also says:

If neurotypicals developed their own empathy skills better, put their understanding into practice by supporting autistic people in their sensory processing and motor challenges, reconsidered their obsessions with conformity and gregariousness, and thereby presented themselves to people labeled with autism in a better light, people labeled with autism would feel comfortable and welcomed. (2013, p. 161)

Yet she continues:

As a society we practice violence against people who are neurologically atypical, and then say that there is something wrong with them because they supposedly lack the capacity to adhere to “our” high moral standards. (2013, p. 162)

The issue is not simply one of re-examining the validity by which NTs proclaim themselves superior in capacities such as empathy, and then base access to the moral community upon it. Rather, it is calling us to explore moral behaviour in areas that autistic people consider significant and in which NTs perform less well than autistics. While Baron-Cohen acknowledges this in the sense that he points to the advantages conferred by “systemising”, this does not really capture the more nuanced and
complex areas of contrasting behaviours highlighted by several first-person accounts by autistic people, where autistics are considered to be better equipped in virtues such as honesty, directness, less inclination/ability to manipulate others – as referred to in criticisms of research bias previously discussed.

1.1.2. Conclusion to this section

It is clear that concerns about a perceived bias within science are matched with concern about similar bias in the (relatively small amount of) published works on autism and ethics. On both counts, those who challenge the conventional definition and view of autistic people as a group who share a series of deficits are calling for an extension of recognition and enquiry into the realm of autistic strengths. And an examination of the qualities and strengths – as well as the impairments – linked with autism moves the ethical terrain into the realm of virtue ethics – implicitly a fuller discussion is called for around the values and attributes that are deemed necessary for personhood. This is a theme that was first identified in my outline of Timimi, Gardner and McCabe (p. 83 above), and which I will pick up later in this thesis (see Chapter 6).

A further point to make here, echoing the concerns expressed by some that autism self-representation is not representative of the whole spectrum (see above pp. 74-75), is that much of the discussion about empathy and moral status relates to able autistic people. This was the specific focus of Krahn and Fenton’s work, while the quotations from autistic commentators all reveal levels of expressive communicative function that are superior to those who, to use a shorthand, experience “Kanner’s autism”. Meanwhile, if those with severe learning disabilities fail the Sally-Anne test, this may say more about their cognitive impairments in general than about a theory of mind.
impairment specifically. I will be addressing the question of the moral status of people with cognitive impairments much later in the thesis (see Chapter 6 in particular). The key observation to note at this stage is that once again the heterogeneity of autism is in danger of confusing what we can say about autism in general, notwithstanding the quest within science and psychology to identify some core commonalities.

Meanwhile, as Barnbaum’s arguments demonstrate, any view on the moral status of autistic people has strong implications for what stance should be taken in relation to attempts to prevent and/or cure the condition. So it is time to explore what has been written about prevention and cure within the academic ethics literature.

1.2. Ethical arguments exploring the explicit goals of curing and preventing autism

There is very little peer-reviewed literature in relation to the ethics of prevention and cure with respect to autism, although there is a wealth of press coverage, as well as internet material from blogs and websites. Some of the latter will be referenced in subsequent chapters, but I will start here by referring just to the peer-reviewed and published literature that relates directly to the topic of cure and/or prevention.

1.2.1. Cure

The most recent published contribution is a chapter by Jami Anderson (2013). Echoing some of the discussion above, Anderson favours viewing autism in non-pathological terms, questioning the rightness of “normality” as a goal, and viewing
autism as a valid identity and even culture. On this basis she argues against seeking a cure. She addresses some of the concepts that I will be discussing later (particularly in Chapter 6), but the privilege of a thesis as opposed to a shorter article is that I can scrutinise some of these in greater detail. I will also be addressing additional areas of ethical significance that she does not include, such as two pillars of traditional medical ethics: beneficence and non-maleficence.

Previous to Anderson’s article, I found just one published article exploring the ethical issues around cure. Barnes and McCabe (2011) attempted not to argue in favour of or against a cure per se, but rather to explore whether there should be a choice – i.e. that cure should be available for those who would like to access it. They make an explicit distinction between the methods by which a cure is achieved, and the idea of cure itself, in an attempt to isolate whether a cure would be welcome “were one to just fall into our laps” (2011, pp. 255–256) from questions about how much effort should be put into finding a cure. They stress that they are not asking whether or not autistic people should be cured, but only whether it would be good for them to have the choice.

Thus, Barnes and McCabe stress that the concept of liberty is key in their argument; it is the advantage of the availability of a cure that exercises them primarily. This approach seems initially to be appropriate, since arguments around parental autonomy in reproductive decision-making are ubiquitous (see Chapter 4 for more on this). Likewise, there is an intuitive appeal to the idea that it is the right of an autistic person to choose what types of treatment they undergo, and to what end, and this does of course chime with ethical issues of autonomy and consent.
But Barnes and McCabe do encounter some difficulties in basing their argument around the idea of a cure just happening to be available. They start from the position that more liberty is to be preferred to less liberty, so in this sense the proposition that it is good for a choice (and therefore a cure) to be available seems to have a head start. But it is not clear whose choice is being protected and valued – parental choice (antenatally or postnatally), or the choice of someone with autism to accept the offer of a cure. At one point, on the basis that “PWA are not competent to consent to major life-altering medical procedures” (2011, p. 257), Barnes and McCabe assert that the choice is available only to legal guardians using the best interests standard. But previously and subsequently they imply that it is autistic people themselves who can or even should be the ones who exercise a choice.

A deeper difficulty in their argument is that in actuality many of their points do relate to whether or not cure itself is a “good goal”, not merely whether it should be an available opportunity to be chosen or shunned. For example, one of the counter-arguments they explore is the possibility that cure might harm the person via the trauma of adjustment or by destroying their identity. Concerning the trauma of adjustment, they feel this is outweighed by the advantages of regaining theory of mind. It seems they are moving from the advantages and disadvantages of choice, to a statement about the advantages of not being autistic.

The emphasis they give to the concept of liberty is finally superseded in a section entitled “Going beyond a presumption for liberty” (2011, p. 266). In this final section, two issues are tackled head-on. The first is membership of the moral community, and
the second is a quality of life argument. This exploration of questions beyond that of choice suggests strongly that the principle of liberty alone is not sufficient as a basis for addressing the range of issues and challenges posed by the possibility of a cure for autism. Thus, their final section starts: “There are many reasons to think that autism lowers one’s quality of life” (2011, p. 267). Finally, their last sentence suggests that it is more than the pursuit of liberty that exercises them – rather it is the existence, or prevalence, of autism itself:

We leave it to the reader to evaluate these findings and reflect on whether the world is better with or without a cure, just as one might ask: would we welcome the news that for unknown reasons the incidence of autism had dropped dramatically (or even to zero). (2011, p. 268)

The implication of this is reminiscent of the observation made by members of the neurodiversity movement that what is really at the heart of many investigations into autism is the NT desire that there should be no more people with autism – in other words that the true goal is not about making a choice available, so much as preventing autism altogether. In reflection of this, an “Autistic Genocide Clock” set for a ten-year countdown was created in response to the statement in 2005 that a prenatal test for autism would exist within ten years (NBC News, 2005).

Barnes and McCabe have done something important by trying to look systematically at the cure arguments, and have raised a number of points that are resonant for further discussion and which I return to in subsequent chapters. Although I have argued that their analysis has problems, they offer an insight into the long list of issues that are implicated in examining the quest to cure autism. These include: concern that a reduction in the autistic population might reduce the level of services and support
available to the (now fewer) autistic people; concern that if being autistic is reframed as the result of a choice, there will be less motivation to accommodate autistic people and pressure will be put on people to choose a cure; concern that it may destroy autistic culture; discussion of special talents linked to autism; questions around potential reduction in diversity; impact on families; “the perfectionist problem” of overblown and unhealthy expectations of perfection in children. I do not propose to rework their arguments now (though several will reappear later in the thesis), but rather to pause and reflect on the authors’ overall stance.

The strain in their argument arises, I believe, chiefly as a result of the precarious “magic wand” scenario in which cure is suddenly an option – rather than one that has been painstakingly and expensively pursued over many years by a significant body of scientists, clinicians and advocates. From all that I outlined in Chapter 2, it is apparent that how autism is understood, viewed and experienced, and how this has evolved, cannot be separated from historical and institutional developments rooted in real events in particular types of society. Chiefly, as I have outlined above, the quest for a cure in real life has not been predicated chiefly on a commitment to liberty and choice, but rather on a more absolute standpoint that cure is self-evidently a good thing; not only is autism not a good thing, but also it is such a bad thing that considerable effort is justified in working out what to do about it.

I demonstrated above (Chapter 2, section 1.4.1) a similar attitude underpinning scientific endeavour with a view to prevention of autism, about which the ethics literature is similarly sparse.
1.2.2. Prevention

Walsh (2010) has interrogated the proposition that it is ethical to seek to prevent autism. Confining her analysis to Asperger Syndrome (AS), with its “strange duality of autism and giftedness”, she challenges the putative obligation (associated most frequently with Harris (2000; 2001)) to avoid bringing disabled lives into the world. She observes that the “inter-causal linkage of ability and disability” (2010, p. 522) – by which AS entails capacities such as attention to detail and systemising abilities alongside the difficulties in social communication – means that choosing to prevent AS would necessarily involve a screening out of exceptional ability at the same time. If, on this basis, AS is an exempted condition from Harris’ general obligation to prevent disabled lives, Walsh then asks whether there might be other exceptions which begin to weaken the categorical nature of Harris’ position more broadly. Walsh thus uses AS as an example to illustrate some of the difficulties in the general obligation posed by Harris. She concludes that such an obligation does not exist but must rather yield to a more nuanced approach in which each case should be submitted to “morally sensitive scrutiny of its circumstances”. Variables such as the degree of impairment, its responsiveness to intervention and the costs of an alternative course of action are cited.

In discussing the morality of seeking to prevent or cure autism, she therefore suggests that there is something about autism in particular (specifically Asperger Syndrome) that makes it different from other conditions – and thereby require specific ethical analysis. And yet she further states that the issues thrown up by focusing on autism have a broader application, highlighting principles that should be applied in relation to all kinds of reproductive decision-making contexts. The question of whether autism
presents as a special case, or whether it sheds light on more generalisable principles at stake, will be taken up in the final chapters of this thesis. For now, it is my intention to explore the specific issues that pertain to autism in particular, while noting that there may be themes with broader applicability that will emerge from the investigation.

First, Walsh’s discussion is specifically in relation to Asperger Syndrome and was published prior to the changes in diagnostic criteria outlined in DSM-5. Asperger Syndrome was confined to those with average and higher-than-average IQ, so her paper did not address whether different principles may apply for those less able autistic people, including many with severe learning disability, in whom special talents are not considered to be as apparent. The possibility that different manifestations of autism may warrant contrasting ethical and practical responses is one that was implied by Sally Ozonoff (see above p. 76), and I will return to this question later. However, Walsh is making an additional, different point. In stating that she was looking at a condition that necessarily combines enhancement and deficit in one individual, Walsh was saying something that has been shown to apply across the whole spectrum. Amongst those whose IQs measure below average, and among the non-verbal, there are several high-profile examples of the talented (e.g. the artist Stephen Wiltshire and the pianist Derek Paravicini).

I will return to these questions as a matter of central importance in later chapters (particularly Chapter 6).
1.3. The essence of autism, autistic integrity and the timing of interventions

So far, I have explored what academic ethics has to say about autism with regard to membership of the moral community and empathy, and with regard to the (sparse) literature focusing specifically on prevention and cure. The literature does however raise some additional issues that contribute to the overall landscape of ethical considerations to which autism gives rise.

The first consideration relates to timing of interventions. Interestingly, despite the problems I have discussed with Barnbaum’s focus on theory of mind and moral agency, she nonetheless introduced a contrasting perspective in the case of postnatal intervention. She makes a key distinction between preventing autistic birth – which she feels is morally obligatory – and aiming to alter the autistic person (particularly adult) – which she suggests is morally problematic (2008, pp. 170–204). In this latter case she reaches a similar conclusion to that of self-advocates, though basing her conclusions entirely on the potential impact of restoration of theory of mind.

"Being “cured” of autism requires a person to undergo radical reconsideration of not only other persons, but also himself. If this is not of direct benefit to him, there is similarly no reason to expect that there are aspirational benefits to be gained from … allowing future adults with autism to be “cured”. (2008, p. 197)"

and

"Any suggestion of re-making the world of an adult with autism – an adult with his own personality, beliefs, and preferences – is a failure to recognize him as his own person. (2008, p. 198)"
This is to be distinguished from therapies that assist “some of the distressing symptoms of autism” such as sensory difficulties (2008, pp. 200 and 203). Here she is echoing the point made by Herbert and Anderson when putting forward a research agenda oriented more to ameliorating issues that autistic people themselves have identified as problematic (see above Chapter 2 pp. 42-43).

What she states clearly is that “cure” for autistic adults is unethical. Instead, “respect for a life without theory of mind, and a notion of autistic integrity, is called for” (2008, p. 204). And yet she has previously stated: “To knowingly keep theory of mind from an individual who lacks it is to deny that individual’s humanity” (2008, p. 139).

How do we reconcile this? Barnbaum’s suggestion seems to be that everything hinges on the stage in an individual’s development at which an intervention is administered. While she judges any aim for dramatic transformation of adults with autism as inappropriate, she distinguishes this firmly from interventions for children, for whom “it is possible that their view of other persons, as well as their own self-concept, is not solidified, such that the acquisition of theory of mind would not prove harmful” (2008, p. 203).

In contrast, those who criticise early intervention, such as Michelle Dawson, suggest that attempts to remove autism are a violation at any age.

Dawson’s is certainly a clearer standpoint in its practical implications than Barnbaum’s, for whom respect for “autistic integrity” should only become an

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35 See above pp. 73-74 and below Chapter 5.
overriding perspective after childhood, at some unspecified point in a person’s development. Yet despite its vagueness, this latter standpoint chimes with a parental perspective that was conveyed to me as follows:

When x was very young, I felt it was right to do all we could to address his autism. But as he’s grown older, and his personality has become more established, it’s less and less easy to separate his autism from who he is, and I wouldn’t want to take away his autism now. (K. E., 2008, pers. comm.)

If this stance is supported, is it possible then to determine at what developmental stage it becomes ethical to undergo the attitudinal shift?

Both this quotation and Barnbaum’s views lead us straight back to questions around autism’s “essence”. Is autism just a set of attributes and behaviours that are “supplementary” and not fundamental to the core individual? Or, as has been asked in the previous chapter, is there behind these behaviours a biological essence, and is this relevant? What the current discussion does is require a further question to be asked: does autism constitute an “identity essence”? And if autism is so fundamental as to be inseparable from self and identity, then at what stage does this autistic identity crystallise?

The “identity essence” issue underpins a significant contrast in people’s approach to autism, as between those who see it as integral – “If you take away my autism you take away me” (Anya Ustaszewski, quoted in Jardine (2008)) – and those who feel it is different from/inhibits the emergence of the true person: “Autism is not my son, and I would be very happy to see autism go. He is beautiful, funny, smart and that is him, not autism” (Laura, 2012).
Such a contrast in ways of viewing and “owning” autism resonates with those who equate autism rights with other forms of minority rights, versus those who view autism chiefly as a medical problem to be addressed. And this in turn takes us back to the contrasts identified in the previous chapter between the social and medical models of disability, and the related differences in what kinds of interventions are deemed appropriate to address quality of life.

I do not want to shut down these questions by offering a definitive or premature interpretation. Rather, I prefer to leave them articulated and open, and in particular I wish to highlight the significance of the “identity” question for later revisiting.

Meanwhile, it is important to take stock of some questions that the above papers generate.

1.4. Taking stock

1.4.1. Definitions and semantic clarification

I observed in Chapter 2 that if and when scientists talk about prevention and cure, there is little or no attempt made to clarify what these terms mean. Having reviewed the ethics literature, a similar picture emerges. Thus one of the most striking results of the entire literature review on ethics and autism is the extent of the mismatch between the heat surrounding the topics of cure and prevention, and the lack of analysis of what these terms actually mean, in theory or practice. Despite the normative power of such terms, there has been little attempt to pin them down.
In fact I am aware of only one attempt to define what is meant by cure or prevention, despite the frequency of the use of these terms. This exception comes from Anderson (2013) who has offered two models of cure: Therapeutic Cure (TC) and Negative Eugenics Cure (NEC).

TC equates to what others have described as treatment or interventions that address the autism in a living person: “On this account, a cure is a beneficial treatment of the patient that eliminates or ameliorates the harms of the disease, disorder or condition” (Anderson, 2013, p. 122). Anderson is therefore talking about addressing the “harms” of the condition, rather than removing the condition itself. This is at odds with a common-sense notion of cure which equates with the entire eradication of the condition from a person. But it is an important distinction which I will attend to in Chapter 5. There may turn out to be an important ethical distinction between ameliorating certain harms linked with a condition, and eliminating the entire condition.

In contrast, Anderson’s NEC model relates to situations where autism is removed from the gene pool, for example via prospective parents choosing not to have a child (as advised by genetic counsellors) or the use of reproductive technology to select against embryos at risk of autism. As such, the NEC model equates with preventing the births of autistic people via preventing the conception or implantation of embryos that might develop into autistic persons. She does not specify the possibility of treating a fetus in utero.
Anderson’s demarcations therefore embrace a pre-birth/post-birth distinction, which resembles the distinction that Barnbaum drew between antenatal prevention of autism on the one hand, and respecting autistic integrity of living autistic people on the other.

While appreciating Anderson’s attempt to clarify terms, I will not use her terminology. This is because I prefer to use “prevention” rather than NEC to cover the pre-birth case: I believe it is in greater use and has significant traction within the medical/scientific and advocacy arenas, and because it covers a scenario in which a fetus is treated (which hers does not).

In contrast, Anderson’s use of the word “cure” to cover post-birth interventions is an accurate reflection of how many people view the term. I wish, however, to distinguish this – which implies a disease model – from other post-birth interventions aimed at addressing the “harms” of the condition (as Anderson says) rather than the condition itself. I feel “cure” does not adequately reflect those interventions that are addressed at only some features of a condition. Nor is it clear whether she includes interventions that are chiefly environmental – that is, they tackle harms that are socially generated rather than located within an individual. (See Chapter 5 for further discussion.)

1.4.2. Contextual and practical clarification

The semantic vagueness of much of the literature referring to cure and prevention means in turn that there has to date been no systematic analysis of the scenarios in which we might envisage “cure” and/or “prevention” taking place, nor what the nature of the cure/prevention measures would be. Instead, for example, Barnes and McCabe focused on the availability of choice. Yet a host of questions are raised once
we start to think about specifics: when does prevention and/or cure take place? What does it involve in practice? What are the outcomes? Who decides?

The literature is largely silent, though, on what issues may be morally significant once we do take these “real life” issues into account. I believe it is important to go further into the realm of empirical possibility and concrete scenarios in order to unravel some of the moral challenges with regard to positions for and against prevention and cure. In other words, by moving away from global statements into specific scenarios, we move nearer to doing what Walsh suggests we need to do (see above p. 108) – to submit each case to “morally sensitive scrutiny of its circumstances”.

Clearly, to explore “each case” individually would be impossible within the context of this thesis. More useful, I believe, is to consider what key themes need to be borne in mind in any morally sensitive scrutiny. So my aim is, rather, to group potential scenarios according to an overarching framework – a framework within which close ethical scrutiny can take place but set against some clear underpinning themes.

2. **Introducing a framework**

In answering my research question and taking forward what has been learned from the literature reviewed, I therefore wish to move from theoretical discourse to practical possibilities in relation to preventing and curing autism. This is because, as I outlined in Chapter 2, if it is accepted that autism can only be understood and experienced within a particular understanding of both the historical and contemporary medical and social environment, then, correspondingly, attempts to prevent and cure it are likely
also to be reliant on a broader context. The ethical issues cannot be resolved in a vacuum.

There remains the challenge of deciding how to organise an array of practical possibilities in a way that contains relevant distinctions of moral content and which allows for greater precision of analysis of the different scenarios, without becoming too elaborate or unduly delineated.

The next section is my response to this challenge.

2.1. Explaining the framework

I have sought to categorise different types of intervention (aimed at prevention and/or cure) in order to address in a coherent and systematic way what are actually multiple ethical considerations based on multiple scenarios. For simplicity, I have aimed to have fewer rather than more categories, and I have aimed to focus on what I see as the most significant dimensions of potential dispute.

In so doing, I have chosen two key demarcations in classifying the different scenarios. These demarcations, I believe, reflect two key “fault lines” of debate which have been alluded to in the previous literature review. One of these, particularly within ethics, relates to timing of intervention, in particular a separation of pre-birth and post-birth interventions. Another fault line, which resonates in terms of contrasting stakeholder responses to autism, is the target for intervention. By this I mean the distinction
between focusing on an individual versus aiming to affect the wider social environment in which individuals operate.

I will say a bit more about these here, before expanding on them more fully in the following chapters.

2.1.1. Timing of intervention

It is possible that there are morally relevant distinctions between attempts to prevent and/or cure autism depending on when such an intervention takes place. I say this in reflection of what has been discussed above. For example, with regard to autistic “identity essence”, it was hinted that assertions around the morality of seeking prevention and cure may be contingent upon life stage. Further, the key text on ethics with regard to autism (Barnbaum, 2008) has made a clear distinction between what principles should govern our attitudes to preventing autism pre-birth, versus intervening once a person with autism is in the world. Anderson (2013) (see above pp. 114–115) also uses the pre-/post-birth demarcation in her distinction between Negative Eugenics Cure and Therapeutic Cure. Likewise, in the broader literature in medical ethics, considerable attention is paid to issues such as reproductive beneficence as a principle guiding parents to prevent the birth of a disabled person, in contrast to an imperative to maximise the welfare of a disabled person who exists. Adopting a pre-birth/post-birth distinction therefore chimes with the wider context in which the ethics of prevention and treatment are frequently discussed.

I will therefore discuss pre-birth interventions and post-birth interventions separately (Chapter 4 and 5 respectively).
In Chapter 4, under the overall heading of **antenatal interventions**, I will make a distinction between three types, according to the stage at which they take place:

1. Pre-conceptual intervention – environmental and individual
   (maternal/paternal);
2. Antenatal prevention involving screening and selective implantation or abortion;
3. Antenatal intervention (on fetus and/or mother) influencing fetal trajectory.

Further explanation of the (potential) moral distinctions between these three awaits Chapter 4. I will outline the issues in relation to each one that I consider to be of key ethical significance, and the questions that remain to be asked in relation to autism in particular.

In Chapter 5, under the overall heading of **postnatal interventions**, three further categories will be discussed. Here, in addition to the issue of timing, the relevant dimension of difference is the target of intervention.

### 2.1.2. Target of intervention

Given the emphasis I placed on contrasting stakeholder responses to autism in the latter half of the last century and up to the present day, I consider it vital to incorporate a societal dimension into the moral landscape in which real lives are lived and choices are made. The relevance of this second conceptualisation therefore lies in a demarcation as to purpose and target of an intervention: to change the individual by
“curing” autism or “preventing” its onset, or alternatively to help the individual cope with their autism, or alternatively again, to change the environment around the individual in order to remove some of the problems associated with being autistic. This discussion reflects the wider literature around social versus medical models of disability and the neurodiversity movement, as well as key bioethical texts that incorporate principles of justice and wider society in their analysis, all of which will be referred to below (Chapters 5 and 6).

Under the overall heading of postnatal interventions I will therefore make a distinction between three types, according to the different conceptualisations of the appropriate target:

1. Postnatal intervention altering an individual’s trajectory away from autism, including the expressed possibility of prevention, cure or recovery;
2. Postnatal intervention focused on amelioration of an individual’s difficulties (both individuals and families are targeted);
3. Postnatal intervention focused on external change – social, practice and policy responses to autism.

Further explanation and discussion of the (potential) moral distinctions between these three, and identification of unanswered questions with regard to autism specifically, will be offered in Chapter 5.
2.2. Concluding remarks

In the rest of the thesis, I therefore hope to offer new insights by offering different ways of conceptualising intervention with regard to autism that take on board both a temporal component (contrasting pre and post birth) and a medical/social model component (targeting autism vs targeting the wider environment). I am not at this stage arguing for or against any of the above positions, but merely explaining the thinking underlying my choice of categories.

I believe my framework offers a new way of categorising the literature on autism interventions. Attempts to provide an overview of autism research have been made elsewhere, and – given the size and scope of the international research effort – each requires a way of organising the range of material. Thus most of these are selective according to particular themes (for example overviews of the pharmacological literature\textsuperscript{36} and the psycho-educational literature\textsuperscript{37}), or financial sources (for example overviews of research funded by different bodies\textsuperscript{38}). My purpose is not to replicate or summarise these, nor is it my intention to arbitrate around the scientific validity or otherwise of contrasting propositions and areas of enquiry. Rather, my aim is to demarcate current and potential interventions in such a way as to highlight contrasting and/or overlapping and significant areas of ethical relevance.

The framework could also have a practical use, as illustrated in Table 1 below. In conjunction with the analysis that subsequent chapters will offer, it could enable

\begin{itemize}
\item \textsuperscript{36} E.g. Bryson, Rogers and Fombonne (2003) and des Portes, Hagerman and Hendren (2003).
\item \textsuperscript{37} E.g. Odom et al. (2010).
\item \textsuperscript{38} E.g. Charman and Clare (2004).
\end{itemize}
current scientists and practitioners to clarify what category of intervention they are pursuing in terms of the kind of ethical questions they need to address. It may also help parents and autistic individuals recognise the moral implications of the kinds of intervention they are considering.

2.2.1. Examples of the six categories of intervention

The categories of intervention are set out below in Table 1. Examples of interventions implicated in the scientific and intervention literature that relate to each episode are given. I have offered several examples in each category, but this is not a comprehensive list (over a thousand are listed on the Research Autism website).

The ordering of the examples is alphabetical (not temporal or reflecting priority).

An asterisk (*) against an example of intervention denotes future rather than current interventions (for example those hypothesised in the literature on postulated causes of autism).

No asterisk denotes current (reported and implemented at least once).

<table>
<thead>
<tr>
<th>Category of intervention</th>
<th>Example of intervention</th>
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<tbody>
<tr>
<td>1 Pre-conceptual intervention – environmental and individual (maternal/paternal)</td>
<td>* Individual (e.g. parental age of conception) * Mercury (e.g. removal of fillings in mother) * Pollution (e.g. withdrawal of implicated pesticide) Rejection of potential “carrier” egg * Traffic pollution</td>
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<tr>
<td>Category of intervention</td>
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| 2  Antenatal prevention involving screening and selective implantation or abortion      | * Abortion of at-risk fetus following testing of amniotic fluid and/or cord blood, etc.  
Embryo selection on basis of sex  
* Embryo selection on basis of genetic marker |
|                                                                                       |                                                                                                                                                               |
| 3  Antenatal intervention (on fetus and/or mother) influencing fetal trajectory          | * Fetal testosterone alteration/other endocrine-related interventions  
* Maternal diet and supplements  
* Maternal fever-prevention  
* Maternal stress-prevention  
* Pharmacological treatment of fetus |
|                                                                                       |                                                                                                                                                               |
| 4  Postnatal intervention altering an individual’s trajectory away from autism, including the expressed possibility of cure or recovery | Chelation  
Diet (e.g. multivitamins, enzymes, supplements, and restrictions, e.g. gluten and casein)  
Early intensive behavioural intervention (EIBI) (some applications)  
* Oxytocin  
Relationship Development Intervention (RDI)  
Secretin  
Son-Rise |
|                                                                                       |                                                                                                                                                               |
| 5  Postnatal intervention focused on amelioration of an individual’s difficulties (both individuals and families are targeted) | Auditory Integration Training (AIT)  
Augmentative Communication  
Cognitive Behavioural Therapy (CBT)  
EIBI (some applications)  
Occupational therapy  
Parent training  
Speech and Language Therapy (SALT) |
<table>
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<tr>
<th>Category of intervention</th>
<th>Example of intervention</th>
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<tr>
<td>Sensory Integration</td>
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<td>Social skills training</td>
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<tr>
<td>Social stories</td>
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<tr>
<td>Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) and other forms of education</td>
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</tbody>
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6 Postnatal intervention focused on external change – social, practice and policy responses to autism

* Adjustments of eligibility criteria for support and welfare entitlements (e.g. not relying on IQ cut-off)

Advocacy – individual and social

Anti-bullying campaigns

Circle of friends

* Enforcement of equality legislation / reasonable adjustments

Environmental adjustments – changes to built environment to account for sound and light sensitivities

Legislation

Neurodiversity movement initiatives – e.g. Autonomy Journal, conferences

* Radical social change

Supported employment and pro-diversity recruitment practices

Table 1: Examples of the six categories of intervention

What follows in Part 2 is an exploration of the ethical issues linked to the six categories of intervention introduced above. I will take some of the above examples
and explore them in greater depth and in so doing revisit and extend some of the themes that have been identified as relevant in Part 1. For example I will be able to offer a more in-depth analysis of what, if any, ethical implications emerge from autistic heterogeneity – in terms of personhood and possible contrasts in how lives are valued between “high-functioning” and people with autism and severe learning disabilities. I will also have more to say about autistic identity. In addition, I will be highlighting key ethical areas that, while significant, have been omitted from published literature about ethics and autism to date, particularly around beneficence and non-maleficence (the notions of harm and benefit), the potential for conflicting interests between autistic people and NTs, approaches to parenthood and how we measure or evaluate what it is to have a good life.
Part 2

Applying a framework to unpack the ethical content of contrasting types of intervention:

Exploring the six categories of intervention
Chapter 4 Prevention as antenatal intervention – preventing the birth of people with autism

Introduction

So far, I have attempted to demonstrate the breadth of ways in which autism has been interpreted and conceptualised across the contrasting domains of medical, non-medical, and ethical analysis. The heterogeneity of the condition, both in terms of behavioural manifestations and life experiences, combined with the multiple but as yet inconclusive channels of biological investigation, and the contrasting ways of interpreting autism as an “essence”, all make it hard to decipher what might be meant by attempts to prevent or cure autism in theory, let alone in practice. However, despite the fact that “autism” is an elusive entity, the goals of prevention and cure are stated frequently within the medical science literature and appear to drive much of the vast scientific research effort, without reference to any potential ethical questions linked to these goals.

I have further suggested that to date the ethical literature relating specifically to autism has not produced an adequate appraisal of the issues involved. Aside from the work of autistic advocates to highlight ethical issues in relation to research practice, the analysis of autism offered from the field of bioethics has been largely abstract and theoretical, with little attempt to cross-reference to the actuality of autistic people’s lives and experiences. I have therefore argued that, in asking questions about whether or not attempts to cure or prevent autism are justified from the perspective of bioethics, we need to be more precise than the literature has been to date about what
kinds of measures are envisaged or implied, and set these against a fuller understanding of what autism may or may not entail in real life.

Moving forward, then, my hope is to draw out the ethical questions that relate to contrasting scenarios. Given the breadth of scope of those scenarios, I have sought to introduce two organising principles by which we can cluster different interventions into groups. The organising principles I have chosen attempt to capture contrasts across two dimensions:

1. The dimension of timing – from measures that might be undertaken before a child is conceived through to measures that might be introduced once an autistic individual is living in the world (from infancy through to old age).

2. The target of intervention – from biological measures influencing the environment in which conception takes place, through measures that attempt to alter the physiology or psychology of an autistic individual, through to measures that seek to change the social and material environment in which autistic people live.

Combining these principles generated the grid outlined in the previous chapter, which proposed six categories of intervention, three pre-birth, and three post-birth.

In this chapter I will be focusing on the first three of these episodes, all of which take place antenatally and have the effect of preventing the birth of children with autism.

These are:

1. Pre-conceptual intervention – environmental and individual (maternal/paternal);
2. Antenatal prevention involving screening and selective implantation or abortion;
3. Antenatal intervention (on fetus and/or mother) influencing fetal trajectory.

Each of these three episodes represents an attempt to prevent the birth of children with autism. Each reflects an intervention implicated by published research or from actual events, and each carries the proposition that particular kinds of children are to be preferred over others. I will discuss each antenatal episode in turn, as A-1, A-2 and A-3.

1. Introduction to ethical positions on selection

In order to discuss specific scenarios in relation to autism, and to fully appreciate the range of ethical issues that are implicated, I will first set out what I hope is not a detour but rather a necessary first step: a preparatory outline of the main ethical arguments concerning antenatal selection of any kind. I feel this is important because one cannot isolate calls for autism to be prevented from an appreciation of the ethics of prevention more generally. What follows is therefore an overview of the positions that have been taken within the field of bioethical debate around reproductive selection as a whole. After that I will be ready to address the specifics of A-1, A-2 and A-3.

What follows can only be a summary of positions, all of which have elicited extensive responses in the literature and to which I cannot do full and complete justice here. What I do hope to do is demonstrate that the area is far from straightforward, which in itself provides a caution to those who may not have thought through the ethical
implications of the direction of scientific research. I will also be drawing on these broad positions when arguing the finer points in relation to autism in particular.

I will divide the analysis into polarity positions and mediation positions. Within the polarity positions I locate those who either strongly oppose or strongly favour pre-birth selection in any situation. Within the mediation positions I introduce additional principles which can be used to reach contrasting decisions in contrasting situations. The overview will also demonstrate how each standpoint, while seeming apparently distinct, is often a composite of a range of moral arguments, and thereby highlight the limitations of taking one approach in isolation.

1.1. The polarity positions: opposing vs favouring selection

1.1.1. Opposing selection

(i) Parental virtues and parental values

The first standpoint is linked with the work of Michael Sandel (2007), who has argued against any form of deliberate selection – regardless of what kind of condition is under discussion, whether to prevent disease and attributes on the one hand or to determine specific attributes on the other.

A range of justifications are incorporated in this standpoint. Part of the opposition stems from a Kantian principle of not treating people as means. Here it is held that to deliberately choose or eliminate particular attributes for one’s child is to treat that child as mere expressions of parental desires, violating not only the child’s autonomy but also – a point emphasised by Habermas (2003) – that of future generations.
Habermas’ concern that the genetic make-up of future generations may be adversely and – crucially – irrevocably affected by selection decisions taken previously is consequentialist in terms of judging an act by its results. Yet it echoes the Kantian critique of using other people as means rather than ends, and it certainly is concerned with the violation of the autonomy of others (2003).

While questioning some of Habermas’ reasoning, Michael Sandel is focused chiefly on disputing the idea that parental desires should be paramount in selection decisions – and thereby gives weight to an emphasis on parental virtues. He is concerned about what he sees as a dangerous hubris on the part of “designing parents”, who are forfeiting a crucial “openness to the unbidden” (2007, pp. 45–46). For Sandel, any kind of genetic engineering represents “the one-sided triumph of willfulness over giftedness, of dominion over reverence, of molding over beholding” (2007, p. 85). He criticises a culture of “hyperparenting”, which “represents an anxious excess of mastery and dominion that misses the sense of life as a gift” (2007, p. 61). In this way, Sandel is linking his opposition to selection to certain ideas of parental virtue and parental values – which Wilkinson terms “The Virtue of Parental Acceptance” (Wilkinson, 2010).

Sandel also emphasises the importance of solidarity with the less “gifted” (2007, pp. 85–92) and he places emphasis on the responsibility of society to adapt to individuals rather than the other way around.

If the genetic revolution erodes our appreciation for the gifted character of human powers and achievements, it will transform three key features of our moral landscape – humility, responsibility, and solidarity. (2007, p. 86)
In requiring society, rather than individuals, to do the adapting, Sandel is presenting a perspective that resembles the social model of disability (introduced in Chapter 2 above). Yet his emphasis on solidarity rests primarily on the virtues it entails in wider society rather than because of a political rights/conflict model which is commonly associated with the next position, that of the disability rights perspective.\textsuperscript{39}

(ii) Disability rights

Based on the equal value principle, the disability rights objection to selection holds that to select against disability contravenes the fundamental equality of all people.\textsuperscript{40} This position may seem to resemble Sandel’s, but its emphasis and roots are different. It is less concerned about selection in general, and primarily concerned about the proposition that disability should be a special reason for negative selection. For example, abortion laws that permit late termination in the presence/serious risk of disability are seen as inherently discriminatory. Further, it is suggested that singling out disability as a distinguishing criterion in reproductive decision-making reduces a whole person to the issue of their impairment, such that their condition “trumps everything else one could discover about the child to be” (Asch, 2000, p 237).

The disability rights objection is usually cited within a social model of disability framework, thereby highlighting the possibility that the main problems associated with a particular impairment are not inherent (as the medical model would suggest)

\textsuperscript{39} It is also distinct from an action-based model based on common interests and/or group identification. (For an in-depth study of solidarity and its several permutations see Prainsack and Buyx (2011). I will return to the issue of solidarity as an emerging concept within academic ethics in Chapter 6.)

\textsuperscript{40} The literature surrounding this is extensive but key texts for my research were Parens and Asch (2000), and Wasserman, Bickenbach and Wachbroit (2005).
but rather externally imposed through environment and oppressive social structures. “While the limitations of a disability can be difficult, it is the oppression that is most disabling about disability” (Saxton, 2000, p. 153). In the sense that this approach is rooted in ideas of justice and rights/duties, it draws on deontology primarily. However, it also incorporates additional arguments which draw on other approaches to ethics.

Parens and Asch state that there are two broad claims within the disability rights arguments. The first is that pre-birth intervention in order to avoid disability is morally wrong because it reveals dubious parental attitudes – resembling the parental virtues argument above. The second claim is the expressivist argument – that selecting against disability sends out a damagingly negative message to people who have that condition that “it is better not to exist than to have a disability” (Deborah Kaplan, quoted by Marsha Saxton (2000, p. 160)). Further, they argue that it is based on misinformation about the lives of disabled people, by overemphasising the pathological, harmful and individual-based nature of any disability, by restricting assessment of quality of life to something that is just a part – and not a defining part – of any individual, and by ignoring the wider social and political forces such as discrimination that, it is held, are the biggest influences on a disabled person’s quality of life.

The expressivist argument extends beyond the equal value principle. It contains a consequentialist strand insofar as it holds that there can be an adverse impact on the lives of all disabled people arising from the implicit message conveyed through a decision to select against disability. This is one reason why the expressivist position is
acknowledged as having significance even by those who on the whole take a very
different view on selection (see for example Harris (2007, p. 100)).

It is to this opposite perspective that I now turn.

1.1.2. Favouring selection – the ethical requirement to select

The opposite standpoint is taken by those who not only see nothing wrong with
deliberate selection, but who go further and see deliberate enhancement as morally
good, or even a moral requirement, and propose a corresponding duty to avoid
disability. This position has been taken both by John Harris (2007) and by Julian
Savulescu (2001). Advocating what he referred to as “procreative beneficence” (PB),
Savulescu said:

Couples should employ genetic tests to have the child, of the possible children they
could have, who will have the best opportunity of having the best life (subject to cost

Both Savulescu’s (original) and Harris’ (ongoing) positions are grounded in a concept
of what will be best for the child. Their perspective sits within a “liberal eugenics”
standpoint,\(^{41}\) which goes beyond holding genetic engineering to be obligatory in
relation to removing human susceptibility to debilitating and painful conditions, and
extends to a standpoint of permitting and encouraging parents to select for any range
of “neutral” qualities such as eye and hair colour. It has been questioned in terms of
what it implies about the values of the parents: “to care one way or the other about

\(^{41}\) For broader discussions on different interpretations of “eugenics”, see Buchanan et al. (2000) and
Wilkinson and Garrard (2013). I do not want to be sidetracked into an extensive exploration of
eugenics, because – as argued by Wilkinson and Garrard – so much of the heat in this area comes down
to semantic differences which are in danger of blurring the underlying moral content.
your child’s hair, eye colour or height so that you test and choose an embryo on this basis, could indicate a somewhat problematic attitude toward parenthood” (Scott, 2006, p. 167). Once again, therefore, the question of parental attitudes enters the discourse around selection.

The moral requirement to have “the best possible child” is a welfare-maximising position, where disability is assumed to run counter to this. The advancement of PB provoked a strong response and counter-response (see for example Parker (2010; 2007), Sparrow (2007), Savulescu (2007)). Critics pointed out that as originally stated, PB ignored the fact that many “advantages” are actually positional goods and that the logical consequence would be to oblige parents to choose children who will be members of the dominant groups in society. In any case, seeking advantage may be self-defeating and also paradoxical (for example, if for an individual the process of dealing with certain “weaknesses” is an essential ingredient to achieving a good life). Further, they argued that a strong concern for the interests of the child does not automatically lead to something as forceful as an obligation to maximise their well-being, given that this is a more strenuous requirement of parents than that which operates once a child is born, and moreover it ignores the possibility that other, strong, moral considerations may also be at work. Both Parker and Sparrow have pointed to the conceptual and practical problems entailed in identifying what ingredients contribute to well-being, let alone what constitutes the best life possible, and point to the profound influence of both immediate and wider context. Parker therefore modifies the maximising “best opportunity for best life” assertion into the statement that “potential parents will have an obligation to ensure, insofar as this is possible,
that any child they have has at least an ordinary chance of a desirable existence”
(Parker, 2010, p. 72).

In response to these challenges, a modified version of PB put forward by Savulescu
and Kahane (2009) appears to address some of these criticisms. The modified form
states:

If couples (or single reproducers) have decided to have a child, and selection is
possible, then they have a significant moral reason to select the child, of the possible
children they could have, whose life can be expected, in light of the relevant available
information to go best or at least not worse than any of the others. (Savulescu and
Kahane, 2009, p. 274)

This represents a substantial dilution of the original version of PB. “A significant
moral reason” is less forceful than an overriding obligation, and implies that there
may be other moral reasons that point to a different course of action. Further, the idea
that a potential life should be “best or at least not worse than any of the others” slides
together a maximising principle with a minimal threshold principle – two very
different notions of the kind of life envisaged and/or aimed for. In any case,
Savulescu and Kahane, like the critics of the original PB, acknowledge that one of the
biggest challenges of all is left open-ended by their discussion: namely, how to define
and/or identify the ingredients of a life that is good/best/no worse than others.

Despite this, they are confident enough to offer some concrete examples of types of
condition that they see as inherently reducing chances of well-being – and specify

autism:

We believe that PB instructs women to seriously consider IVF if natural reproduction
is likely to lead to a child with a condition that is expected to reduce well-being
significantly, even if that condition is not a disease. This is clearest if natural reproduction is likely to result in a child disposed to, say, clinical depression or autism. But we believe that reproducers also have strong reasons to seek to prevent even an innate tendency to negative affect, or the severe impairment in social skills associated with Asperger’s syndrome. (2009, p. 181, my italics)

They have therefore moved from stating issues of principle to commenting on particular conditions. The relationship between well-being and autism will be further discussed in Chapter 6. But here my key point is that a moral case for preventing autistic births, as stated by Savulescu and Kahane, can be built with reference to consequentialist principles of welfare maximisation. While the approach differs to that of Barnbaum, whose focus was on membership of the moral community (see Chapter 3, section 1.1 above), the conclusion is the same. This convergence of conclusions arising from contrasting philosophical approaches could serve to bolster the justification for prevention, since it could be argued that – regardless of philosophical approach – key philosophers have framed antenatal prevention of autism in strong terms as a moral obligation.

In both cases, though, I have expressed unease about the arguments that are used, chiefly because of all the considerations they omit to take into account. It would be premature to make a categorical statement about the morality of antenatal prevention of autism until these additional arguments are examined, both in terms of broad moral approaches and in terms of specific scenarios, and so it is time to press on by addressing these. Having set out the polarities of ethical positions in terms of opposing selection or requiring it, it is now time to explore additional principles that cut through the polarity, though in contrasting ways.
1.2. The mediation positions – parental autonomy and welfare balancing

1.2.1. Autonomy in reproductive choice

Autonomy in reproductive decision-making has, of course, a strong role within feminist analysis, particularly with regard to decisions around abortion. I will be addressing abortion below within A-2. For the purposes of the discussion at this point, the relevance of elevating autonomy to an overriding principle is that it provides a position through which one can sidestep pro- vs anti-selection arguments by upholding the principle that only the prospective parent has the right to choose either way, and/or is in the best position to appreciate and appraise the multiple issues that apply in her particular situation and that of her future child. It means that even if a prospective parent makes a decision that others might judge to be highly detrimental on welfare grounds, even to the extent of causing harm, the perceived welfare considerations should on the whole be subordinated to the autonomy principle.

Thus Savulescu has argued in favour of reproductive autonomy, even to the extent that it may outweigh procreative beneficence. In the context of the controversy around a deaf couple opting to have a deaf child, he felt the choice was wrong but that no one else had the right to impose a choice (not to have a disabled child) on them. In stating this, he made a strong plea for value pluralism:

I believe that, like deafness, intellectual disability is bad. But my value judgment should not be imposed on couples who must bear and rear the child. (Savulescu, 2002, p. 772)

and
Reproduction should be about having children who have the best prospects. But to discover what are the best prospects, we must give individual couples the freedom to act on their own value judgment of what constitutes a life of prospect. … It is easy to grant people the freedom to do what is agreeable to us; freedom is important only when it is the freedom for people to do what is disagreeable to others. (Savulescu, 2002, p. 772)

Savulescu extends his belief in reproductive autonomy into a positive right: he holds that couples who would like to positively select for disability should be able to seek the assistance of fertility clinics, and as such he appears to eschew any restrictive role for the state. The only limitation is one of available resources, a topic I will refer to in Chapter 6.

The attractiveness of holding autonomy as an overriding principle for prospective parents is that it appears at first glance to simplify some of the issues discussed so far. However, even here we encounter some conceptual and practical problems. The first relates to what conditions need to operate for a reproductive decision to be truly autonomous. Several commentators have pointed to the indirect coercion exerted by medical and technological power which has led to antenatal testing becoming routine, such that prospective parents are unconsciously steered into certain decisions (see for example Jennings (2000) and Shakespeare (2005)). Further, as discussed above, how well-informed are decisions if the media and medical profession are feeding prospective parents with entirely negative messages about disability; if – as disability advocates would argue – this is misinformation?

The second relates to the implications of permitting absolute autonomy. Notwithstanding Savulescu’s assertion that autonomy trumps beneficence, this is disputed when subjected to reflection on real-life practice. Parker describes a range of
situations in which competing principles can be at work (2012) notwithstanding a strong commitment to autonomy. He has therefore asserted categorically that “there are situations in which even against a broad background commitment to reproductive autonomy beneficence trumps liberty” (2010, p. 75). Similarly, Benatar has said: “Preventing the existence of those who will suffer or stand a significant risk of serious harms is a sufficiently important moral consideration to warrant some limit on a right to reproductive freedom” (Benatar, 2010, p. 102).

This leads to the second “mediating position”, in which the categorical standpoints discussed so far yield to a more flexible, context-based assessment of the relative welfare consequences of any particular choice.

1.2.2. Welfare balancing

Even if one is comfortable with a commitment to autonomy at all times, this does not provide easy answers when competing autonomies are involved. To make progress in clarifying the morality of individual decisions, one needs to go further in knowing whose autonomy one is talking about, in what context, at what stage of decision-making, how severe is the possible constraint on someone’s autonomy, and to what end. These competing autonomies may be expressed in terms either of rights or of welfare. For example one might want to explore the balance of rights of parents vs children 42 (incorporating discussions of the right to an open future – see above in Chapter 3 page 93); the rights of one sibling versus another sibling (see for example Kittay and Kittay (2000)); the rights of one generation versus subsequent generations (Habermas, 2003).

42 See David Archard (2010).
Alternatively, one might want to introduce an implicit welfare calculus, in which the relative harms and benefits that are likely to arise from any choice are examined, as they impact on the different individuals affected by the choice. For example, parental virtues would then be interpreted as relevant insofar as they impact on the resulting welfare of the child (and level of contentment of the parents). The disability rights perspective would then be framed as a way of addressing the quality of life and welfare issues that are at stake for disabled people. The procreative beneficence argument is already located in a welfare perspective, whereby the absence of disability is equated with greater chances of welfare maximisation. Only the autonomy argument appears to be self-standing, but even here it can be reframed as a device for serving the greater goal of welfare maximisation, where parental autonomy is upheld chiefly on the grounds that it is the parent who is best placed to decide on how a particular decision will turn out in welfare terms.

When it comes to specific scenarios, it is hard to avoid the assertion that some kind of consequentialist welfare-balancing thinking is a useful tool in weighing up the issues, where individual decision-making is governed at least in part through assessing the relative harms and benefits to the various stakeholders in any given scenario. Furthermore, it is this way of thinking that unites most commentators around taking seriously the expressivist argument (introduced above p. 133), which holds selection as a cause for concern if it leads to a significant welfare reduction for people living with the condition that is being selected against. I say more about the welfare-balancing process below, and in my discussion of specific scenarios, during much of this and in the following chapter.
1.3. Discussion of general ethical issues on selection

In the previous section I have briefly outlined the contrasting standpoints that have been adopted in relation to selection in reproductive choice, in an attempt to demonstrate that calls for prevention of autism – when viewed as part of a bigger debate about selection pre-birth as a whole – are full of ethical challenges. My analysis has been far from exhaustive. Given the richness and breadth of the discourse around selection, which I have merely touched upon, it is not surprising that a large body of ethical literature around reproduction brings to bear a range of perspectives, and that arguments and counter-arguments are still being worked through.

For example, I have not tackled the specific question of positive selection – where prospective parents deliberately opt for a child with a specific condition such as deafness, even though this has a rich and interesting literature in its own right (for example Wilkinson (2010), Wilkinson and Garrard (2013), Savulescu (2002), Hope and McMillan (2012)). I have also not entered the debates around enhancement, be this intellectual, physical or moral, even though there is scope for separate work exploring whether Walsh’s term the “duality of giftedness and disability” of autism might make it a condition in which positive selection and enhancement are conjoined. I am not going to attend to these significant issues here because they represent a diversion from the main question of the thesis, which focuses on

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43 But see reference to this later, p.306 (and note 80).
44 Debates about potential moral distinctions/equivalences between enhancement and therapy, and enhancement and positive selection, occupy a lot of space in the literature – see for example Resnik (2006), Buchanan et al. (2000) and Wilkinson (2010).
prevention and cure, notwithstanding that I recognise there are potential overlaps
which might warrant further exploration.

Also, I have not yet offered an account of contrasting interpretations of “harm” and
“benefit”, which have been referred to above in the context of welfare balancing.
They are concepts that appear throughout the wider literature, both explicitly and
implicitly. I will be addressing these later, in the context of specific scenarios below
and in the final chapter.

What I hope I have done is demonstrate that over and above the firm positions that
have been set out, the discussion has also led to more qualified perspectives on
whether one can be in principle for or against selection as a whole, and indeed
whether or not it is possible to grade competing principles in terms of their relative
force. Further, I have suggested that an eclectic but welfare-based consequentialist
approach sweeps up the “non-absolutist” standpoints of a range of ethical works on
selection. It captures the positions of those who do not share wholesale hostility to
selection on the one hand, nor create a wholesale obligation for “enhancement” on the
other. Qualified support for antenatal intervention to influence what kind of child is
born is a position linked with Glover (2006) and Buchanan et al. (2000), all of whom
adopt notions of welfare and harm as supremely significant yet adopt caveats,
providing illustrations of ambiguity around the concepts, and incorporating additional
moral criteria including justice.

Thus Jonathan Glover distances himself from what he calls “procreative
perfectionism” but does not eschew all applications of selection. Referring to
overcoming “the injustice of genetic disadvantage” he suggests that “where an obstacle to flourishing can be eliminated in a way that is not unreasonably burdensome, its removal is something we owe our children” (2006, p. 72). The wording here implies a mix of parental obligation, a particular take on justice and an assertion that “flourishing” (for all its ambiguities) is a legitimate goal.

Buchanan et al. say of the notion that parents should seek to produce the best children possible: “this is not a plausible ethical position” (2000, p. 161) – since typical attitudes about parental responsibilities in child-rearing do not require them to do everything within their power. On the other hand, “both justice and our obligations to prevent harm make genetic interventions to prevent disabilities not only permissible but also obligatory” (2000, p. 302). They adopt a justice perspective, and echo Feinberg by arguing in favour of promoting equality in exercising a child’s “right to an open future” – which in turn incorporates a view on the child/future adult’s autonomy.

I will argue below that all these positions have some force, but that as a mechanism for situational decision-making the welfare calculus carries the greatest power. By this I mean that when it comes to actual situations in which decisions have to be made, competing and sometimes conflicting points of principle may all be relevant and – because of this – a process of welfare balancing almost inevitably takes place.

And with this in mind, I am now ready to explore the first three categories of intervention which all relate to attempts to prevent the birth of autistic children. They will both reflect and augment the outline presented so far, by introducing actual
situations that require ethical debate. They will introduce additional concepts, for example by exploring in greater depth ideas around harm and benefit, and the complex area of identity.

2. The three categories of antenatal intervention

2.1. Pre-conceptual intervention (A-1)

I will focus within A-1 on three scenarios which together illustrate the kinds of ethical discussion that are relevant for most kinds of (or maybe all) interventions at this stage. All three “interventions” take place at an early point, before conception or creation of an embryo, i.e. there is no possible future child yet in existence.

2.1.1. Example of prevention externally imposed – removal of environmental cause (A-1(i))

This first example is based in a hypothetical world in which it has been found that people who consume non-organic food that has been cultivated using pesticide Brand X experience greater probability of having a child with autism. The possibility, as yet unproven, that certain pesticides cause autism, is referred to by Rossman and DiCicco-Bloom (2008). Preventing autism would be through banning the use of Brand X pesticide, or through Brand X’s owner company voluntary withdrawing its use.

Whereas most pre-conceptual measures (e.g. deciding what age to have a child) are private and individual, this first scenario is not only externally imposed on couples and their future children, but also affects the whole population within the area of
pesticide use, and ignores any private or personal opinions about autism that prospective parents may have.

We might also enquire whether there might be a moral distinction according to whether or not the withdrawal of the pesticide is voluntary (a decision taken by the company producing it) or whether it is enforced by statute. The ethical terrain here covers significant issues of autonomy and the role of the state with respect to public health measures generally (see for example Angus Dawson (2011)), and to selective reproduction in particular. This in turn echoes discussions in the literature in relation to liberal vs state eugenics, where different standpoints are held by several commentators (though not all) depending on whether changes in the gene pool come about as a result of a series of private decisions or are required by the state. (See p.134 note 41).

The challenge of reconciling private decision-making and more generalised consequences is an important one to which I will return repeatedly, and this area of challenge I will term “the big conundrum”.

There are further potential areas of ethical content within the pesticide scenario. What happens if, instead of the withdrawal of the pesticide being brought about by a deliberate desire to avoid autism, the pesticides are withdrawn for separate reasons, and so the result just happens to be a reduction in autism? We will see later that, for some, a key moral factor in the discourse around reproductive decision-making is the question of motive and intentionality; there are overlaps with regard to the expressivist argument about wider consequences versus local choices, and with regard to parental virtues which I discuss in Chapter 6. The issue of intentionality is implicit in the question of my thesis (the quest to prevent or cure autism), and so it is the first
possibility – of deliberately influencing the wider environment to reduce autism – that is of greater relevance at this point in the thesis.

My purpose in drawing attention to the above areas of potential debate is not to come down on one side or the other at this stage, but rather to highlight that even within this first scenario, we have to recognise that the ethical issues generate debate within bioethics. And that is before we take on board the further issue raised by contrasts in how autism is viewed.

To reiterate, this first scenario would impose a single approach towards autism on all within the area of pesticide use. There is no room for the possibility of different couples holding contrasting attitudes to autism, and factoring these in amongst a host of other considerations in their reproductive decision-making. Whether or not this is a problem, and why this depends on how autism is viewed, is illustrated if we consider two contrasting analogies.

1. In the case of thalidomide, the requirement of the drug company not only to withdraw its use during pregnancy but also to compensate the families concerned was not morally contested. If we were to view autism as a profoundly debilitating condition, then we might see this pesticide as analogously toxic. Preventing autism via removing an environmental contributor might then be considered to be an obviously good measure. The problem of removing private choice from the prospective parents would not be seen as significant.

2. If, on the other hand, the agent in question were assessed as leading not to results similar to those affecting the thalidomide children, but instead to specific personality dispositions that carry the potential for both harm and
benefit, it would be harder to achieve consensus on the right policy response. An example could be a disposition that predisposes individuals to exceptional courage bordering on the foolhardy. This character trait might contribute both to increased rates of hospitalisation and risk of death for those affected and yet also generate respect and appreciation from society, with such people contributing positively to valuable services such as fire-fighting. If an external agent increases the likelihood of such people being conceived, how would the deliberate removal of such an agent be viewed? There might be debates about the positive and negative features of such personalities, about the economic costs and benefits, and the rights of parents to choose whether or not to aim for or avoid having a child with such attributes.

Clearly, these are not absolute equivalents with autism. But they do illustrate a spectrum of views that is analogous to the contrasting approaches to autism outlined in Chapter 2. Those who see autism as a major debilitating disease might lean to the thalidomide analogy. In this case, antenatal prevention of autism would raise fewer ethical concerns than amongst those who emphasise the strengths alongside the impairments involved in autism. Those who see it primarily as “difference” rather than disability would lean towards the second analogy, with attendant disquiet about the moral justification for wholesale and arbitrary withdrawal of the pesticide for the specific reason of preventing autism.

What is clear from this first example is that even here, there are some ethical challenges over and above all the issues already discussed in Section 1 of this chapter. But things get even more complicated in the next scenarios. I will be using two
examples, both of which relate to selection in reproductive decision-making prior to conception in order to avoid the birth of an autistic child.

2.1.2. Example of prevention as private choice – avoiding versus not avoiding late parenthood (A-1(ii))

In this second example of an intervention that takes place before a child is conceived, it is the specific aim of preventing the birth of a child with autism that is being addressed. Unlike the previous example, it is an intervention that couples can choose to adopt or ignore, rather than have it imposed from outside.

I am using the example of a decision being made either (1) to avoid being “older parents” by starting a family while relatively young, or (2) to postpone parenthood, while knowing this increases the risk of having an autistic child. I choose this because the possibility has received considerable attention within the media following on from research publications (Hughes, 2012) and also because it will permit a more detailed exploration of the ideas of harm and identity referred to earlier in this chapter. As with the pesticide case, it remains at this stage hypothetical in the sense that a link between late parenthood and raised chances of having an autistic child has not yet been conclusively proved, though it remains an ongoing area of investigation.

The choice of postponing versus not postponing a pregnancy in order to prevent a child being born with a debilitating condition has received considerable attention within bioethics. It is an area that occupies a lot of space in discussions around selection, reproductive choice, and harm, and is most famously linked to the original scenarios and questions posed by Derek Parfit (1976; 1984).
Parfit discussed a hypothetical case of a woman who knows that if she conceives now while there is a rubella epidemic, her future child is at risk of having congenital rubella. She could postpone getting pregnant until the rubella epidemic has passed and thereby reduce the risk of her child being born with congenital rubella. The scenario is used to explore whether, by conceiving during the epidemic, the woman harms the child. The challenge is this: there is a sense that she has done the wrong thing, and that she should have waited and created an alternative, rubella-free child. Yet, for the particular child born, as long as her existence is better than non-existence, no harm has been done.

This, and other scenarios that pose similar issues, introduces the non-identity problem, which has been the focus of lengthy discussion in the literature. The distinction, the argument goes, is between two alternative notions of harm, one that relates directly to an actual victim, and one that is impersonal and general.

Whereas we may be able to explain impersonally why some reproductive choices are wrong, because they increase suffering in the world, we are unable to explain that wrong in … “person-affecting” terms. That is to say, although bringing somebody into existence may sometimes be wrong, it cannot be wrong, the argument goes, because of what it does to that person. (Benatar and Archard, 2010, p. 8)

So, if a harm has been done, it is not a harm to the child who has been born. It can only be seen as a harm if we have a notion of a generalised, impersonal harm – harm that is non-person-affecting.

The parallel between the rubella case and our couple is this: if, notwithstanding the greater risk of having an autistic child among older parents, the couple decide to postpone pregnancy until they are older, they actively increase the chances of bringing an autistic child into the world. If we accept, for now, that autism is an impairment of a severe nature equivalent to congenital rubella, then the question is...
whether the couple have done anything wrong, and whether they have harmed the child. If it is argued that postponing parenthood would constitute a harm, then this harm is a general harm only. It is not a person-affecting harm because the only alternative for the autistic child is not to exist at all.

For those who hold that harm is necessarily person-affecting, then the prevention of autism by means of choosing to have children early cannot be morally justified on the grounds that it prevents harm to the child. Many ethicists uphold this person-affecting idea of harm, which is adopted for example to justify positive selection for disability (see Wilkinson (2012) amongst several others).

In contrast, however, Harris has insisted that a child can be harmed, even if the alternative for that child is non-existence: “A harmed condition obtains whenever someone is in a disabling or hurtful condition even though that condition is only marginally disabling and even though it is not possible for that particular individual to avoid the condition in question” (Harris, 1998, p. 109, my italics). Similarly Kamm (2002) argues in favour of an “objective” harm-based account that is not person-affecting. That is, it does not rely on harm being something that makes a specific individual worse off than they otherwise would have been.

The Harris/Kamm position is not generally adopted. Rather, reflecting Parfit’s position, the conclusion would be that the child who is finally born has not been harmed (with rubella or autism) as long as that child’s existence is better than not having been born. Several other commentators follow Parfit and restrict their notion of harm to one that is necessarily person-affecting (see for example Glover (2006, p. 25), Bennett and Harris (2002), and Wilkinson (2010, pp. 91–95)). Wilkinson defends his position by arguing that an impersonal, broader welfare argument is in danger of
leading to a *reductio* (Parfit’s “repugnant conclusion” (Parfit, 1984, p. 381)). Taken to its logical conclusion, he says it would justify maximising world population up until the point at which one extra child would reduce total welfare – which could be a fairly minimal existence for all.

Considering all this, then, it seems that our couple’s attempt to prevent autism is morally neutral because it neither harms nor benefits the child who is born. Correspondingly, should they decide to postpone parenthood and thereby increase the chances of having an autistic child, then once again they are neither benefiting nor harming the child who is born, and as such their choice is again morally neutral.

I will be arguing below, however, that some applications of an impersonal and general, as opposed to person-affecting, welfare calculus *are* appropriate. Whether or not this is logically inconsistent, or just contextually distinct, is an area that authorities such as Buchanan et al. have referred to it as “an important unsolved problem” in this area of ethics (2000, p. 254). For others, the area is essentially one of semantics (the debate focuses on “alternative conceptions of harm and benefit” (Archard and Benatar (2010) p.9).

I therefore do not want to draw out the discussion on harm and identity indefinitely, since it is in danger of overriding other underlying issues of significance. Instead, I wish to put down a marker for some important areas that emerge from this discussion which will be pursued later in this thesis:

*Broader states of affairs vs specific situations – the big conundrum*

I have shown that there is an ongoing tension about what might be called “micro” and “macro” ethical questions in the above discussion. On the one hand we are invited to
consider general and impersonal welfare considerations (a sense of harm that is not 
person-affecting), and on the other we are invited to explore the moral content of
“local” actions as they impact on a specific individual (person-affecting harm). Hope 
and McMillan have offered a way forward and given a clear guide as to how and 
when these contrasting perspectives apply. They hold that general and impersonal
states of affairs are relevant considerations for those whose responsibility is for these
broader states – public health in the case of the medical profession (2012, p. 28). In
contrast, individual physician decisions bring to bear a different set of criteria –
“where respecting patients’ autonomy and preventing individual harm may often 
trump the maximization of a population’s health, or indeed welfare more generally”
(2012, p. 25).

Because of this, they consider that

there are at least two separate moral principles that are relevant to cases such as
embryo selection … and delaying pregnancy:

1. The moral importance of avoiding harming a person
2. The moral relevance of acting in a way that will, as far as one can foresee,
bring about the best state of affairs. (2012, p. 27)

They later develop this point, recognising that there is a question about the relative
importance of these two principles. I will have more to say about this in later
sections. I have introduced it here because it will be a recurring theme.

*Autism – the analogy challenge*

Another of the recurring questions in this thesis is what I shall term “the analogy
challenge”. In the original example (pesticide scenario, see above pp. 145-148), I
offered contrasting potential analogies with regard to autism – thalidomide versus
distinct personality qualities. I did so in order to demonstrate how sensitive to one’s
view of autism are the ethical issues at stake. The theme will recur throughout the rest of the thesis and take centre stage in Chapter 6.

The analogy issue has also been apparent in the discussion of harm and identity. Within the broader ethical literature on these topics, the issue of what kind of condition is under scrutiny is highly relevant. Several applications of the person-affecting harm principle suggest that it can only justify preventing births when non-existence might be preferable to existence; notions of harming individuals by bringing them into existence can only hold weight when the condition is so awful as to make non-existence preferable. This is why commentators frequently distinguish between Tay-Sachs and deafness as an illustration of the contrasts – one equates with an unendurable life, while the other offers up the chance of a good life. Only in the former sense is an individual harmed by being born.

By using the rubella-induced condition that I have referred to as a possible equivalence for the moral issues under scrutiny, I have been in danger of implying a view of autism that is extreme (and, some would say, offensive and inaccurate). My purpose is not to propose the rubella case as the most appropriate analogy for autism as a condition, but only to draw out the ethical points around harm and identity-affecting versus identity-altering decisions, when timing a prevention-oriented intervention in this way. What I hope I demonstrated is that even if one persists with a harsh analogy such as the effects of rubella, it is not possible to gain unanimous agreement that to postpone parenthood in a way that increases the chance of having an autistic child is wrong, nor that having children early to avoid autism is morally right – that is, if the person-affecting distinction is adopted and if the argument is made in terms of the impact on the resulting child.
Finally, before moving on to the next example, there is another possibility within the current scenario of the couple that needs to be addressed. This relates to the distinction between different-number cases and same-number cases. Once again it is Derek Parfit’s work that has proved to be so influential here.\textsuperscript{45}

The total impersonal welfare principle

Let us suppose that the couple were originally planning to have two children, but by the time they have reached their late 30s, they have had just the one child. At this point, they decide to stop trying for a second child because they are aware that the chances of having an autistic child are now greater and they are clear that they do not want to have an autistic child. In this situation, a decision deliberately to restrict family size in order to prevent autism has taken place. The decision is not merely identity-affecting as between two possible children, it is one that affects total number of children.

Taking a total-welfare argument, it can be argued that the decision to limit family size in order to prevent the birth of an autistic child leads to a reduction in total welfare relative to an alternative future with an additional, possibly autistic, child. Yet it also conveys the proposition that – for this couple – to have an autistic child as their second child is worse than having no second child at all. In terms of competing entitlements, we cannot argue in favour of the entitlement of a child that will never exist, so the parental rights carry the day. But in terms of total welfare, we are confronted with an apparent calculation and balancing challenge. We have to infer that the reduction in their welfare is considered greater through having a second,  

\textsuperscript{45} See for example McMahan’s discussion of same-number choices vs different-number choices and the impersonal comparative principle (2005, pp. 144–152).
autistic child, than any possible welfare gains that might accrue from this child’s existence.\textsuperscript{46}

One problem with the total impersonal welfare argument has been referred to above (page 151): that it leads to a \textit{reductio}: its implication is that, in order to maximize total welfare, people should keep procreating until the point at which a new member of the population would decrease total welfare, which would represent a minimal quality of life for all. A further problem with this way of thinking is that it seems to bear so little relation to the real-life motivations governing reproductive decision-making; it assigns to individual couples an obligation to be governed by the quest to maximize total welfare that, they may argue, is way beyond the scope of their immediate responsibility.

What we have here, once again, is an apparent disconnect between micro and macro ethics which features in many areas of moral philosophy. How, if and when it is right to prioritise local and immediate interests over broader, societal interests, is a well-worn area (see for example Williams (1973) and Slote (2007)). For many, the impersonal welfare argument fails to take account of morally legitimate concerns to do with attachment, proximity and obligations, and I say more about these issues in chapter 6.

For now, my interest in the total impersonal welfare principle echoes the points I have made above (pp. 152-153) concerning “the big conundrum”. The challenge for me is

\textsuperscript{46} Insofar as this decision sends out a very negative message about autism, this scenario is one that chimes with the expressivist objection to selection. According to Wilkinson, the objection can only be seen reasonably to apply in different-number cases (though he has other caveats as well – see (Wilkinson, 2010, pp. 181–184)).
this: on the one hand the total impersonal welfare principle seems, as I have suggested, to be inappropriate as a goal governing the ethics of local reproductive decisions. That is, it is not relevant as an over-arching goal for decision-making. On the other hand, I do not want to eschew its usefulness as a tool in local decision-making. This is for the following reasons:

First, I am not convinced that we can eschew the total-welfare principle merely on the grounds of a reductio. It would not be the first ethical proposition that leads to unpalatable scenarios when considered in extremis on the basis of thought experiments. The maximising principle that underpins the reproductive choice arguments stated so far is a consequentialist one, yet the alarming implications of unfettered consequentialism have been the subject of exhaustive critique elsewhere. Nevertheless, this does not lead to a wholesale abandonment of discussions based on consequentialist principles within the realm of bioethics. Instead, as argued above (pp. 142-144), it leads to qualified and context-based discourse, in which additional principles are given room (such as autonomy, parental virtues, justice, adherence to rules). This is the position taken by key commentators such as Buchanan et al., Glover and Wilkinson.

The second reason why I do not want to eschew the total impersonal welfare principle is because I believe it has empirical power when applied in some contexts and for certain purposes. By this I mean that it explains real-life decisions and plausible scenarios, particularly those around interpersonal trade-offs, in a way that reflects what Savulescu and Kahane have described as “common sense morality” (2009, p. 276) – it can provide a sense of plausibility within real-world contexts when it is

47 For example see. Scheffler (1988).
applied for particular purposes. Returning to the couple; if they agree that having a child with autism is not in any sense a harm to that child (compared with non-existence), they might still countenance the possibility that an autistic child will impact on their own lives detrimentally. For example, they may be aware of studies that report greater parental stress related to having autistic children than to typically developing children. If this is part of the thinking behind a couple deciding not to postpone pregnancy, then there is a total-welfare calculus implicit in their decision-making. Despite the addition in total welfare for the new (autistic) child, they offset this with an awareness of the potential impact on their own welfare, relative to having a (non-autistic) child sooner. Even if some might find problems with the content of these propositions – which I will address at length in Chapter 6 – I do believe that assessing impact on overall welfare or wider states of affairs (albeit within a family unit rather than for society as a whole) is a realistic approximation for the mechanism of decision-making that is used, even if they are not governed by a desire or sense of obligation to maximise impersonal welfare.

In contrast, there may be reasons that influence a couple’s choice such that notwithstanding a relatively greater chance of having an autistic child with a later pregnancy, they may feel that they will be better or more well-resourced parents if they start a family later – potential benefits that more than offset any perceived disadvantages to them of having an autistic child. In this situation, even if they view autism as a negative, they feel this is not so negative as to outweigh the benefits of having a family when they themselves feel “ready”. Once again, without wanting to comment yet on the validity of the factors they take into account, it is still the case

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48 Further discussion and citations are offered below in Chapter 6 Section 1.1.3.
that the mechanism used to make a judgement relies on “balance of welfare” considerations.

What this suggests is that the total-welfare principle can be a useful tool for conceptualising not only different-number cases but also single-number cases. Further, it may underpin the thinking in cases of “family balancing” and judgements about (the impact on) siblings. As such, it is not just a device for “macro ethics” or public health but a tool for appraising specific and local decisions. Further, this discussion reminds us once again of the range of moral principles that may be at work. To what extent are parents “allowed” to incorporate judgements as to the impact on their own lives without these implying an unethical view of the rights and obligations of parenting, for example viewing children at least in part as means to their own ends? And if it is wrong, within a Kantian framework, for the interests of siblings to influence reproductive choice – thus treating the potential new child merely as a means to their siblings’ end – does it nonetheless make a difference in terms of parental virtue that the parents are thinking about their other children’s lives, rather than just their own lives? Whose potentially competing autonomies are at stake? These are questions that the mediation positions (see above pp. 138-142) incorporate, while the underlying moral balancing that takes place is explicitly or implicitly based on a welfare principle that extends beyond the issue of whether the child in question is harmed.

Concluding remarks on antental prevention as private choice (category A-1(ii))

Returning to the question underpinning this scenario: is it morally right to avoid pregnancy after 35, in order to prevent having an autistic child? I have argued in favour of a welfare-balancing approach as a tool for weighing up different choices,
though not as a maximizing principle governing the objective of such choices. I have also suggested that the principles of welfare balancing might apply in both same-number and different-number cases, and that applying a welfare principle is a realistic approximation of the thinking that couples may adopt, scaffolding their decision with additional considerations.

For these reasons, based on the arguments so far, it is unlikely to be possible to judge in absolute terms about the ethics of avoiding older pregnancies to avoid autism. However, what is apparent is that few ethicists would justify prevention on the basis of a person-affecting argument about harm to the child, unless autism is seen as so bad as to make non-existence preferable. Crucially, there will need to be further exploration of two key factors that will influence the welfare calculation, neither of which has been addressed thoroughly yet. These are contrasting perspectives of (1) autism and its impact on welfare, and (2) the ingredients of welfare, in terms of what constitutes a good life/flourishing. While I have suggested that welfare balancing underpins the *process* of ethical decision-making, it still leaves wide open how to assess what makes up a good life/well-being/flourishing, and what impact the way autism is interpreted and experienced may have on such an assessment.

I will have a lot more to say about both these issues in Chapter 6, and the next scenario will show just how important conceptions of autism are in real-life decisions surrounding prevention of autism. While the contrasting perspectives on selection, and the moral arguments outlined above, preoccupy many commentators who focus on the principles influencing selection decisions in general rather than on autism itself, the next example will reveal a scenario that requires the way autism is viewed to take centre stage, and unlike the previous two it is not hypothetical.
2.1.3. Example of prevention externally imposed – rejection of potential “carrier”

eggs (A-1(iii))

The reader will recall that what distinguished the first and second scenarios is that the second pre-conceptual measure (i.e. deciding what age to have a child) was private and individual, whereas the first (withdrawing the pesticide) was not only externally imposed on couples and their future children, but also affected the whole population within the area of pesticide use, and removed any element of private choice. In other words, what separated the scenarios are issues of autonomy and the role of external agents with respect to selective reproduction. The third scenario is different again, because while it involves external imposition, it only impacts directly on a small group of people.

Not only is the third scenario a real-life one, but also it has been reported and debated in the public domain. In 2009, Helen Keeler was rejected as a potential egg donor by four fertility clinics in England, because one of her children has Asperger Syndrome (Keeler, 2009). As with the first two examples, no future child was yet in existence. In contrast, though, the decision to prevent – or at least reduce the chances of – an autistic child being born was made by medical professionals based on unclear criteria, and took place at a point that pre-empted any opportunity for potential recipients to exercise autonomy, and against the wishes of the potential egg donor.

It falls within the “different-number” scenario discussed above, because the decision reduced the pool of available embryos in a context where supply is insufficient to meet demand. Because of the supply shortage, the implication of the decision is clear, even if its message is starker than intended. The message is that it is better not to have
a child at all than to have an autistic child, and that it is better that fewer children are born than that a new, autistic, child is born. In Helen Keeler's words:

There is an acute shortage of altruistic egg donors; in rejecting me the message is that it is better to be childless than to have a child with AS. (2009)

It is informative at this point to revisit the discussion within disability rights about what message is being conveyed. More will be said about this below in relation to category A-2(ii) (see p. 171). For now, it suffices to point out that there are contrasting views about whether or not any message is really being sent out in an individual act of negative selection, and whether or not such a message requires intentionality on the part of the decision-maker in order for it to be discriminatory (see for example Nelson (2000), Baily (2000) and Press (2000)). Thus it may be that the clinic professionals did not privately or in principle believe that non-existence is preferable to autistic existence – and they may not have intended any particular message to be sent – but, rather, they may have been worried by potential unintended consequences, such as the instigation of wrongful life or wrongful birth legal cases.

On a strictly legal point, UK law does not cover this situation. While it is clear on selection between embryos, it is not clear in the case of rejecting offers in the case of supply shortage. It relates to situations when certain at-risk embryos “must not be preferred” – implying that more than one possible embryo is available. Thus, the Human Fertilisation and Embryology Act states:

Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop –

(a) a serious physical or mental disability
(b) a serious illness, or
(c) any other serious medical condition

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must not be preferred to those that are not known to have such an abnormality. (Great Britain, 2008, Section 14(4)(9), my italics)

Helen Keeler was not asking for her eggs to be preferred, but only to make her eggs available.

The second point takes us back to the discussions within bioethics about the relevance or not of intentionality of message. For Helen Keeler, and for several commentators about what messages are conveyed in selection, what is important is that regardless of any intention, the message is unarguable. This reflects the argument put forward by Nelson that policies and practices can have “semantic properties in a way that does not essentially refer to mental states, open or hidden, of those choosing to … institute the relevant prenatal … practices” (2000, p. 209). Yet it actually goes further than a semantic property, because it leads to an actual state of affairs: because of the desire to prevent the birth of an autistic child in this way, the clinic professionals may have brought about a situation whereby one less child will come into the world, either autistic or neurotypical.

Further, a message of rejection of the parental autonomy principle was also conveyed. Keeler argued that in rejecting her offer, the professionals were not willing to facilitate a situation in which potential recipients could be informed of the potential chances linked to the genetic predisposition of the donor’s family, and thereby make the choice for themselves:

While it could be said that prospective recipients of donor eggs would be unlikely to accept them from someone with AS in their family history, I don’t think this justifies not offering the choice. … It would be unthinkable for a doctor to tell me that I was not allowed to conceive naturally due to my family history of AS, so why is it acceptable for doctors to make this decision on behalf of those who need assistance conceiving? (2009)
This echoes discussions elsewhere about the contrast between reproductive decisions made privately, and those requiring the intervention of licensed clinics that are operating within a regulatory framework.

Even if we are persuaded by arguments in favour of tighter restrictions in the case of fertility clinics, it is possible still to question whether the decision to reject Helen Keeler’s offer was justified. Once again, we are faced with the analogy challenge, since the perspective on autism is key here. Revisiting the contrasting analogies of thalidomide and the distinct personality disposition (above pp. 147-148), Keeler would clearly uphold the latter as more appropriate:

> When my daughter struggles, she does so considerably, however when she flies, she soars. I wonder if it is either possible or desirable to breed out these extreme states from our species. (2009)

Once again, quite aside from the questions of message, intentionality of message, denial of autonomy and so on, there are significant issues that emerged in A-1 (i) and are again implicated in this scenario: the first is the analogy challenge – how to reach an accurate understanding of autism and its impact on welfare, with attendant ambiguities about the ingredients of welfare, in terms of what constitutes a good life/flourishing. The second major area of challenge that Helen Keeler’s case highlights is the disconnect between local decisions and broader consequences. Beyond the expressivist argument about the negative message that this instance of preventing autism conveyed, it actually impacted on a concrete state of affairs, restricting the number of possible children who might be born. While the clinicians in question may not have intended this, it nonetheless was a consequence of their decision. This is a prime example of what I described above as “the big conundrum”.

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It is beginning to seem as if, notwithstanding the contrasts of scenario in all these instances of pre-conceptual prevention, there are some themes that they share. It is time to see whether or not they are the same themes that underpin the ethics around the next two categories of antenatal intervention, A-2 and A-3.

2.2. Antenatal prevention involving screening and selective implantation or abortion (A-2)

In the previous section I discussed measures to prevent autism at a pre-conceptual stage. In contrast, this current section refers to interventions that take place when possible future people exist, and a choice needs to be made about whether they go on to be born. An attempt to prevent the birth of an autistic child in these circumstances would bring to an end the chances of the life of a particular existing entity continuing, through pregnancy, to being born. Within A-2, I am thinking of two situations: first, where several embryos have been created as a result of IVF, but where only one is implanted and the others are rejected; and second, where a fetus already exists in utero. In the first case, a decision to reject embryos at risk of autism (as a result of sex selection or pre-implantation genetic diagnosis (PGD)) is implied. In the second case, rejection of the fetus through abortion is implied.

The reason that A-2 is conceptually distinct from A-1 is therefore the existence of a potential child. This conceptual distinction leads to an equivalent moral distinction among many commentators. For example, even those broadly opposed to selection such as Sandel and disability rights advocates are rarely exercised about general health promotion measures that are aimed at preventing the likelihood of any future
entity being disabled. The disquiet only sets in once the choice becomes selection between specific entities (embryos and fetuses) on the grounds of contrasting attributes of those entities. The key issue for interventions within A-2 is thus the stage at which they take place – that is, once a potential future entity exists.

Selection against autism at this pre-birth stage in the development of a potential child is not currently available – except, indirectly, on sex grounds, which will be discussed. There are however some candidate scenarios based on current practice and research, which between them offer examples of the ethical issues that need to be addressed at this pre-birth, but already-existent, stage. The scenarios I will cover are selective implanation (A-2(i)) and abortion of at-risk fetuses (A-2(ii)).

**Examples of selective implanation (A-2(i))**

Much of the impetus for ethical exploration around how reproductive technology should be used in selection has come from the onset of pre-implantation genetic diagnosis (PGD). If PGD of potential autism were to become a practical possibility, then the ethical issues that flow from this reflect the discussion of the varied standpoints on selection discussed in Section 1 above, and do not need to be repeated at length here. What I do want to do in this section is point out the ways in which the issues are being played out with respect to autism in particular.

Unlike some conditions in which a single gene provides total predictability of a condition, autism – as indicated in Chapter 2 – is likely to be affected by multiple candidate genes. Despite enormous endeavour, none of this research has yet led to the identification of specific markers. Nonetheless, some commentators and researchers remain bullish about the prospects, both of empirical progress in pinning down
biological markers and about the justification of using these as active prevention measures.\textsuperscript{49} Further, if research does start to narrow down the candidates, it may be possible for selection decisions to be based on relative probabilities – rather than certainty – of contrasting embryos developing autism, based on clusters of candidate genes.

The idea that a “blunt instrument” that leads to selection decisions on the basis of minimal specificity might be introduced, and that this instrument would use probabilities rather than certainties, has already been tested. The device of selecting against all male embryos, because autism occurs four times more often in boys than girls, is already a reality in some parts of the world though not currently in the UK.

In the UK, on the basis of a postulated higher risk of autism amongst boys, an application was made in 2006 to allow implantation only of female embryos for couples undergoing IVF who already had two autistic children. Joy Delhanty, who headed the application, was quoted as saying that couples would be unlikely to want to undergo treatment unless autism had already “inflicted severe suffering on the family”.\textsuperscript{50} Whether intended or not, what is apparent is that the reported arguments put forward in relation to this scenario were built on three key propositions:

\textit{(1) Parental reproductive autonomy}

It was felt appropriate to translate parents’ desire for a neurotypical child into active procedures to facilitate the birth of a child whose chances of being autistic were reduced. This is active respect for parental autonomy – moving to a positive

\textsuperscript{49} For example, Richard Alleyne (2010).
\textsuperscript{50} See Feinstein (2010, p. 271).
obligation to devote health resources to enable preferences to be enacted. However, it is not an unqualified endorsement of parental autonomy. Of note is the implication that there is a threshold (third child, following two autistic children) at which the claims of parental reproductive autonomy “kick in”.

(2) Equation of autism and suffering

Joy Delhanty’s suggestion that parents would be unlikely to seek sex selection unless autism had already inflicted severe suffering on the family does not specify whether such suffering is a whole-family experience, or whether it relates chiefly to the parents, and nor does it speculate on what factors might be contributing to such suffering. For example, is the suffering caused because of a sense of shame and stigma, or is it caused because the family have not been able to access support from external sources? The possibility that there may be different reasons for such “suffering”, and that some reasons are more “reasonable” or ethically problematic than others, is discussed in Chapter 6 in relation to parental virtues and wider social support.

The significance attributed to an equation between autism and welfare was made explicit when a similar application was discussed by the Human Fertilisation and Embryology Authority (HFEA) in January 2014. Here, the discussions specifically contrasted the impact of Asperger Syndrome with “Autism Spectrum Disorder (ASD) (Classic)”, where the latter could lead to a very difficult quality of life for those with the condition, “due to their complete reliance on other people to perform day to day actions for them and their inability to communicate effectively with their family, peers and the wider society” (HFEA, 2014, Item 6, Discussion point no. 10). While endorsing the seriousness of the condition as described, the committee rejected the
application because the use of sex selection would only “possibly” reduce the risk of having another autistic child given the absence of a specific conclusive test.

(3) Family balancing

While arguments about family balancing are generally located within discussions of gender balance (see for example Wilkinson (2010)), the principle within this scenario is that it is permissible to use selection to balance ability/disability or neurodiversity within a family. This is interesting insofar as – if it is a direct equivalent – it would echo discussions as to whether family balancing is discriminatory or not. In other words, there is a case to be made that family balancing need not convey a negative attitude to autism, but rather a celebration of variety and diversity. Against this, the rationale behind the applications was clearly nothing to do with family balancing, with the emphasis on the implied burden of autism itself.

Discussion of selective implantation (A-2(i))

None of the above sits comfortably with a strong disability rights perspective, and it ignores the question as to whether the impact on families could be ameliorated substantially through improved societal support and acceptance of autism.

Discussions around the second, 2014 application sidestepped issues of heterogeneity by specifically separating ASDs into AS and ASD (Classic), even though these distinctions no longer reflect official diagnostic criteria. The separation of “types” of autism was also articulated as a strong predictor of quality of life, and there was no hint that ASD (Classic) might entail strengths and benefits for the individual or for those around them.
The implication that there is a division between types of autism that correlates levels of intellectual functioning with quality of life was referred to previously, and it is made extremely explicit in the committee’s records. There is a strong suggestion that prevention of autism-with-intellectual-disability is considered, at least by some, to be ethically distinct from prevention of autism-without-intellectual-ability. I have referred above to this suggestion, which is often made (for example see above p. 37, p. 88 and p. 109). How this sense of demarcation stands up to further scrutiny is further explored in Chapter 6.

Meanwhile, the Reproductive Technology Council (RTC) of Western Australia (2013) has approved pre-implantation sex selection in a family “at high risk” of having a child with autism and seemingly without the caveats of already having two autistic children. The RTC only approves applications for PGD of “serious genetic conditions”, and their inclusion of autism within this category does not distinguish between “types” of autism in the way the HFEA committee tried to do. The decision led to a series of web-based articles and comments (Brice, 2013; Symons, 2013), with one commentator favouring measures to prevent birth on these grounds:

“It is without question that a person’s life would be improved if they were free from intellectual disability, if they had the facility to communicate more freely, and if they had the capacity to live independently.” 51

This argument contains a conceptual confusion between measures to improve the life of an existing person, and measures aimed at preventing the birth of certain types of people. It conflates the conceptual distinction discussed above (in A-1 pp. 150-152) between identity-altering and identity-preserving interventions (improving an existing person’s life is identity preserving, while selection decisions are identity altering). It

51 Andrew Whitehouse, quoted in Symons (2103).
is this distinction that provides a conceptual demarcation between A-2 and A-3, which I will discuss later. But, to reiterate, examples that fall within the current category, A-2, are identity altering, and so arguments about improving an existing person’s life do not belong here. This may seem like a nit-picking point, but I include it because I believe it is indicative of the danger of category errors when arguments about prevention are made in broad terms. I feel this bolsters my desire for greater specificity about scenarios, in order to unpack the many, distinct, issues of ethical significance.

2.2.2. Example of abortion of at-risk fetuses (A-2(ii))

The previous examples related to selection/rejection of embryos without affecting the total number of people born. In contrast, termination ends the possibility of a particular potential life but does not replace that with an alternative potential life. However, and in any case, there is a more substantial distinction between A-2(i) and A-2(ii) than the issue of same-/different-number cases. This is the stage of development at which prevention takes place. In A-2(ii) a fetus now exists and is developing in utero.

There is a large body of literature in relation to the moral status of fetuses, and to whether, how and why an entity’s moral status might be greater post-implantation than pre-implantation. Similarly, there is a wealth of discussion around the stage of gestation at which a fetus acquires legal protection from termination, and the onset of personhood. In essence, the debate interrogates the proposition voiced by Steinbock,

52 Against this, it might be argued that termination, when it is followed by a further pregnancy and birth, does not constitute a different-number scenario in the longer run. (See McMahan (2005, pp. 144–146) for more discussion of this.)
that the claim of moral status of a fetus “grows stronger as the fetus grows and develops” (2000, p. 118). I do not intend to rehearse these ethical issues (following Wilkinson (2010, pp. 13–15), who also puts them to one side in his detailed exploration of the ethics of selection). They have been extensively covered elsewhere, and in any case the question asked by this thesis does not rely on arguments about the status of the embryo or fetus.

It is however worth noting two issues of relevance to this thesis. The first is that if there is a moral distinction between selection pre implantation and post implantation, then there is a corresponding moral distinction in terms of the means and timing of antenatal prevention of autism. Further, for those who oppose all abortion on ethical grounds, then aiming to prevent autism through selective termination is not ethical, even though general statements in favour of preventing autism, unless caveated, are not sensitive to such moral distinctions.

The second issue is the position held by many disability rights advocates. In contrast to general objections to all abortion, the disability rights perspective is critical specifically of those abortions that are carried out on the grounds of potential disability – and, in the UK, of the fact that later terminations are legally permitted on such grounds. Some of these reasons were touched upon above (Section 1.1.1(ii) p 132). Concerning the expressivist argument, there has been an important debate about whether a private decision to abort on grounds of potential disability says anything discriminatory in general. Thus Kittay and Kittay, citing Rayna Rapp’s studies, suggest that few people choose abortion because “they believe that disabled persons shouldn’t have the opportunity to live a life” (2000, p. 185). And Bailey (2000) distinguishes a private preference to avoid the additional struggles involved in having
a disabled child from a broader attitude of discrimination and stigma. In response, Press argues that other reasons for abortion (e.g. family size, personal circumstances) are “not an intrinsic attribute of that child, but rather of that pregnancy … But a disability is intrinsic to the child” (Press, 2000, p. 215). And Asch agrees that there are qualitatively different reasons for abortion in the case of disability: usually the pregnancy is wanted, such that abortion is only sought when there is news of potential disability; the condition thus “trumps everything else one could discover about the child-to-be” (2000, p. 237). It is for these reasons, it is argued, that abortion on the grounds of disability is ethically different from other abortions.

For some, the relevant deciding issue is one of severity and seriousness of the condition in question, so that while an objection may be made to terminate on grounds of most or all disability, it would not be made in relation to the prospect of a painful and life-shortening illness. But concern has been expressed about the prospect of “severity creep”: “It is … foreseeable that ‘severity creep’ will take place over time, and that more and more conditions will be labelled as severe” (Holm, 1998).

Similarly Parker (2012) refers to these questions in relation to the dilemmas faced by genetics professionals when people request PGD for conditions that are “minor”:

> the close coupling of prenatal testing and termination of pregnancy has the potential … to generate ethical problems for genetics professionals because it has the effect of turning decisions about access to prenatal testing into questions about access to abortion and hence – at least sometimes – into questions about “seriousness”. (Parker, 2012, p. 79)

The issue of seriousness takes us back to the analogy challenge referred to previously (p. 153). We saw that the Western Australia RTC decision referred to on p. 170 reflected a view that autism aligns with other “serious” conditions, and yet, as we saw in Chapter 2, the heterogeneity of autism does not make this conflation
straightforward. Further, as Parker has indicated, “seriousness cannot simply be read off from the biological facts” since “the question of what is ‘minor’ or ‘serious’ in any particular case must inevitably depend to at least some degree upon the patient’s beliefs, values and experiences” (2012, p. 75).

To date, the scientific community has tended to sidestep the issue of whether or not certain types of investigation will uncover ways of preventing autism through screening and abortion. While Baron-Cohen has called for an ethical debate, and further stated his personal belief that abortion on such grounds would be unethical, this does not appear to have curtailed his or others’ scientific investigations in areas that might one day require such decisions to be made.53

To some degree this may be because they believe that scientific discovery could open up alternative ways of addressing autism that do not require abortion (Baron-Cohen, 2012, pers. comm.). Although screening and abortion are often perceived as inextricably linked (see for example Parker (2012, Chapter 4)), termination is not an inevitable outcome, even if the quest to prevent autism is not questioned. Such a possibility is encountered in the third episode of pre-birth intervention.

2.3. Antenatal prevention influencing fetal trajectory (A-3)

In this section, I will be exploring situations where medical intervention is carried out to influence the development of an existing fetus who will then go to term. The distinction between this episode and its predecessors is that it takes place post-implantation and does not require a decision to reject an embryo or a fetus. Neither does it govern decisions and choices made pre-conceptually, and nor does it affect the

53 See for example Wardrop (2009)
number of people who are born. There is a physical continuity in the fetus pre and post intervention, which makes this an “identity-preserving” intervention, whereas the other interventions to date have been “identity altering”. A-3 offers an alternative method of prevention for those who shun termination, but it also requires an active intervention affecting an existing fetus (which pre-implantation interventions do not).

The question of whether or not there is a morally relevant distinction between identity-altering and identity-preserving interventions has been explored above when discussing different concepts of harm (see above pp. 151-153). It is also explored in detail by Hope and McMillan in terms of the contrast between (1) intervening to alter a fetus in order to achieve a particular kind of child, and (2) honouring parental autonomy in choices around positive selection in favour of a particular kind of child. Using the example of attempts to create a deaf child, Hope and McMillan argue that identity-preserving “harm” is not morally permissible (for example, administering a drug to the fetus to change it from a potentially hearing child to a non-hearing child), whereas identity-altering intervention (positive selection of an embryo that will never be potentially hearing) should on the whole be upheld, even though both interventions lead to the same outcome – the birth of a deaf child (2012).

The idea that identity-preserving interventions are morally distinct also holds sway from a disability rights perspective. Disability rights arguments usually acknowledge as relevant the distinction between (a) actions preventing the likelihood of any potential child being disabled, and (b) actions that prevent the birth of entities (embryos, then fetuses) who have already been created and who are on a trajectory to becoming born. Thus, within (a), measures such as putting iodine in salt to prevent learning disability, or enriching flour with folic acid to reduce the incidence of neural
tube disorders are “not viewed as intrinsically morally problematic” (Steinbock, 2000, p. 116).

What relevance might this have to the current scenario in aiming to prevent autism? Whether or not intervention on an existing fetus to prevent autism is regarded as beneficial or discriminatory, my question is whether greater moral weight, and additional moral considerations, should be given to an intervention on an existing fetus who will go to term, compared with the previous identity-altering categories.

At an intuitive level, there is a sense that much depends on what is involved in such an intervention, affecting as it does an existing fetus.

At this point it is helpful to consider, then, what these kinds of intervention might look like. I will do this by extrapolating from the medical/scientific literature about potential causes of autism and, hence, the interventions implicated where these relate to the point at which the fetus is developing in utero.

**Current research for intervention affecting a fetus**

Autism’s potential link with fetal development has been the focus of considerable research, some of which has had extensive news coverage. Not all ideas have equal respectability within the scientific community, but I will mention just a few to give a flavour of recent findings. Maternal stress, and its impact on the level of proteins in the placenta and ultimately on fetal brain development, is one candidate theory (Ronald, Pennell and Whitehouse (2011)). The structure of the placenta has also come under the spotlight (Walker et al., 2013). Finally, several research groups are proposing that maternal antibodies damage the brain of developing fetuses such that
they go on to develop autism (for example Brimberg et al. (2013), Wood (2013) and see DeWeerdt (2013)).

The findings have ethical implications if, on the back of identifying causal links, interventions are then developed to alter fetal trajectory. My point is that some interventions will be more ethically problematic than others. I will give two contrasting examples to draw out some of the ethical issues that are relevant.

2.3.1. Example of routine health promotion measures (A-3(i))

Under this heading sit the types of intervention that a pregnant woman would be advised to take as “common sense” based on existing knowledge of sound antenatal and general health promotion. Here I am thinking of the implications of findings such as a postulated link with autism and mothers taking insufficient folic acid in pregnancy (Schmidt et al., 2013), mothers experiencing uncontrolled fevers during pregnancy (Hsu, 2012) and maternal stress (as above). Reducing the chances of having a child with autism in these cases would seem to go hand in hand with sensible and evidence-based practice to deliver beneficial outcomes in general ways – good nutritional status, fever management and stress avoidance. The possibility that they may also reduce the chances of having an autistic child is in a sense a secondary issue. This echoes a distinction made above between terminations due to a desire not to have any child, versus terminations due to a desire to avoid that particular child. It also has echoes of the pesticide example in A-1(i) insofar as one might interpret differently an intervention that just happened to reduce the prevalence of autism from one that was deliberately aimed to do the same thing (see p. 146).
There is an extensive discussion within bioethics about whether acts and omissions can be morally equivalent even if they lead to the same outcome, and about the potential significance of intentionality. A key text on this is James Rachels’ discussion of end-of-life decisions (1975). Reflecting this theme, questions are asked as to whether mothers who fail to take health-promoting measures should invoke the same kind of disapproval as those who more deliberately damage their fetuses (Parfit, 1976). Does careless pregnancy, in which inadequate attention is paid to nutrition, occupy the same moral ground as acts of deliberate harm? Conversely, therefore, do general health-promotion measures that just happen to reduce the chances of having an autistic child occupy the same moral ground as those same measures taken solely to prevent having an autistic child?

2.3.2. Example of targeted medical intervention (A-3(ii))

In contrast to the above, some interventions aimed at altering fetal trajectory would most likely take place only after screening, where the screening is a deliberate intervention to identify particular conditions. I am therefore contemplating the possibility that, through the use of screening when the woman is pregnant, factors that indicate potential autism are identified and remedial measures, e.g. surgery, drug treatments, gene therapy, are then introduced. Thus, Zimmerman and Connors (2014) suggest that current knowledge does “raise the possibility of preventing the autistic phenotype in offspring by predelivery pharmacological treatment” (2014, p. 620). Another example would be an antenatal intervention that would involve deliberate and possibly invasive measures to alter the hormonal balance in the fetus or amniotic fluid (Auyeung and Baron-Cohen, 2008) or some kind of immunomodulatory intervention to address a postulated link between maternal inflammatory state and
fetal neural development (and postnatal behaviour) (Morris et al. (2008); Patterson et al. (2008)). These measures remain hypothetical but are illustrative of potential types of intervention that ongoing medical research may in due course lead to. They are already referred to as potential treatments by Patterson et al. (2008, p. 301) – albeit as “a … difficult challenge” – and by Morris et al. (2008, p. 324).

At first glance, these measures are different both in goal and in their nature from those in example A-3(i) for three reasons: they are targeted entirely at preventing autism rather than at broader health promotion; they imply some kind of invasive medical procedure; and their side-effects and consequences are arguably more risky and/or less certain.

How then are such measures to be evaluated from a moral perspective?

**Benefits and harms**

The first question is whether or not the outcome – moving the fetal trajectory away from autism – is beneficial. If the intervention does succeed in altering a fetus’ trajectory such that the child who is born does not go on to develop autism, how beneficial or important a change is this for the individual concerned? Secondly, how beneficial or important is it for those around the individual – or indeed wider society? The answer to these questions, once again, depends on where one sits in relation to autism – the analogy challenge (see above p. 153) – and one’s views on the ingredients of welfare, or the good life.

Linked to this, consideration will need to be paid to whether or not the potential disadvantages of the intervention will outweigh the potential benefits. There may be discomfort in the procedure, there may be known and unknown side-effects, and
hence there may be significant elements of uncertainty and risk. As an apocryphal example of such adverse consequences, one need look no further than the way Auyeung and Baron-Cohen’s early and, at the time, unreplicated findings about fetal testosterone led to unregulated hormonal intervention against autistic children which – it has been argued – was tantamount to chemical castration (Research Autism, 2014b; Fitzpatrick, 2009a). At a macro level, as discussed above, there is a powerful message that such interventions convey. If the interventions are invasive and uncomfortable and even dangerous, but still go ahead, what message does this convey to autistic people about how their condition is viewed, and the lengths to which people will go to prevent it? This expressivist concern reflects the disability rights perspective discussed previously, and offers an example of a theme I have introduced earlier in the chapter – the big conundrum – in which micro choices may have unintended macro consequences.

*Identity and autonomy*

The references so far in this chapter have all been concerned with numerical identity. Thus, measures that affect an existing embryo or fetus are identity preserving, while the previous examples were identity altering, but all were in relation to numerical identity. In contrast, at stage A-3, it is narrative/qualitative identity and not numerical identity that is the significant concept. Narrative identity, quoting Hope and McMillan, is “the kind of identity to which we might be referring when we ask a question like: Whom am I?” (Hope and McMillan, 2012).

This idea of identity is closely linked with notions of autonomy. While parental autonomy is given considerable support in much of the ethics literature around selection, even if qualified in some ethicists’ views by other concerns including
beneficence, A-3 covers a new scenario. Here we are talking about measures that will affect the nature of the person who will be born. I described this in Chapter 3 in terms of “identity essence” – something that is powerfully expressed by individuals who view autism as integral to their personal identity. Those who perceive the neurotypical (NT) perspective as one of hegemony will be profoundly concerned by the idea of NT-driven tampering with potentially autistic fetuses. We may speculate as to the concerns that would be expressed if there were antenatal interventions to alter the potential sexual orientation of a fetus – where issues of individual autonomy move into the wider domain of minority-group status, including social and cultural identity, group solidarity and collective interests.

In contrast, we are reminded that Barnbaum, following Joel Feinberg’s view about the importance for children of an “open future“, has used autonomy as the basis of her assertion that autistic births should be prevented (see p. 93). For Barnbaum, autism is seen as a condition that restricts opportunities for future autonomy and limits the range of choices and lifestyles available. To promote a person’s long-term autonomy, according to this view, an intervention that affects fetal trajectory would be driven by a morally legitimate goal. This also seems to be the tacit position of those in the medical and scientific community who justify research on the grounds that it may lead to measures for prevention, although in this latter case the conceptual framework is more about suffering and damage than about rights and opportunities.

If questions are raised in terms of the ethics of tampering with someone’s “narrative” identity before they have a chance to make choices for themselves, then this is because clearly parental autonomy does not signify carte blanche to intervene on the fetus in any way the parent chooses. Even the pro-intervention stances will need to be
mindful of the nature of the intervention, its risks and impact, set against the potential benefit of any outcome. The fact that there may be risks in interventions cannot be overlooked:

we should recognize our limitations as designers of life. The charge is one of hubris, but it is rooted in what we owe our children.

The hubris is partly a matter of being too dismissive of risks. In the case of gene therapy, the technology may be less safe than we suppose. A disaster with this technology may do irreversible damage affecting someone’s whole life.

There is also the charge of being oblivious of another kind of mistake. In human life there is a recurring theme of over-confident reconstruction. (Glover, 2006, pp. 63–64)

Although in the above extract Jonathan Glover is speaking primarily of genetic intervention at an earlier stage of reproductive choice, the sentiments apply strongly to interventions within A-3. In the above extract he suggests that the identity and autonomy question is also closely linked with questions around parental virtues (and indeed virtues of medical/clinical interventionists). This is reminiscent of Sandel’s concerns about “one-sided triumph of willfulness over giftedness” and also Habermas’ concerns about the impact of reproductive selection on future generations (see above pp. 130–132).

3. **Concluding remarks to Chapter 4**

So far the chapter has adopted a broad concept of autism as encompassing all manifestations – regardless of intellectual ability, challenging behaviour, communication and independent functioning. Yet as was indicated in previous chapters, the monolithic nature of autism is under increasing challenge.

The chapter has also tended to run with the negative assertions and assumptions made about the impact of autism on the self and others, but this will be interrogated in much
more depth when I tackle the analogy challenge head-on (see below Chapter 6). Even with a negative view on autism, though, it is clear that the ethical case for antenatal prevention is neither self-evident nor straightforwardly argued. There are layers of ethical complexity surrounding all three categories of antenatal intervention.

I hope I am at the very least building the blocks of an argument that says this: to take as self-evident the proposition that preventing autism is morally right – at least at a pre-birth stage – is in danger of extreme over-simplification. Indeed, the complexities extend way beyond “traditional” moral concerns around termination and the status of the fetus – probably the first area that springs to mind in relation to antenatal intervention. I have put down some markers about what the unresolved areas of complexity are: autonomy and choice, parental virtues and values, beneficence and justice, how we judge a good life, and the relationship between “micro” decisions and “macro” states of affairs with particular reference to the expressivist argument. And that is even before we address one of my central issues – the analogy challenge.

Many of these themes will flow through into the next stage of my enquiry, when I explore interventions that take place once an autistic (or potentially autistic) person has been born. And they will be further addressed in greater detail in Chapter 6.
Chapter 5 Post-birth interventions with regard to autism

Introduction

At the end of Chapter 3 I introduced six categories of intervention with regard to autism. The demarcations between the categories reflected what I suggested were the key fault lines of ethical significance. In Chapter 4 I addressed the first three of these, outlining a series of scenarios in which interventions to prevent autism might take place before a child is born. Concerning these first three (A1–3), it was shown that different ethical considerations come into play depending upon the stage at which an intervention is undertaken – pre-conceptually, pre implantation and during fetal development. I demonstrated that judgements about the moral legitimacy of such interventions are complex and bring into play a host of contrasting standpoints within ethical discourse. These contrasting standpoints alone are sufficient basis on which to reach one conclusion:

The quest for antenatal prevention of autism is not unequivocally justified on moral grounds. This is partly because the whole domain of pre-birth selection and intervention is a complex moral landscape, such that justifying the search for antenatal prevention relies on particular stances on certain key moral issues, all of which can be criticised and around which there is no consensus in the bioethical community.

I further argued that – regardless of what moral position one takes on some important issues such as abortion, autonomy, welfare-maximising approaches and contrasting
notions of harm – there can be no resolution to the issue of whether such intervention is justified with respect to autism, in the absence of a clearer and broader conception of what autism is and what it entails, for the individual and for those around them. This is what I have called “the analogy challenge”. Referring to ethical texts on issues of selection is only partially helpful, insofar as it is not clear where autism sits in relation to often-quoted analogies in the ethical literature, such as Tay-Sachs (generally held not to be compatible with a life worth living); conditions that bring with them opportunities for a good life (deafness and achondroplasia); conditions that denote difference/minority status rather than functionality-affecting bodily alterations (homosexuality and left-handedness).

I did not seek at that stage to set out my own stance on these points, but rather to illustrate the complexity of underlying standpoints that are implicated. However, I consider that the complexity alone is a powerful reason to be wary of merely assuming the moral validity of antenatal prevention of autism. Preventing autism before birth is not self-evidently a good goal.

Before developing these observations and attempting to reach a set of concrete conclusions (Chapters 6 and 7 below), there are three more categories of intervention to explore. These relate to interventions that occur after a person has been born, and they are the focus of the current chapter.

In separating post-birth interventions from pre-birth interventions I have chosen a demarcation that is reflected in much of the literature around selection and disability. Reflecting the idea of distinction in the moral status of the infant versus the fetus, the
pre-/post-birth distinction does reflect a strong organising principle within bioethics. As discussed previously (Chapter 3 section 1.3) it is also the key distinction that Barnbaum adopts in advocating for pre-birth prevention measures on the one hand, but post-birth acceptance (as opposed to cure or intrusive interventions) on the other.

The focus of the current chapter will be on identifying what, if any, additional ethical considerations apply to post-birth interventions with regard to autism, as well as paying attention to any considerations that carry through from the discussion of pre-birth interventions. As with the previous chapter, I will present three distinct categories of intervention, and the timing at which an intervention is undertaken will again be shown to have significance.

In order to understand the salience of the demarcations I am about to discuss, it is helpful to revisit the two overlapping areas of debate with regard to post-birth interventions into autism that I introduced in Chapter 1: the treatment vs acceptance debate, and the profound disagreements surrounding applied behaviour analysis (ABA) and in particular early intensive behavioural intervention (EIBI) with regard to autism. Together, these debates set out the main axes of dispute and the areas requiring further analysis with regard to the ethics of post-birth interventions, and so I will say more about each in this chapter. The treatment vs acceptance debate sets the scene immediately for the three categories of post-birth intervention in Section 1, and EIBI will be the focus of a case study in Section 2. Overall observations will be offered in Section 3.

54 EIBI has also featured in discussions around the evolution of specialist teaching approaches (pp. 44-45) and the neurodiversity movement’s concerns about research and practice bias (see p. 73).
The treatment vs acceptance debate – recap

As outlined in Chapter 1, the controversy highlighted several questions that I wanted to reflect on in this research: differing interpretations of what autism is and entails; different views on whether and how autistic people want to, need to or should be treated; linked differences in views of autism as illness, disability, difference. These combine to generate contrasting views as to whether autistic people have most to gain from wider societal and attitudinal change, versus specific help and services tailored to individuals, versus the development of measures that could cure or prevent autism.

Reflecting all of the above, I consider that the underlying ethical question, as polarised in the treatment vs acceptance debate, is whether – in the spirit of seeking to help autistic people – interventions should target autism itself, or alternatively the wider environment, or a mixture of both. The further question, for those who argue that autism requires more than environmental change, is what is the most helpful intervention? Is it one that aims to address autism in toto, or is it one that seeks to provide targeted support for just selected aspects of difficulty?

The distinctions between these propositions are captured in the three categories of postnatal intervention:

P-1 Postnatal intervention altering an individual’s trajectory away from autism, including the expressed possibility of prevention, cure or recovery;

P-2 Postnatal intervention focused on amelioration of an individual’s difficulties (both individuals and families are targeted);
P-3  Postnatal intervention focused on external change – social, practice and policy responses to autism.

All three types of intervention can be seen as beneficent in intent:

- The most helpful thing to do is to eliminate autism altogether, through prevention or cure (category P-1).
- The most helpful thing to do is to equip and enable autistic people to overcome at least some of their impairments (category P-2).
- The most helpful thing to do is to tackle the wider conditions that lead autism to be equated with poor prognosis in terms of quality of life (category P-3).

Yet the contrasts between them lead to bitter disputes, reflecting contrasting attitudes to autism, to society and to what is empirically possible.

These three categories also reflect the two dimensions of intervention that I argued in Chapter 3 were of key significance: timing of intervention and the target of intervention. With regard to target, P-3 reflects views aligned with the social model of disability and neurodiversity paradigm (see above pp. 64-68), and also takes into account the views of those parents for whom the key struggles of having an autistic child relate to battles with external agencies. In contrast both P-1 and P-2 relate to interventions towards individuals, reflecting Scully’s identification of the medical model as being “disability as individual trouble” (p. 65). In terms of timing, P-1 is most frequently equated with early intervention – targeting young children and even infants – while P-2 and P-3 interventions are, in principle, not age-specific.
I will therefore explore the implications and ethical questions that emerge from the three categories, reflecting as they do such a major polarisation of opinions. I will first outline them with reference to some examples of the types of intervention and approach that fall within each. This will not be an exhaustive list of examples, but rather a demonstration of the conceptual contrasts that apply. I will then show how they play out with reference to the ABA/EIBI controversy, since this has received the greatest attention in terms of ethical discussion. Last, I will explore potential overlaps and interdependencies between the three categories.

1. **Outline of the three categories of post-birth intervention**

1.1. *Postnatal intervention altering an individual’s trajectory away from autism, including the expressed possibility of prevention, cure and recovery (P-1)*

What the interventions in P-1 share is the goal of removing autism *in toto*. They also share a particular use of language, which implies a shared conceptual framework of autism. Whereas I suggested in Chapter 3 that there were no clear definitions of the terms “prevention” and “cure”, category P-1 does require closer attention to their meaning. The words “prevention” and “cure” give a message about how autism is perceived and carry an implication that targeting autism is an act of beneficence within a medically oriented discourse. The term “recovery” also has medical connotations, and although it is used to mean different things (as I will demonstrate),
these different uses are themselves revealing of some of the conceptual confusions and ethical challenges that need to be addressed.

The semantic distinction between prevention and cure is about the timing at which an intervention takes place. An intervention that prevents autism is one that ensures it doesn’t happen. In contrast, “cure” implies that autism does “happen” – that is, by definition, autism has not been prevented, such that someone with autism exists – but then, at some later point, thanks to the curing intervention, its effects are no longer apparent. Reflecting the semantic differences, the practical implications of prevention and cure, in terms of what treatments are involved, are also distinct. This will become clearer when I offer examples below. I will discuss the various potential meanings of the term “recovery” in the EIBI case study. It has salience within P-1 when it is interpreted in a particular way, which I will outline below. In saying more about each notion in turn in the next section, I will also offer up an analysis of how each term entails contrasting notions of autism and what constitutes a good outcome, and – therefore – contrasting ideas of the morally right way to intervene.

1.1.1. Prevention

Dawson (2008) provides an overview of contemporary biological knowledge around autism and puts forward a model in which interventions could be explicitly geared to preventing autism.

For the first time, prevention of ASD is plausible. Prevention will entail detecting infants at risk before the full syndrome is present and implementing treatments designed to alter the course of early behavioral and brain development. (2008, p. 775, my italics)
She feels prevention is now plausible thanks to advances in the fields of cognitive and affective developmental neuroscience, developmental psychopathology, neurobiology, genetics and ABA, which have contributed to a “more optimistic outcome for individuals with ASD”. This she compares with three decades previously when Autism Spectrum Disorder (ASD) was considered to have an “extremely poor prognosis”.

Throughout her article, Dawson draws together what were for a while contrasting strands in the development of autism interventions – cause-related biological enquiry on the one hand, and educational/behavioural interventions on the other. Dawson highlights the reintegration both conceptually and scientifically. She does not see EIBI as an alternative to causal-based intervention, and she is clear about the positive implications for genetic research too: “One goal of genetic research is to identify infants at increased risk for ASD at birth so that intervention can begin as soon as possible” (2008, p. 777).

She refers back to the belief expressed by Belmonte et al. (2004, p. 650) in relation to multi-gene conditions: although the small effect of each gene by itself makes it difficult to identify specific genes, “the advantage in terms of treatment is that intervening to restore regulation to a single gene or to a small set of genes may diminish the multiplicative effect enough to yield large preventative or therapeutic effects”. Dawson continues: “The identification of autism susceptibility genes and other biomarkers will allow detection of infants at increased risk for ASD at birth” (2008, p. 781).
The choice of words here is interesting. First, the idea of “restoring” regulation implies a narrative of autism in which normality was the original design and purpose, and that autism intervened as a deviation. Second, Dawson is careful it seems to avoid the implication that antenatal testing should lead to intervention affecting the fetus before birth. Hence she refers to detecting risk “at birth”, which is why “prevention” is a concept that resides both in this chapter and in the previous chapter.

Citing her developmental model of risk (Dawson, Sterling and Faja (2009)), she posits that early intervention can alter the abnormal developmental trajectory of young children with ASD and help guide brain and behavioural development “back toward a normal pathway” (2008, p. 776). And later, she suggests that the earlier the risk is detected and intervention starts, the greater the chance that the intervention will alter the abnormal developmental trajectory “and help guide brain and behavioral development back toward a normal pathway and in some cases, prevent the full syndrome of ASD” (2008, p. 793).

This chimes with the conceptualisation of autism put forward by the biomedical movement (described in Chapter 2 and referred to again below p.196) – that “beneath” his autism, or in the event of his autism being removed, the affected individual would be “normal”. We are given a sense of a child in whom autism has somehow diverted him away from his “real” destiny, which should be one of neurological and behavioural normalisation.

The ethical significance of this lies in its echoes of an important theme within bioethics, that of “normal species functioning” as a goal and proxy for flourishing.
good life. This term has its origin in work by Christopher Boorse (1975) on the
definitions of disease and health. Norman Daniels used it as a basis for setting targets
for a just health-care system (1985) and it is used by Buchanan et al. to distinguish
between the ethics of treatment vs enhancement (2000). Attempts to pin down what is
meant by these ideas occupy a big space within ethics, and they are of supreme
relevance if we are to evaluate the impact of interventions that change people’s
trajectory or life chances. As was hinted at in Chapter 4 with regard to antenatal
selection, conceptions of harm and benefit are intimately linked to what are
considered to be good goals for people. The role autism plays in illuminating some of
these questions will be considered in more depth in Chapter 6. The important point to
make at this stage is that there are powerful normalising assumptions about “the good
life” that lie within commentaries that celebrate the possibility of preventing autism.
This echoes themes that emerged in chapters 2 and 3 with regard to the possibility that
there is a bias towards neurotypical ways of behaving and viewing the world, in both
scientific and academic ethics approaches to autism.

Dawson then offers an overview of the literature and findings around behavioural risk
indices (for example Bryson et al. (2007); Landa, Hollman and Garrett-Mayer (2007)),
and neurophysiological risk indices (citing brain structure and chemistry studies:
Elder et al. (2008); Courchesne and Pierce (2005); Sparks et al. (2002)). To this end
large collaborative infant-sibling brain-imaging projects have been launched in the
USA and the UK.\textsuperscript{55}

\textsuperscript{55} See the British Study of Infant Siblings (BASIS) (BASIS, n.d.) for a UK example and the Baby
Siblings Research Consortium (Autism Speaks, n.d.) for a USA example.
Dawson argues for a composite approach to “environmental enrichment” in which psychopharmacological input is combined with attempts to enrich early patterns of interaction. For example, she refers to studies suggesting that oxytocin and vasopressin promote a wide range of social behaviours, and that recent psychopharmacological studies have demonstrated that intravenous (IV) oxytocin administration reduces repetitive behaviour and increases comprehension of affective meaning in people with ASD (Hollander et al., 2003; Hollander et al., 2007). She also supports her argument with reference to animal studies demonstrating the effects of early enrichment on behaviours in mice and rats that echo autistic behaviours, such as social behaviour, sensitivity to sensory input, and anxiety during learning tasks (Turner, Yang and Lewis, 2000; Rodier et al., 1997; Schneider, Turczak and Przewlocki, 2006). She argues that the process of combining these developments raises the possibility that early interventions aimed at stimulating young infants and toddlers at risk for ASD can substantially change the course of both behavioral and brain development. (2008, p. 789, my italics)

She further asserts that the literature concerning infant-toddler interventions “designed to prevent or reduce Autism Symptoms”, indicates that:

by facilitating early social engagement and reciprocity between the at-risk infant and his/her social partners, it may be possible to prevent ASD in some cases (2008, p. 792, my italics)

What the combination of early social enrichment and pharmacological input would look like in practice is not set out, although the above quotations raise questions about the intensity and invasiveness of the measures she has in mind. The issue of what kinds of interventions on infants are to be morally justified relates both to the objective and the nature of the intervention. This is something to which I will return,
once I have completed the outline of the interventions that fall within category P-1.

Next is the topic of cure.

1.1.2. Cure

“Cure” shares with the “prevention” perspective a notion that there is a “normal” person waiting to be released, and that autism has somehow diverted the individual away from their “real” destiny, which should be one of normalisation. It is conceptually distinct from prevention insofar as it relates to interventions that take place once autism is established, rather than before.

“Cure” has been used in relation to autism to denote a good and possible outcome in three main contexts. The first is in general information targeted to educate early enquirers and members of the public. One of many examples is this:

There is no “cure” for ASD, but a wide range of treatments – including education and behaviour support – can help people with the condition.

The above quotation forms an early part of the introduction to the ASD section of the online information site “NHS Choices” (NHS, 2013). The description of autism as an incurable condition is typical of many or even most of the most reputable information sources. It immediately links the concept of “cure” to autism. For a new enquirer into autism, the idea and implied desirability of cure is instantly presented, so that the two notions – autism and cure – are inherently integrated in definitional terms. Likewise, any new challenge to the notion of incurability forms the basis of multiple news items or discussion pieces (see for example below p. 222 note 61).
The second context where “cure” is adopted as relevant is in the scientific literature reviewed in Chapter 2. Here it is usually applied in broad and general terms as a justification for continuing scientific research into causes. For example:

Though no closer to a cure for ASD than Dr. Kanner was in the 1940s, our clinical and basic science understanding of ASD symptoms and disease pathogenesis has improved dramatically. (Rossman and DiCicco-Bloom, 2008, p. 3)

These references share a lack of precision in terms of concrete scenarios and methods by which attempts to cure might be put into practice.

The third context in which “cure” is adopted is in biomedical movement - the field of parent-led autism advocacy. The name of the advocacy group Cure Autism Now (which subsequently evolved into Autism Speaks) is the most obvious example, but – as outlined in Chapter 2 – it has echoes in Defeat Autism Now! and Treating Autism. Such groups have earned the nickname “curebies” by members of the neurodiversity movement. This has become a catch-all phrase and is applied particularly to parents aligned to the “biomedical” approach – those who believe that autism is a consequence, and symptomatic, of possible environmental assaults on the baby such as toxins (e.g. heavy metals or vaccinations) and who hold autism to be a whole-body phenomenon, rather than purely neurological. “Cure” then implies a physiological intervention addressing biological process and releasing the potential for normal development freed from the distorting effect of disease or biological disturbances.

56 It is frequently used in applications for research grants, by scientists wishing to demonstrate the potential usefulness of their work (July 2013, private conversation with grant-giver).
I believe that these groups may represent in particular those parents who perceive that their children have additional medical problems beyond the core features of autism, particularly gastro-intestinal difficulties. Insofar as this co-morbidity is painful and presents as a medical pathology, “cure” does not seem inappropriate as a goal for addressing the co-morbidity itself. However, the confusion lies in assuming that all of someone’s autism requires curing, as opposed to any medical problems that are not part of the core features of autism reflected in the official diagnostic categories. (I will say more about this in Chapter 6.)

The groups who advocate broadly “biomedical” interventions focus on a range of physiological treatments, ranging from specific diets to invasive measures to detoxify their children, such as chelation (referred to in Chapter 2). Although the literature upon which they draw does include peer-reviewed scientific papers, these groups have nonetheless provoked concerns about the lack of theoretical and empirical coherence of the conclusions they draw and practices they institute on the back of scientific knowledge. Concern is also expressed about the mushrooming of interventions that are made commercially available and offered (perhaps chiefly) because they are potentially lucrative (see Fitzpatrick (2009b) and Hannaford (2013)).

Reports of the impact of these interventions rely on anecdote rather than on the conduct of controlled trials. As suggested in relation to prevention measures above, the issue of what the intervention involves in practice is a significant one. Some parents speak forcefully of the beneficial impact of these interventions. Against this, many interventions have been subjected to criticism because they involve unpleasant and dangerous procedures – in particular chelation and “chemical castration” (see
above pp. 60-61). As such, they are challenged in ethical terms both because they cause distress and because false claims are made about their efficacy.

Aside from any financial interests, these interventions may be motivated by beneficence, but still turn out not to be beneficent, when applied. Indeed it is argued that they contravene the principle of non-maleficence since they can actively cause harm. In contrast, as the analysis of category P-2 will explore, there are scenarios where the practice is non-maleficent, and may even be enjoyed, but is nonetheless ineffectual in achieving its goal.

Meanwhile, I will outline two further terms that are closely linked to the idea of “cure”.

1.1.3. “Remediation” and “recovery”: “prevention” and/or “cure” by another name?

Both “remediation” and “recovery” echo the sense outlined above of a process of restoration towards “normality”. In the case of “recovery”, the reference is strongly evocative of a medical picture of autism. “Remediation” is more reminiscent of educational practices devoted to compensating for underperformance relative to a norm. I wish to spend some time exploring how these terms have been used, in order to further demonstrate the ideas around normalisation that apply within P-1, and – later – P-2 and P-3. The term “recovery” will also be discussed with greater focus in the context of the ABA case study below.
Remediation

This word is the term adopted by Gutstein, who by implication suggests the possibility of prevention even if he doesn’t use this word (2009). Gutstein’s intervention, entitled Relationship Development Intervention (RDI), addresses what he believes is lacking in autism, though ubiquitous in typical human development – the acquisition of dynamic skills that comes via the Guided Participation Relationship (GPR): “the GPR is not a technique, or artificial program developed by a psychologist or educator, but a universal learning process unfolding in every culture throughout recorded history” (2009, p. 63, my italics). In autism, however, the GPR “fails to develop in its typical intuitive manner” and so “RDI seeks to restore the natural Guided Participation Relationship found in every culture” (2009, p. 63, my italics).

This emphasis on restoration and naturalness reflects a view that a positive intervention is one that aims to restore normal species functioning:

I believe that if we can provide a second chance to restore or establish the GPR in a more deliberate mindful manner … we can help the majority of ASD children and families embark on a more normal path of cognitive, emotional and social development. (Gutstein, 2009, p. 150)

This guidance towards normality, Gutstein suggests, is done through the RDI, which is a systematic process of correcting deficits to the point where they no longer constitute obstacles to reaching one’s potential and attaining a quality of life. (2009, p. 147, my italics)
“Quality of life” is therefore equated with attainment of normal species functioning. He describes this as offering the “soon to be” autistic child a “second chance” (2009, p. 147).

Like Dawson, Gutstein implies that the onset of autism comes about as a feature of the brain’s development. While Gutstein uses the term “remediation”, what he says above is conceptually similar to the position of Dawson in terms of prevention. The contrast lies in the fact that RDI is a purely educational/interactional intervention whereas Dawson’s model incorporates psychopharmacological input. They share the possibility that post-birth interventions should be delivered to infants not (yet) identified as autistic but considered at risk of being later diagnosed as autistic. The theoretical underpinning of this approach relates to the idea of brain plasticity and of a finite window of opportunity in which the developing brain can be influenced.

So far, I have suggested that these interventions relate to a particular idea of what causes autism. In contrast, “recovery” does not always entail a corresponding theory of causality.

**Recovery**

I discussed previously the fact that “cure” implies a physiological intervention addressing biological process and releasing the potential for normal development, and that the term “curebies” has been given to those who wish to see a cure. This latter group also adopts the word “recovery” in relation to cited examples of noted improvement in their children – where improvement is equated with the loss of autistic symptoms arising from a range of biomedical treatments. An example is the
advertisement of a workshop entitled “Autism: A Roadmap to Recovery” (Klinghardt Academy, 2009), focusing on alleged damage caused by electromagnetic radiation and how dietary and other interventions can address this.

Like “cure”, the term “recovery” thus implies a medical view of autism. And yet – as outlined in the EIBI case study below – the use of the term “recovery” sometimes extends beyond the above community, to denote a general improvement in functioning across a range of indicators and arising from educational/psychosocial or even societal, rather than purely physiological, interventions. It is an eye-catching term used to market interventions. Thus, the Son-Rise programme, based on the experiences of Raun Kaufman, whose story is told in Kaufman (1976) and Kaufman (1994), has been assertively marketed with emphasis on the concept of recovery.57

In this wider use of the term, “recovery” is not used to denote a physiological change away from autism, but rather to categorise the phenomenon of marked changes in behaviour so that the individual no longer appears to be autistic. The lack of precision around the term has been noted by Fitzpatrick (2009b, pp. 70–71) who says, “‘Recovery’ tends to undergo subtle redefinition as ‘dramatic improvement’ or transition to ‘mainstream’ education, or ‘loss of behavioural diagnosis’ of autism”.

For the purposes of its use within P-1, though, “recovery” has a more restricted meaning, one that in effect means “cure”. This is the primary suggestion of the word, as illustrated by Fitzpatrick’s introduction to the topic:

57 An example is the large lettering and the content of the A5 advertisement in Metro (Son-Rise Programme, 2009), entitled “Autism Recovery” and subtitled “2 Hours to change your child’s life with American Autism expert Raun K Kaufman, himself fully recovered from Autism” (italics in original).
The most extravagant of the claims arising from the biomedical movement is that autism is not only treatable, but that it is curable. Numerous reports have appeared claiming that children have not only improved on biomedical interventions, but that they have actually “recovered”. (2009b, p. 70)

1.1.4. Key points arising from the discussion of P-1

Optimal outcome through the prism of P-1

In moving within P-1 from ideas of prevention and cure through to “recovery”, I identified two ways of viewing optimal outcome:

- **Biological** change leading to organic features of autism no longer being present;
- **Behavioural** change leading to the loss of an autism diagnosis.

I will refer to these as P-1 (a) and P-1 (b) respectively. I will later contend that the ambiguity relating to these two interpretations has generated more heat than light.

The distinction takes us back to discussions in Chapters 2 and 3 about how we view the essence of autism and the challenges of using purely behavioural criteria to diagnose and define it. If we aim for cure, is the goal to shed the diagnosis (behaviourally defined), or to impact on some deeper organic essence? And if it were possible to achieve one without achieving the other, which would be more important? These questions were touched upon in the discussion of Minshew’s model (see pp. 36-37), when I pointed out that “cure” can have several meanings at a biological level.
Given the conceptual distinctions, there may well turn out to be a challenge in defining what constitutes a positive outcome from interventions, and this will be taken up again below. It also seems likely that there may be additional ethical differences about what is involved in the practice of different types of intervention.

What are the ethical issues related to practice?

Aside from outcome and intervention goals, the discussion around P-1 has also hinted at some thorny ethical issues when it comes to analysing how interventions are practised. The questions such a proposition gives rise to – in all interventions – include:

- Are they effective in achieving their goal?
- Do such interventions involve discomfort?
- Do they entail adverse side-effects, in the immediate through to the long term?

Additional issues apply specifically to early intervention on babies and infants. Although some research points to interventions on babies not yet identified as autistic, while the more traditional view of early intervention is that it is applied once a diagnosis is obtained, the ethical principles in terms of interventions on babies and young children – whether merely at risk or actually diagnosed as autistic – are similar:

- What are the autonomy and consent issues at stake, given the age of the babies and infants?
- What moral issues arise for an intervention that may impact on the sense of identity (narrative identity/autistic identity-essence) of the developing person?
At what stage of development is it right to instigate and/or abandon these types of intervention?

Is there a developmental stage other than birth at which we are morally required to “switch on” or “switch off” interventions targeting autism?

Finally, in terms of how practice fits into wider policy and social institutions, additional questions arise:

- Are there resource implications, for example if focused interventions on the young reduce the support available for autistic individuals who are older?
- If there is an economic argument in favour of diverting children away from autism, will families be “coerced” into adopting these interventions even if they believe them to be wrong for their child?

Before carrying such questions over into subsequent discussions, the additional categories of post-birth interventions will be outlined.

1.2. Postnatal intervention focused on amelioration of an individual’s difficulties (both individuals and families are targeted) (P-2)

I suggested above that the motivation behind P-1 interventions can entail a belief that it is a beneficent goal to eliminate autism. A second feature of P-1 interventions is the belief that this is, or will one day be, an actual possibility – either at a biological level (P-1 (a)) or merely in terms of behavioural indicators and, hence, diagnosis (P-1 (b)).
In contrast, the standpoint within P-2 relates to the idea that the most helpful thing to do is to equip autistic people with strategies to overcome at least some of their difficulties, taking the impossibility (or inappropriateness) of “curing” autism (removing it in toto) as a given. Thus, while interventions that fall under P-1 tend to address autism as a unitary condition that can be removed or alleviated, it is within P-2 that we would place interventions that address just particular aspects of an individual’s difficulties, such as communication, or executive function, or social interaction.

Within P-2, interventions also differ as to the age at which they occur. Whereas P-1 interventions usually happen early in life and/or early post-diagnosis, P-2 is not confined to early intervention. Some therapies – such as speech and language therapy (SALT) or psychology services – might be considered appropriate on and off throughout a person’s life depending on presenting issues and challenges. In real life, however, parents often rue the fact that such services, while sparse when the child is young, are completely unavailable for older children and adults (often explained as being due to prioritising in a context of resource constraint).  

A further conceptual distinction between P-1 and P-2 relates to the degree of certainty implied about the possibility of making dramatic inroads on someone’s autism. Those who use the terms “prevention” and “cure” (as with remediation and recovery) to denote legitimate goals usually do so from a perspective that holds this to be a real possibility either now or at some point in the future; not only are they viewed as good goals but also they are considered to be realisable. As such, the language surrounding

58 See for example the parental perspective quoted in Chapter 6 on p. 332
interventions within P-1 implies something about empirical possibility as well as desirability. In contrast, interventions within P-2 see autism as a given within an individual and consider it to be a lifelong condition, regardless of intervention. Indeed, the idea of autism as lifelong leads some practitioners and academics within this conceptual framework to assume that anyone who loses their diagnosis was wrongly diagnosed in the first place (see Feinstein (2010, p. 283)).

Interventions that fall within P-2 include educational approaches such as Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) (discussed in Chapter 2 above p. 56), which locates a programme of education within a wider multi-agency system. The approach combines a focus on both the individual and their environment. The education component of TEACCH makes few demands on the pupils to interact but seeks to foster their abilities to follow visually scheduled sequenced tasks, and learning takes place in a low-arousal, low-distraction “prosthetic” physical environment.

Within P-2 we find programmes that focus on parental and family interaction with the child such as social-communication interventions piloted in the Pre-school Autism Communication Trial (PACT) (Green et al., 2010). All kinds of “therapies” from health professionals such as SALTs, occupational therapists, psychologists fall within P-2. So too do specific communication systems such as the Picture Exchange Communication System (PECS), signing and augmentative communication aids designed for autistic people who do not speak, and social stories for those with higher linguistic ability. P-2 covers the broad sweep of responses to autism offered within the established professions, and in addition several interventions – both generic and
“branded” – that have been developed by voluntary and commercial organisations, and support groups, such as social skills groups or the NAS Early Bird programme (NAS, 2013). It also covers the category of complementary and alternative medicine (CAM), music and art therapy, where these are geared not at prevention/cure/recovery, but to help autistic people in particular areas such as self-expression, difficulties with sensory overload and emotion regulation.

1.2.1. Ethical issues within P-2 interventions

With the exception of ABA – which I will discuss below – from a practice/harm standpoint, the interventions in P-2 attract less ethical scrutiny than those in P-1. Perhaps because of this, the additional issues of consent and autonomy are rarely held up as a concern in relation to these interventions. While the capacity to consent is still a relevant concern where interventions occur on young children and/or adults with limited capacity due to their learning difficulties, there is a sense that this is a less serious issue if the interventions seem to carry with them fewer questions about harm and side-effects. However, from an efficacy standpoint, many of the practices as they relate to autism are vulnerable to the criticism of having a poor evidence base, so it is not clear that the requirement of beneficence is fulfilled, despite the beneficent motivation.

While CAM and some other therapeutic interventions are not routinely funded from public agencies, there are others that, by virtue of being offered by established health and education professions in the public sector (within the UK), are at least in name freely accessible to autistic people and the beneficence of their input is routinely assumed. There are institutional and historical explanations for how the established
health professions have come into being, how they are managed and how resources towards them are allocated which give them a structural legitimacy within western health-care systems. But what they offer autistic people is sometimes held to be ineffectual, insufficient or inappropriate, according to different stakeholder perspectives, with parents in particular often the most outspoken critics (see below p. 213). Thus, opinions and beliefs as to the limitations of such approaches tend to derive from outside the professional and academic domains in which the practices reside.

Beneath questions about impact lies the foundation question regarding what is judged to be a positive outcome. I have argued that – unlike the interventions in P-1 – the P-2 interventions are not aiming to remove someone’s autism wholesale, but merely to tackle particular discrete areas of difficulty. However, while each practitioner may place limits on the objectives and outcomes of their particular intervention, it is less clear that many would differ in their judgements as to what is a good overall goal and outcome for an autistic individual. In these cases, the distinction between P-1 and P-2 does not lie in the emphasis given to the overall (un)desirability of moving away from autism, but more in the limits placed on the scope and potential of any particular intervention or therapy.

In other words, P-1 interventions make the goal of prevention and cure explicit, whereas P-2 interventions do not, but this may hide a congruence of overall aspiration amongst at least some stakeholders, which indicates that the boundaries between P-1 and P-2 are in some cases blurred. Thus, I have drawn attention to the terms prevention and cure because they share explicitly the implication that autism is
analogous to disease and that moving away from autism is a beneficial target. However, it is important to note that some of the literature in relation to P-2 interventions contains the second assumption by implication. Experimental studies regarding P-2 interventions often judge positive outcome on the basis that there is a departure from/reduction in autism symptoms (for example the use of the Autism Diagnostic Observation Schedule (ADOS)). Thus, PACT (Green et al., 2010) is generally held up as exemplary in methodology and ethically unproblematic insofar as it addresses parent-child interaction primarily, and this feels less like an all-out assault on autism than some of the more direct teacher-led approaches. While these authors might shy away from using the terms “prevention” or “cure”, their studies nonetheless adopt ADOS – with the implication that reduction in autism symptoms is a laudable target.

In addition, most information disseminated about autism from mainstream professional and charitable sources until very recently described autism as an incurable condition – as referred to with regard to P-1 above (p. 195). I suggested that this use of terminology reflects an underlying way of thinking that deems the concept of “cure” as an implicitly desirable one when linked with autism. What is being referred to is a belief in the impossibility of cure, but still there is an unstated endorsement of a medical framework through which autism should be viewed – in which cure, if it were available, would be self-evidently good.

So it seems likely – though not empirically tested as yet – that at least some academics, practitioners and organisations working within or advocating for P-2 interventions do not question the overall desirability of moving away from autism, so
much as (i) its empirical possibility overall and (ii) the limits they place on the specific targets of their particular intervention – focusing only on discrete areas of functioning. Furthermore, the emphasis of their intervention is still primarily individual change, rather than wider societal adaptation.

This is important because of the underlying moral claims that are sometimes made in relation to P-2. There is in some quarters a tendency to vilify P-1 interventions, while upholding the integrity of P-2 interventions. This may be a consequence of the influence of the self-advocacy movement, which, as I discussed in Chapter 2, has played a big part in shifting attitudes away from wholesale pathologising of autism and, hence, away from the use of language associated with P-1. P-2 interventions do not give rise to equivalent objections from the neurodiversity movement. There are many self-advocates who, while objecting to P-1 interventions, do not contest the purpose or potential usefulness of P-2 interventions. An example of this perspective is offered in the following quotation from John Elder Robison:

I support the idea of changing society to make it more accommodating for people who are different. I also support the idea of developing therapies, treatments, and tools to relieve suffering and disability from both autism and the conditions that accompany it for some people. (Robison, 2013)

Thus Robison, while advocating for wider measures in the environment (P-3, to be discussed below), clearly embraces the role of P-2 interventions. In the same blog post as that quoted above, he reproduces the text of a letter of resignation from Autism Speaks, which includes the following:

We do have problems, and we need help. Some of us need counseling or training, while others have significant medical challenges. We also need acceptance, and support. There is a great diversity in our community, which means we have a very
broad range of needs. Unfortunately, the majority of the research Autism Speaks has funded to date does not meet those needs, and the community services are too small a percentage of total budget to be truly meaningful. We have delivered very little value to autistic people, for the many millions raised. (Robison, 2013)

Here we see a key self-advocate and campaigner arguing, in effect, that P-1 is morally problematic in terms of its goals and its prioritisation within research funding, while P-2 interventions may be actively helpful within an autism rights framework.

In pointing this out, I wish both to reiterate the ethical distinction between P-1 and P-2, but also to suggest that in reality there may be a significant distance between what the practice seeks to do, and what the practitioners themselves may actually believe is a morally appropriate goal or good outcome overall.

For example, I am suggesting that some interventions that purport to be P-2 are actually practised as part of an overall P-1 world view. As such, some P-2 practitioners get an “easier ride” (e.g. from the neurodiversity movement) in terms of the nature of their intervention, because they do not seem to provide a head-on attack on autism. And yet it may be that actually they are simply less ambitious in what they believe they can achieve.

Yet others who favour P-2 interventions may have a very different view of autism and of the purpose of their intervention. They may not equate a good outcome with a reduction in core autism. Their view of the purpose of P-2 interventions is to offer tools to address some of the problems an autistic person has. This type of intervention may bring about improvement in aspects of an autistic person’s life without representing a shift in terms of the features that make up the diagnostic criteria. An
example is challenging behaviour. An intervention that helps someone cope with their anxiety and reduces their need to “lash out” may be seen as highly beneficial – and sensible – but this is not, in strict terms, the same thing as addressing autism as it is currently diagnosed.

I wish also to flag up the inverse possibility that practitioners who are allegedly undertaking a P-1 intervention may in fact be working within a P-2 framework, and – further – that they judge as positive those outcomes that actually don’t relate to the fundamental features of autism at all. The case study below will, I hope, clearly demonstrate this last point.

1.2.2. Key points arising from the discussion of P-2

*What is a good outcome for autistic people?*

Referring back to the outcomes of P-1, I suggested that a good outcome was conceptualised as either P-1 (a) biological change leading to organic features of autism no longer being present, or P-1 (b) behavioural change leading to the loss of an autistic diagnosis.

From the discussion in this section, I have shown that neither of these applies in the case of P-2. Rather, it is a third goal that most closely sums up the objectives of interventions in P-2: behavioural change leading to the ability to function in society, but retaining a diagnosis/identity as autistic. What I have also suggested is that while

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59 I am here using the term “behavioural” to apply in its broadest sense, to encompass the acquisition of functional skills such as communication (be this augmentative or through speech), greater receptive comprehension of others’ speech, coping mechanisms for sensory overload and so on.
only this third outcome is deemed to be empirically possible by P-2 practitioners, some at least may regard autism in toto as pathology, with a clear view that autism is a significantly worse way of being in the world than being neurotypical (NT).

*What are the ethical issues related to practice?*

I have also suggested that P-2 interventions tend to raise fewer objections than P-1 interventions because they seem – in comparison with some P-1 interventions – relatively harmless. Revisiting the questions posed in relation to P-1 above, what I am saying is that they do not raise concerns in relation to the second and third questions below:

- Are they effective in achieving their goal?
- Do such interventions involve discomfort?
- Do they entail adverse side-effects, in the immediate through to the long term?

I have also suggested that it is not always clear what P-2 interventions aim for, and moreover that not all P-2 interventions are well supported with evidence as to effectiveness. However, lack of ability to answer the first question seems to get overlooked within mainstream service provision (at least in the UK), even though parents in particular frequently express great dissatisfaction with the services on offer. The following quotation is typical of the kind of messages that are posted on parents’ e-groups regularly:

> After two years of regression, failed targets, no NHS S&LT, OT or physiotherapy breakthroughs of any kind, of challenging behaviour, self harm and extremely delayed motor skills, we had fallen out of hope with the SEN system’s glowing rhetoric (Anon, 2014a)
The further ethical questions in relation to early intervention when applied to P-2 (autonomy and consent, sense of identity, issues around coercion) again seem to raise fewer objections within the professional and academic communities, perhaps because the interventions do not seem to require anything that appears to be a negative intrusion on the subjects and/or they do not appear to have an unwelcome or radical impact.

The key exception to these observations is in relation to ABA, where both the impact and the process have been enthusiastically upheld by some and yet deeply criticised by others. One of the key areas that I believe has not been fully addressed is whether ABA should be viewed as a P-1 or a P-2 intervention, as will be outlined more fully in the case study below. In exploring this issue, I am preparing the ground for further observations about the treatment vs acceptance debate, and how we might find a way through the controversy.

But before that, I will introduce the third category of post-birth intervention – that which bypasses the autistic individual altogether and addresses the wider environment.

1.3. Postnatal intervention focused on external change – social, practice and policy responses to autism (P-3)

In Chapter 2 I mentioned some long-term follow-up studies about what happens to autistic people in adulthood (see Howlin (2013, 2014)). The outcomes referred to in the studies included not just individual functional and behavioural change within or
by the autistic person, but wider social indicators – place of residence, income, employment.

In reporting the findings, the authors did not venture strong opinions as to what explains these negative outcomes. They do however invite several interpretations. The first is that autism predicts poor long-term outcomes full stop. The second is that more needs to be done in the way of active intervention strategies to effect an improvement in these outcomes. Third, we might argue (in keeping with the social model and neurodiversity movement) that these outcomes reflect a hostile wider social environment – one that has as yet failed to accept and celebrate people who depart from the norm.

In other words, notwithstanding the gloomy prognosis suggested by these long-term studies, the most important questions are about whether the impediments to achieving an improvement in the future reside within autism itself or within wider societal attitudes and obstacles. Depending on the answer, the locus of ethical intervention will target individuals, or it will target the wider social, political, economic and cultural climate.

Interventions that fall within P-3 relate to this wider dimension, covering measures that aim to alter the social, economic and political context in order to improve autistic people’s chances of inclusion without targeting the behaviour or biological functioning of autistic people themselves. As such they are nothing to do with the “disability as individual trouble” model and everything to do with the social model (see p. 64).
Examples include institutional and policy measures such as the UK Autism Act, and positive employment measures where autistic employees are specifically and proactively recruited and supported in their workplace. Calls for measures to address the built environment to make it more “autism friendly” fall within P-3, as do social and cultural initiatives such as providing autism-friendly concerts and cinema screenings. These measures chime with a social model of disability, in which the responsibility for change falls not on the individual but on wider structures and institutions. Most radically, and in keeping with the ideas put forward by Timimi, Gardner and McCabe (2011) (see above pp. 81-83), some will argue that only very radical social change will bring about a significant transformation in the life chances of people who are “different” or “disabled”.

The further implication of P-3 interventions is that behaviour change is required not by autistic people but by the rest of the population. An example here is the anti-bullying campaign that has been set up by autistic activist Kevin Healey (2014). The sentiments about the need to address the bullies who victimise people with autism, rather than trying to teach autistic people to be less prey to bullying through greater conformity to social behavioural norms, are echoed by autistic campaigner Sarah Hewitt.

Instead of focusing on the so called vulnerability of the victim, how about focusing on the behaviour of the people who abuse and exploit people with autism? It is crazy to focus on the behaviour of an autistic person as the one in need of rehabilitation when they are, in fact, the victim of the abuse. It doesn’t make sense. (Hewitt, 2013)
So far I have set out what I mean in terms of the three categories of intervention, highlighting their contrasts in terms of both goals and also about beliefs around what is achievable. The conceptual delineations between the three categories reflect, I believe, the fault lines of ethical dispute that characterise many debates within autism and in particular that fall under the overall heading of “treatment vs acceptance”. I have also hinted that while the categories seem distinct, the underlying world views of some advocates for P-1 and P-2 may not be dissimilar. Conversely, I have also suggested that the outcomes that practitioners consider to be beneficial may not equate with autistic symptoms per se (as defined in the diagnostic criteria). This means that there may be people undertaking what are “marketed” as autism interventions who actually seek outcomes that relate to reducing particular problems autistic people have, but who consider this to be distinct from a reduction in their autism.

With these possibilities in mind, my next task is to put flesh on the issues by means of a case study of how they play out in real life. The case study I have chosen is that of ABA, since it was here – as I suggested in Chapter 1 – that many of the moral questions that stimulated my interest in the research question were incubated. It is also revealing of the layers of controversy that co-exist within the debate, both around epistemological questions regarding what is “known” in relation to autism, what is believed, and how the language that is used can exacerbate and reinforce standpoints in which there may be hidden congruence. Because of these several layers and subtleties, it will be a lengthy case study, and I ask for the reader’s patience. What I hope to demonstrate is that demarcations that border on the simplistic (such as the P-1, 2 and 3 demarcations) might be useful as a way of cutting through the latticework of
argument and counter-argument – but in order to do so I will need to offer a preliminary account of this latticework.

2. Case study: controversy surrounding ABA applied to autism

In Chapter 2 I explained the history of the emergence of autism-specific programmes that use the principles of applied behaviour analysis (ABA) and in particular the application of early intensive behavioural intervention (EIBI) linked with Ivar Lovaas (see 44-45). There are several interweaving strands of the objections to EIBI, and I will briefly summarise the arguments under the headings of these strands below, and then discuss their relevance in relation to the categories of post-birth intervention P1-3. Some of the criticisms are particular to the Lovaas model and some apply to EIBI and ABA more broadly.

2.1. Objections to EIBI

2.1.1. Attitude to autism

The ABA movement has been criticised as being inhabited by “curebies”. It is argued that within EIBI, autism is viewed in entirely negative terms. As demonstration of this, the most-heralded outcomes by Lovaas et al. were ones in which autistic children became “indistinguishable from their peers” as a result of intervention (see above in Chapter 2). Practices such as the focus on extinguishing behavioural signs of autism, such as stimming, are felt to be particularly objectionable by many members and supporters of the neurodiversity movement. In this sense, then, EIBI is regarded as a

60 "Stimming" is a shorthand for self-stimulatory behaviours such as hand-flapping and rocking.
P-1 intervention – those who view it as an all-out attack on autism feel that in effect it is like seeking a cure.

Furthermore, it is pointed out that Lovaas’ work prior to his experiment with EIBI and autism focused on the attempt to prevent homosexuality in young boys through behavioural means. This sets up his entire work as morally dubious; if attempts to address autism are on a par with attempts to change sexual orientation, then, it is argued, this says something about the inappropriateness not just of his methods but of his goals.

A linked objection to EIBI relates to the spirit, or atmosphere, in which an intervention is undertaken. Reactions to EIBI incorporate objection to the use of language that, it is felt, is revealing of an underlying attitudinal hostility to the children. For example, the emphasis on “compliance”, and “bringing a child under instructional control”, which are familiar phrases within EIBI, reinforces the idea that it is a kind of conformity-indoctrination regime which leaves no room for a child’s individuality.

In response to such criticisms, it has been pointed out that Lovaas worked at a point in history when autistic people were written off as having no chance of being educated. His work overturned this negative stereotype, and as such was embraced by families who had rejected the “no hope” message coming from the establishment. Thus ABA has been described by Mary-Beth Walsh (2011) as “the best defense against the tyranny of low expectations”.

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Raising the bar in terms of what people with autism are seen as capable of achieving and aspiring to, and providing the means to achieve this as a matter of entitlement, is viewed in this way as affirming, rather than devaluing, autistic people. It provided ammunition to those who said that autistic children are, in effect, “worth the effort” and that they need – and should – not be abandoned to life on the fringes and institutional abuse.

If we plug this latter, contrasting interpretation of the intentions of the Lovaas approach into the categories of intervention, then it changes from being a P-1 intervention to a P-2 intervention: belief in the positive potential of a person to do well, while retaining their autism. This echoes the views of Jennifer Hubbard, a teacher at an ABA school in the UK:

Her staff would be “horrified” at the thought that ABA aims to take away a child’s autism. “We know they will have autism as a lifelong diagnosis. The only behaviour we are stopping is that which is causing them harm or stopping their learning.” (Lambert, 2013)

2.1.2. Autism identity

Linked to concerns about how EIBI has tried to extinguish autistic behaviours is concern that the children are being devalued and attacked for the way they are, with devastating impact on their sense of self-esteem and sense of self. This is a view implied from the following quotation by Dr Liz Pellicano, as reported by Lambert (2013):

“Although therapists wouldn’t say that they’re trying to normalise children with autism, that is the underlying ideology of ABA – to make them indistinguishable from their peers.”
This is not only ethically questionable, she says, it could be harmful, too. “Being told there’s something wrong with you is going to potentially make you more anxious and more depressed, which is already highly prevalent in people with autism.” (Lambert, 2013)

If an intervention is conducted from a spirit of devaluation of the autistic child on account of their autism, then it is argued there is a prima facie ethical objection. In this way, advocates have taken a deontological and human rights position that holds certain practices as morally wrong in themselves.

I have already argued in Chapter 4 that issues of consent and autonomy link closely with issues around narrative identity. While in Chapter 4 we discussed this in terms of the nature of the person who has yet to be born, we are now talking about a situation in which the autistic person is with us, albeit as – in some cases – a very young child. If NT tampering with fetuses is a concern for autistic advocates, it must be of even greater concern when the recipient of the intervention is a young autistic child. We are reminded of the question in Chapter 3: at what stage is there or should there be a cut-off in terms of interventions that impact on narrative identity, if – as Barnbaum argued – by the time someone is an autistic adult it would be wrong to tamper with their integrity as an autistic person or – in the spirit of Pellicano’s concerns – their sense of self-worth as an autistic person?

In terms of the narratives offered by autistic people reflecting on interventions (not necessarily behavioural) in their childhood, we see a mixed picture. References are made to autistic adults who have “repudiated ABA as a coercive technique” (Fitzpatrick, 2009b, p. 141, referring to Dawson (2004)) while there are other adults who reflect positively on their experience of ABA (see for example Alex Lowery’s comments (Lowery, 2013) and Applied Behaviour Analysis Ireland (2014).
Whether or not the practice is harmful is therefore a matter of disagreement.

2.1.3. Oppressive practice

In light of the above, some critics of EIBI state that, regardless of outcome, the process itself is “oppressive” (Arnold, 2013, pers. comm.), even in the absence of aversives, and that it is dehumanising (likened to dog training). In addition, it has been criticised for being robotic, for ignoring and thereby devaluing the intrinsic and independent learning of the child, and for lack of reciprocity and the dominance of the adult (Gernsbacher, 2006).

It is true that some applications of ABA continue to incorporate the use of aversives in order to punish certain behaviours (the most notorious being the Judge Rotenberg Centre, which uses electric shocks on its adult residents). And in its early incarnation, the Lovaas approach also used aversives. In addition, there are some Lovaas-specific practices that are not used in other parts of the ABA world, but which have nonetheless become equated with the whole of EIBI in relation to autism. For example, the requirement (expressed by some) for it to take place for 40 hours a week, chiefly in the form of “drills” (Waltz, 2013).

Contemporary academics and practitioners within the field of psychology who are more sympathetic to ABA have responded to these points, refuting the 40-hour-per-week requirement, illustrating the varied and evolving techniques within the ABA

61 The most sensationalist use of this analogy was the following headline in a television discussion programme: “Cure for Autism? Treat Children Like Dogs!” (Wright Stuff, 2013). See also Bovell (2013).
repertoire, including moving away from drills and eschewing any form of aversive; emphasising the primacy of positive reinforcement working in congruence with intrinsic motivation; and stressing the significance of adult-led learning only in areas where intrinsic learning is not apparent – i.e. those areas for which direct instruction may therefore be necessary. (For a more comprehensive overview of their response to several criticisms of ABA, see for example Schreibman (2005, in particular Chapters 6 and 9) and Hastings (2012; 2013a; 2013b)). They therefore state that contemporary ABA practice has evolved enormously and that the Lovaas approach is but one part, and a small part, of behaviour analytic practice. The ethical defence is more assertively stated by some: what could be more beneficent than to base one’s approach on systematic attempts to motivate and positively reinforce a child based on data taken about their preferences, interests and style of learning, rather than guesswork? As such, not only is the practice justified in terms of consequences, but also, the defenders of the practice would argue, it does not in any way harm the child in order to achieve the desired consequences; it is actively and inherently based on positive experiences.

Some parents have therefore observed that, contrary to the perspective of some of the critics, their children appear happy to learn through ABA principles, even from a young age and for long periods at a time (see McCready, 2014). They say there is a lot of interaction, play, fun alongside the structured teaching approach, and they stress the very real gains in understanding and communication that their children achieve. In countering the emphasis on aversives they not only point out that this is no longer a part of practice, but they also stress that Lovaas’ original work occurred at a time when corporal punishment and draconian teaching methods were the norm, and the
fact that he stopped using aversives except for a harshly expressed “no”, it is argued, invalidates an ongoing fixation on his use of aversives. Furthermore, aspects of the contemporary school system are pointed to as illustrative of the ways in which conformity, adult dominance and sidelining of individual children’s learning styles are commonplace and, it is argued, if EIBI is guilty in this regard then so too is much of the education system.

Similarly, they argue that using punishment/withdrawing rewards, requiring compliance in certain situations and aiming to alter behaviour are common to all child-rearing practices (from placing boundaries around toddler behaviour, to teaching children to express their needs without recourse to physical violence and tantrums, to requiring homework to be done).

In addition, many parents respond to critics by pointing out the inadequacy of alternatives to ABA. They cite their child’s failure to progress in other settings using different approaches, as indicated by the parent quoted above (p. 213), and consider that objections to ABA are too often a cover-up to defend ineffectual practices.

Once again what we see is some dissonance with regard to whether the practice of EIBI signifies it to be an intervention that sits within category P-1 or P-2.

2.1.4. The EIBI industry

Some autistic advocates raise concerns about the economic and institutional structures surrounding EIBI. Commercial providers proliferate in the US, supported by medical insurance funding the intervention. The considerable commercial interests
surrounding autism have been described as a “quasi-military-industrial complex” (Murray, 2013). Within the UK, the picture is somewhat different. Those who advocate or choose ABA often feel driven to employ independent practitioners and providers because there is significant resistance to its introduction within the NHS and maintained-school system. While the fact that independent practitioners are paid to provide EIBI seems to be a demonstration to critics that ABA is a commercially driven intervention, the same reality is cited by parents as demonstrating an unfair and biased disregard of ABA within the maintained system and NHS (see Anon (2104a)).

Here the controversy should be seen in terms of the wider context of funding and institutional structures. In North America in particular, access to funding for something as intensive as EIBI has entailed convincing decision-makers within a private insurance-based health system both of the potential financial payback from EIBI and also of locating autism within a medical model. Thus, by arguing that EIBI was “medically necessary”, parents were enabled to access mandatory funding for EIBI in Canada, while also eliciting a profound objection from autistic writers such as Dawson who claimed this was a violation of human rights (Dawson, 2004). In the UK, until recently, access to funding has been chiefly (though usually grudgingly) from education budgets, and so the language of advocacy has been less medical and more about learning needs.

Either way, there are two points to note. First, it is felt by critics that while EIBI remains outside the main publicly funded sources of intervention, practitioners’ pecuniary interests may influence the claims they make about impact. For example, the EIBI research published in peer-reviewed journals is nonetheless not perceived to
be truly independent (Dawson, 2004). Critics therefore suggest that it is inaccurate to imply that such spectacular changes can be reasonably expected overall, and that the way in which EIBI is marketed creates false hope. Critics of the excessive claims made by some EIBI enthusiasts include people otherwise sympathetic to its use (e.g. Schreibman (2005), Hastings (2012; 2013a; 2013b) and Metz, Mulick and Butter (2005)).

Second, what we see here is how wider institutional factors influence the framing of the debate around EIBI. Insofar as macro forces such as the organisation of funding streams and the framework of legal entitlements within different countries impact on access to, and justifications around, EIBI, then it is also the case that these wider forces resemble the kinds of issues more logically located within P-3. By this I mean that a change in wider systems could subtly but significantly alter the discourse around EIBI, and the language in which such a discourse is conducted would then impact on what kind of intervention (P-1 or P-2) its advocates and critics perceive – and describe – it to be.

A further example of this is a further criticism of ABA; that the successes that are achieved are due to their greater resource input and intensity, rather than to the specifics of the practice itself, and further that it is just “not fair” that some children receive more expensive interventions than others. Because of this, an equity argument is sometimes used to criticise ABA, which is not really about ABA’s efficacy but about resource allocation. An alternative response by critics of ABA on

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63 Private conversations with special educational needs (SEN) teachers and some autism academics.
the basis of its expense (Pellicano, 2013) could be to call for a corresponding increase in the availability of resources for other methods of intervention (which would also allow comparative efficacy research). In this case, criticism of what is viewed as a P-1 or P-2 intervention may again disguise the need for a P-3-type intervention.

2.1.5. Behaviourism’s theoretical base

Rooted in the work of Skinner, ABA is a target for those who are unconvinced by Skinner’s writings, and/or who believe that the processes by which children in general – and in particular autistic children – learn cannot be reduced to the learning theory set out by Skinner. These critics include those from a critical sociology perspective (for example Milton (2014)) and from the field of psychology (for example see Baron-Cohen (2014)).

It is hard for me to take an informed stance without immersion in the specialist psychology literature, which is a field beyond the scope of this thesis. However, it is possible to respect the view of a range of experts in this regard who, even if doubting the primacy of Skinner, do not view the practice of behaviour analysts in the same light as discredited approaches such as those emerging from Bruno Bettelheim’s views on refrigerator parents and other approaches (see above p.54 and p.61).

Notwithstanding the criticisms of Skinner, it is far from being the case that such a wholesale discrediting has occurred. While ABA itself has detractors, the broader behavioural principles on which it is based tend to receive few criticisms, such that the National Institute for Health and Care Excellence (NICE) reviews refer to a combination of behavioural and developmental principles as the basis for most
effective interventions, and most “reputable” teaching approaches and tools – such as PECS, TEACCH, positive behaviour support – incorporate behavioural techniques (see Hastings (2014) and responses to his blog post).

2.2. The question of efficacy and linked issues of welfare balancing

I believe that the critical focus EIBI has received in relation to practice is due to a combination of two things. First, there are – as with any intervention – ethical issues to address in relation to practice and I have outlined these above.

But second, I believe that EIBI brings into sharp relief a more fundamental ethical question because strong claims are made for its efficacy. An important moral question is this: where should we stand on interventions if (a) they can involve some distress and yet also (b) bring about significant gains? If aspects of ABA are felt to be uncomfortable at least, or positively harmful as argued by some, when would this be a sufficiently strong reason to stop the practice, if it was felt that there were substantially beneficial consequences? Here is the fundamental consequentialist question as articulated by Lorna Wing when describing her reaction to early applications of ABA at the Maudsley Hospital: “I was really quite impressed – but also horrified. Did the ends justify the means?” (quoted by Feinstein (2010, p 159)).

In answering such a question, it is clear that a lot rides on claims about the beneficial consequences, as well as the claims about what kind and level of harm is entailed. For some, the answer seems at first glance to be clear. Thus Milton has written:

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Ethically speaking, behavioural outcomes should never be prioritised over reflection regarding the processes that one uses to accomplish such tasks and the stress that such processes can create for the autistic person.” (Milton, n.d.)

And he cites Donna Williams’ account of the impact of behavioural strategies:

“[Behavioural strategies] ... may feel like a senseless ritual of abuse, regardless of its ‘good’ intentions.” (Milton, n.d., citing Williams, 1996, p. 51)

If we read Milton again, however, we note the emphasis on “reflection regarding the processes” (my italics). He seems to be calling for an imperative to reflect on practice, rather than always to subordinate outcomes in any potential trade-off.

So we need to appreciate fully the nature of claims around efficacy, harms and benefits. I first need to say a bit more about the debate regarding efficacy of ABA in general and EIBI in particular, and then take up the issue of balancing benefits and harms.

2.2.1. The evidence about ABA’s efficacy

There is no unanimity as to whether or not EIBI has been demonstrated to achieve significant outcomes – or at least more significant outcomes than alternative interventions. This is in part due to disputes about what the data reveals. As indicated above (see p. 73 and p. 226) Michelle Dawson and others are forthright in their critique of the claims that are made on behalf of ABA, due to what they consider to be substandard science.

A key challenge here is to establish a robust intervention trial protocol that does not fall foul of the numerous methodological challenges in conducting rigorous trials and I outlined these in Chapter 2 (see pp. 46-47). Notwithstanding these problems, many
reputable sources suggest that there is a greater body of evidence supporting the claims for positive outcome from EIBI than in relation to most other interventions. Within the UK, the evidence for EIBI did not make it through the rigorous Grading of Recommendations Assessment, Development and Evaluation (GRADE) criteria to constitute a concrete recommendation within the UK NICE process, but it is nonetheless an intervention with persuasive evidence according to the Research Autism website, which has official NHS-approved status as being a reliable source of information.

Having said this, no one disputes that the dramatic gains attributed to ABA achieved by some are not repeated in all cases. There is wide heterogeneity of outcome, which may reflect the heterogeneity of the research subjects in baseline abilities, learning styles, interests and preferences – or it may in addition reflect marked contrasts in practitioners’ attitudes, abilities, access to supervision and so on. Even in Lovaas’ original work, less than half of those children receiving EIBI achieved optimal outcome. Experts who have worked in the field will cite a wide variety of responses to EIBI – from those who achieve best outcome to those who make virtually no progress (Lord, 2013). The sensationalism around the “best outcome” group has hidden two important points. On the one hand, less attention is paid to the 53% who did not achieve the dramatic gains. Yet on the other hand, parents whose children do not fall within the 47% but who have received EIBI often declare that in any case, they were not aiming for “optimal outcome” and they still assert that any progress their child does make is thanks to the behavioural approach of the teaching. The iterated position of several pro-ABA parents in non-peer-reviewed publications and

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64 See Bibby et al. (2002).

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on the internet is that only ABA has managed to bring about improvements in their children (for example see Padawer (2014)).

The debate will no doubt rage for decades, and fortunately my case study does not require me to make assertions about the outcomes of EIBI. What I do wish to do is to propose that if EIBI can lead to positive outcomes in certain cases (and I believe it can, for some people and in particular contexts), then by what principle do we set these against potential disbenefits?

2.2.2. Weighing harms and benefits – the welfare calculus

It should first be pointed out that there are some baseline practice standards that are rooted in deontology rather than consequentialist approaches. The fact that most of the ABA community have firmly distanced themselves from the Judge Rotenberg Centre, which still uses electric shock treatment, demonstrates an adherence to some fundamental human rights principles about harm (see Davies (2014)).

Yet on the whole, outcome provides what is felt to be sufficient rationale behind practices in those cases where they do cause discomfort to the child. Thus Gunnar Frederiksen (2013) offers the analogy of a surgical procedure, which will be messy and bloody but necessary and soon forgotten.

Reflecting this consequentialist approach, I consider that many objections about practice are in fact disputes about the consequences of practice. Much of the opposition to ABA is based on its impact on consequences – for example arguments
that it ignores intrinsic learning and that it is overly adult-led fall back at least in part into debates around efficacy.

There are some grey areas however. Mitzi Waltz’s objection to “40 hours of drills” per week for a child is based on the idea that in any other situation, such an approach would be deemed to be abuse. Yet those in favour argue in consequentialist terms that it is when a child is young that s/he is likely to gain most from EIBI. This is linked to ideas about brain plasticity. There is, they say, an optimal window of opportunity to influence a child’s development, and postponing an intervention until they are able to consent might mean that the intervention never happens and that the child is denied access to a potentially life-changing intervention.

However, the Waltz objection still raises questions about whether or not different kinds of intervention are more/less acceptable for those without capacity to consent for themselves. Are different interventions more or less ethical according to the age of the child or infant? No matter how arduous a 40-hour regime of drills might be for an adult, Waltz would presumably feel more comfortable if the adult in question had consented to the programme. But a child is given no alternative, and has not consented. Notwithstanding that Waltz’s objection is based on outdated practice, it is nonetheless a pointer to the significance of the concept of harm and questions of what is acceptable for a child rather than a consenting adult.

These issues can be framed as a further application of Feinberg’s right to an open future (Feinberg, 1980). Taking this stance, arguments in favour of EIBI link to an idea that it will be the best – or only – way of truly “opening up” the child’s future.
Clearly, the above concerns chiefly relate to those children who do not seem to enjoy being on the receiving end of EIBI. While there are those who refer to the negatives of ABA practice, there are other autistic people who look back in extremely positive terms (Applied Behaviour Analysis Ireland, 2014) and large numbers of parents testify to how much their children have enjoyed their behavioural programmes (McCready, 2014). The following, anonymous quotation from a mother sums up how many parents feel:

I make no apologies for the fact that my son is on an ABA programme. He has always loved it. And it has worked very well for him. Behaviourism these days is highly sophisticated, multi-layered, with all sorts of checks and balances built in. (Anon, 2014b)

So far I have suggested that, overall, arguments in favour of EIBI rely on demonstration of positive outcome. I have argued that once we start talking about consequences we are in the territory of trading off harms and benefits, which in turn requires us to appraise contrasting outcomes against a set of goals. I have also referred to the argument that if the goal of reducing autism symptoms is a sufficiently good goal, then some pain along the way in achieving this outcome is justified. Conversely, though, if the goal of reducing autism symptoms is inappropriate, then the fact that the process of achieving it may also carry its own discomforts is an added reason not to embark on the process.

The further point to make is that some or even most EIBI enthusiasts are not exercised about autism symptoms per se, or at all, but are rather just keen to assist the children to have as good a life as they can. This point is illustrated graphically by the following
quotation from another mother who participates in the email community previously cited.

My little girl with severe autism plus epilepsy and learning disability used to self-harm over 500 times a day, drawing blood, slamming her own knee into her face, the works. No-one could help us, no-one had any strategies and I pretty much just had to hold her arms down 18 hours a day, to prevent serious injury. ABA has not stopped the self-harm altogether, nor has it yet given her words, but it has given me the tools to redirect her self-harm, to teach her other, fun things to do with her time, ways of expressing her own personality to me through play and a small selection of signs she has learned. The self-harm is now only maybe 50 times a day. Doesn’t sound like much, does it? But to our little family it is everything. We have our lives back and a window in on our little girl’s world. (Anon, 2014c)

So the next important question to address relates to what positive outcomes actually consist of. It is now time to look more closely at the debates that constellation around what constitutes a good outcome, still using EIBI as a focus point for our discussion.

2.2.3. Unravelling “the good outcome”: contrasting ideas of normalisation and recovery

I have suggested above (see Section 2.1.1) that EIBI is often criticised because it pathologises autism and tries to eliminate autistic behaviours such as flapping and other “stims”. Thus, for some self-advocates, this is a pointer that ABA is actually an intervention that aims to extinguish all manifestations of autism – P-1.

Yet for others, including the mother quoted above, the use of ABA is viewed simply as an attempt to address problems for the individual, for example by promoting their safety and enjoyment. For parents whose children receive ABA and who continue to have difficulties of communication and learning, their reasons for favouring ABA are couched in terms of impact and efficacy but not in terms of achieving normal functioning or a reduction in autism symptoms. For example, we learn of children
who can now use the toilet, who no longer display distressed and violent behaviour, whose frequency of self-injury has reduced, who no longer experience pica (digestion of non-nutritious substances like paper, stones, glass), children who have acquired the ability to use augmentative communication systems – thanks, the parents say, to ABA. Such parents have no agenda of eliminating their child’s autism, nor their learning disabilities, but rather in making life easier, safer and more rewarding for their child in key practical areas. Not only are they citing ABA as a P-2 intervention, but also they are offering an insight into the kind of outcomes that they hold valuable – outcomes that for them are far more relevant than whether or not their child is any less autistic than they originally were.

Where some behaviour analysts do defend the approach to reducing certain types of “stims”, they argue that this will make the child less vulnerable to bullying and marginalisation. If autistic children can learn to function amongst others in a way that draws less negative attention, then – it is argued – surely it follows that enabling them to behave in ways that are less stigmatising can only be to the good (Schreibman, 2005, p. 238). Schreibman is arguing that it is in the child’s best interests to learn to adapt and modify his/her manifestations of autism and that this is different from attempting to modify autistic behaviour for its own sake (as implied by critics).65 Proponents of ABA want the children to have a good life long term, regardless of whether the children retain or shed their diagnosis.

65 A further, practice issue that ABA practitioners stress is that they do not merely extinguish behaviours, but rather, teach children to redirect their behaviour into a more socially acceptable channel, so they can achieve the same satisfaction without incurring so much stigma.
The problem with this well-intentioned justification is that, according to a neurodiversity perspective, it is unfair to require the victim to do the changing when it is the NTs who are doing the bullying, and further that the process of trying to “pass” can be very damaging. An example of the one-way nature of behavioural adaptation that is being required is offered by Ari Ne’eman, cited by Ruth Padawer (2014):

“Eye contact is an anxiety-inducing experience for us, so suppressing our natural inclination not to look someone in the eye takes energy that might otherwise go towards thinking more critically about what that person may be trying to communicate. We have a saying that’s pretty common among autistic young people: ‘I can either look like I’m paying attention or I can actually pay attention.’ Unfortunately, a lot of people tell us that looking like you’re paying attention is more important than actually paying attention.”

What all these examples demonstrate is the multiple ways we might view a “good outcome” – to eradicate autism in some organic sense, to behave as if one were NT, or to access certain goods, like being free from stigma and acquiring the means to have one’s preferences and needs understood by others. Some might argue that it is not possible to achieve the third unless one addresses the first and/or second, or they feel that it will be easier for the minority (autistic) population to adapt to the majority, than for the majority (NT) to alter their requirements of acceptable social interaction.

Perhaps unsurprisingly, therefore, views within ABA of what “normal” and “recovery” mean in relation to what is the underlying “good outcome” have been wide open to interpretation. I am now going to explore the differences of meaning in some detail in order to tease out further the ambiguities underlying any sense of a positive outcome and – crucially – to identify what is perhaps one of the biggest areas of potential agreement.
2.2.4. “Recovery” and “normalisation” within ABA

I suggested above (p. 212) that a good outcome has variously been conceptualised as resulting from interventions that achieve either:

- Biological change leading to organic features of autism no longer being present (the goal of P-1 (a) interventions);

or

- Behavioural change leading to the loss of an autism diagnosis (P-1 (b) interventions);

or

- Behavioural change leading to the ability to function in society, but retaining a diagnosis/identity as autistic (the goal of P2 interventions).

What I am about to demonstrate is that arguments about whether claims of ABA’s beneficial impact relate to P-1 (a) or P-1 (b) have often distracted critics from recognising that ABA is best viewed as a P2 intervention.

The heat and discomfort around all of this is most apparent when claims for ABA are made both for both recovery” and for “normalisation”.

“Recovery” has been associated with the best-outcome group of the Lovaas studies, even though Lovaas distanced himself forcefully from the term. He also made a distinction between “normal” functioning in terms of performance against various standard measures, and the attainment of neurological typicality. He allowed for the possibility of residual problems (1987, p. 8) even in his “best outcome” subjects.
Further, in response to criticism that using the word “recovery” has bad connotations, Smith and Lovaas (1997) stated,

we have never even considered cure as a possibility … The use of cure would certainly be unethical because it would imply falsely that we had identified the cause of the autism displayed by children in the study, and then removed this cause … Instead of “recovery” or “cure” we have used either “normal functioning” (referring to performance in the average range across outcome measures) or “best outcome” (referring to a subgroup that appeared to have a much more favourable treatment response than other intensively treated children). … On one occasion, we used “recovered” as a column header in a table (Lovaas, 1987, Table 3). In retrospect, this may have caused unnecessary confusion (which we regret), but we did not claim recovery or cure. (1997, pp. 203–204, italics in original)

Further, they asserted (1997, p. 203) that accusations of claims to produce recovery verged on slander. They were therefore seeking to distance themselves forcefully from the use of the term. As such, they are in effect claiming that their view of a good outcome is most definitely not P-1 (a), though there is still ambiguity as to whether it is P-1 (b) or P-2. However (and, I believe, unfortunately), others within and around ABA circles have continued to use the term “recovery” (e.g. Helt et al. (2008), Rogers and Vismara (2008)).

In the title of their 2008 paper, Helt et al. ask the questions, “Can Children with Autism Recover? If So, How?” The criteria for recovery they put forward contain a composite of “before” and “after” characteristics in the individual. The “before” relates to the requirement that the child has a “convincing history of ASD” where this includes early childhood diagnosis and early language delay. The “after” relates to current functioning, whereby the child is learning and applying a core set of skills at a level and in a way that “reaches the trajectory of typical development in most or all


areas” (Helt et al., 2008, p. 340, italics in the original). They are therefore equating “recovery” with a P-1 intervention, without specifying whether the outcome is P-1 (a) or P-1 (b).

The current functioning elements are further spelt out to include meeting no criteria for any pervasive developmental disorder (PDD) or ASD, and the absence of individual or autism-specific learning support in school. Similarly, but not identically, Rogers and Vismara (2008) define recovery to mean outcome IQs in the normal range, and educational placement in typical age-level classrooms without support (pp. 24-25), and then later as “test scores in the normal range, regular successful school placement and performance, and lack of disability” (2008, p. 31). This again implies a P-1 intervention without clarifying whether its outcome relates to (a) or (b).

However, of note is that these criteria do not relate to identifiable biological features (e.g. specific neurological facts), but rather describe a combination of behavioural characteristics – linked to the diagnostic criteria for autism previously discussed – and institutional functioning within the education system – mainstream classroom and no learning support. Given the variations of education policy and practice criteria for accessing both mainstream classrooms and additional learning support, and the fact that these do not correlate in any absolute way with clear, fixed levels of “need”, the latter component does not offer a precise tool for defining a child-specific level of functioning (see also Fitzpatrick (2009b, p. 71)).

The question is, then, whether the “recovered” individual using the Helt et al. criteria has changed organically, or only behaviourally; that is, whether the outcome is P-1 (a)
or P-1 (b). But in addition, there is a further variable in the form of the additional component of mainstream schooling. This introduces an environmental variable that is societally located and as such may be independent of the child’s individual characteristics. So Helt et al. have implied a P-1 intervention that is at least in part dependent upon issues that rely on the conditions associated with P-3 interventions.

The fact that the definition of recovery is imprecise is acknowledged by Helt et al.: they go on to illustrate modifications to these “working criteria” for recovery as they apply to individual children, with the implication that in practice such modifications may frequently be necessary, and as such the concept of “recovery” is imprecise (2008, p. 340). They also acknowledge that there are many researchers and clinicians who are highly sceptical about the possibility of recovery in autism and who assert that the organic nature of autism means that “recovery” is somehow by definition unattainable (e.g. Schopler, Short and Mesibov (1989) and Mundy (1993)). Similarly, Cohen (1998) asked, “Are these individuals recovered, or are they autistics with near-normal functioning?” (1998, p. 170). What the sceptics are implying is that the term “recovery” should be preserved for application only in relation to organic change – i.e. P-1 (a) outcomes. This is even though there are no mechanisms yet for identifying whether such change has taken place.

In contrast, Helt et al. suggest that “recovery” /optimal outcome applies in the case of P-1 (b). But – like Lovaas, who talked about the possibility of residual problems – they go further, and suggest that this is not the same thing as being free of any vulnerabilities.
The claim of recovery from autism does not necessarily entail the claim of fully normal cognitive, social and emotional functioning. Children who have recovered from autism are at risk of other disorders, and thus may not be fully normal. Research is required to identify these continuing vulnerabilities, both for what they can tell us about autism, and for what they can tell us about the children’s continued treatment needs.” (2008, p. 341, my italics)

This now introduces an idea of recovery as something different from the attainment of “normal species functioning” and it also raises the question of what constitutes “optimal outcome” in the context of these continued vulnerabilities. On the basis of their trawl of the data that is available, Helt et al. tentatively suggest that “the residual vulnerabilities of the recovered children appear to include anxiety (especially social anxiety), depression, tics, attention problems, and perhaps continuing difficulty with higher-level, complex social and language interactions” (2008, p. 348).

These are not trivial vulnerabilities. What we can infer from Helt et al. is that “recovery” does not mean the same thing as “cure”, where this implies freedom from all difficulties and symptoms associated with an underlying disease. Further, it does not herald “optimal functioning” if that is taken to mean a symptom-free existence. They seem to be implying that the organic features of autism may have lasting impact on an individual, even if this impact is not captured or described by the criteria for diagnosing autism or conferring the status of recovered.

In response, critics of ABA, such as Broderick (2009), state that even if ABA practice acknowledges falling short of attaining neurological or biological normalcy, it still, wrongly, holds as valuable the goal of behaving as if one were neurologically normal (or typical).
However, the salient issue is not whether Lovaas or other behavioral researchers use the term recovery …

The salient issue is that engagement with this discursive construct of recovery relies on and reinscribes particular ideological beliefs about the nature of disability and the constructs of normal and abnormal. Autism is constructed as a disability, certainly, but one from which one may recover and gain (or regain) the invisible privilege of the status of normalcy”. (2009, p. 275)

As such, Broderick is critical of what she perceives to be an ABA agenda favouring P-1 ((a) or (b)).

2.2.5. P-1 (b) as a goal that reaches beyond ABA?

It is worth pausing at this point to challenge Broderick’s isolation of ABA as the lone or indeed the key villain here. The pressure to behave as if one were not autistic is something that extends far beyond ABA. Able autistics – including those who have never received any intensive behavioural interventions – have spoken about the imperative, which emanates from wider social pressures throughout their lives, to attempt to feign neurotypicality in virtually all social and public situations. The above quotation from Ne’eman was revealing in this regard (p. 236)67. “I get so tired of having to switch on my ‘neurotypical emulator’ in social situations” is how one autistic colleague, who had never been the subject of any ABA intervention, expressed it (Anon, 2006). Further, as I have stated elsewhere, many intervention studies that are not related to ABA use reduction in autism symptomatology as a measure of positive outcome. One wonders therefore whether those who have developed their own “NT emulators” are simply those who have achieved – unassisted – precisely the same outcome as that which the criticised ABA practitioners aim to achieve through their particular approach to teaching. In both

67 See also Lawson (2008) for extensive analysis of this.

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instances, one may rue the fact that autistic people have to try to “pass” as NT, but see this also as a necessary step to participation in wider life.  

2.2.6. Describing positive outcome in new terms?

The challenge is therefore to find indicators of outcome that are genuinely reflective of a shared understanding of progress towards a good goal for autistic people. Those who defend trying to change autistic behaviours may implicitly be arguing for a hierarchy of goals: normal functioning may not be valued for itself but may nonetheless be viewed as the best way to ensure that a person will access a life that they will enjoy and find fulfilling. Here we see that eliminating autism is not the end goal, but rather it is viewed as a significant proxy for achieving a good life.

The question then is this: should new terms be sought to reflect this, or can “recovery” and “normalisation” shift to a new meaning – one that reflects P-2 or even P-3? I will show in the following section that both terms have in fact been used in this wider sense, which takes them a long way from the standpoints of P-1 (a) or (b).

2.2.7. “Recovery” as P-2 (or even P-3?)

On the basis of the analysis thus far, it appears that there is some drift between what “recovery” seems to convey – the phrases “optimal outcome” and “normalisation” are often used interchangeably – and the actual functioning or well-being of the individuals who attain it. The drift becomes even more marked when one explores other literature where “recovery” does not even require – as it does for Helt et al. –

\[68\] Such observations echo the wider analysis of stigma offered up within sociology and disability studies about the pressures to pass (see Goffman (1968) and Scully pp.126-127)
the removal of the autism diagnosis. Grandin was described as a “recovered autistic individual” by Bernard Rimland when he wrote a foreword to her autobiography, as she went from “an extremely handicapped child who appeared to be destined for permanent institutionalization” (Rimland (1986) p. 7) to an independent and professionally successful adult. An important point about Grandin is that while describing herself as recovered, she also holds on to and positively affirms her autism.

Thus, Grandin described her own “recovery” in the following passage:

I recovered because my mother, Aunt Ann, and Bill Carlock cared enough about me to work with me (Grandin and Scariano, 1986, p. 184)

Broderick cites other examples of autistic people who have done well but who have not lost their identity as an autistic person. Sean Barron described himself as “overcoming autism” (Barron and Barron, 1992, p. 255), but without the expectation of being cured: “I know quite well that my autism will always be part of me, that it isn’t something I can expect to be ‘cured’” (p. 254).

Broderick offers a way forward here by extending – or arguably transforming – an understanding of what “recovery” might mean, so that it need no longer negate the narrative identity or diagnostic status of someone as autistic. She suggests that in the biographical cases, “the term recovery appears to be discursively constructed to describe a particular level of participation in ordinary life (e.g. jobs, college, friends, marriage) without necessitating a disavowal of identifying one’s experiences and one’s self with autism” (2009, p. 268).
Broderick asserts that this view of recovery is “qualitatively different from the meanings and significances” of the term in the discourse surrounding ABA. She argues that only “biography-based discourse”, emphasised by the non-behavioural communities, values the process of increasing participation and success in ordinary spheres of life, and that only non-behavioural discourse enables individuals to experience the effects of autism in a way that is not disabling or substantially limiting. She suggests further that it is non-behavioural discourse that enables us to move a view of “normalisation” away from individuals’ behaviour, towards the Scandinavian model of normalisation, which favours external criteria such as de-institutionalisation as a feature of the rights of people with learning disabilities:

The normalisation principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society. (Nirje, 1980, p. 33)

Likewise, Broderick points out that the meaning of “recovery” can shift from a requirement that the diagnosis of autism is lost, to a broader social notion of inclusion and participation of the autistic individual. In other words, as a goal for intervention, Broderick’s analysis has shifted the nature of the intervention necessary to bring about “recovery” from the individual, through to a social and political intervention linked with transforming social conditions and honouring rights.

So, summarising Broderick’s position thus far, she is critical of ABA because she feels it is a P-1 intervention, while her preferred intervention is located within P-3. She has set up a polarity between (a) “the process of increasing participation and success in ordinary spheres of life” and (b) her interpretation of ABA discourse, where recovery is actually about “being normal” (italics in the original).
I have suggested regarding the latter point that the idea of aiming for this kind of “recovery” extends beyond ABA discourse, and further that actually even within ABA the goal of “normal behaviour” is in some quarters viewed purely as a proxy in order to achieve “normalisation” in the broader sociological sense. Where there is interesting room for debate is in how we analyse the impediments to achieving this alternative view of normalisation. Broderick is implying that we should de-problematise autism per se, and instead look at what are the impediments to participation and success in the ordinary spheres of life. If we do this, she suggests, we might have a very different set of targets for autism interventions.

Thus, these contrasting ideas of “recovery” and “normalisation” suggest something significant about how we view interventions in autism more broadly. Broderick is suggesting that the quest for normal species functioning is a red herring. For example, when drawing on the meaning of recovery within literature on and by survivors of psychiatric illness:

> Recovery is not fundamentally or primarily about reduction or remission of symptoms or other perceived deficits to more closely approximate or regain a status of behavioral or psychiatric normalcy. Instead, this notion of recovery acknowledges the discriminatory and disabling circumstances that one often experiences in relation to the cultural stigma and concurrent loss of cultural capital associated with one’s identity as a psychiatric patient. This focus on the social contexts of recovery is not in place of a focus on symptom reduction but is the undeniable and central context within which one’s efforts toward symptom reduction are couched. (2009, p. 278)

Broderick’s critique has identified the limitations of viewing positive outcomes solely in terms of individual functional and behavioural change towards NT behaviour within or by the autistic person. She broadens the arena in which we are required to address ourselves, to incorporate moral, social and political context. She has argued,
in effect, for the necessity, and the superiority, of P-3 interventions, even though P-2 interventions are acknowledged as important.

But it is not clear that the behaviour-analytic community would dispute this analysis. It is possible that Broderick has set up a false opposition in implying that wider societal interventions are not supported broadly, and/or that the type of normalcy aspired to within behavioural discourse does not incorporate this wider perspective. This is the view offered by Eyal et al., whose sociological approach to autism nonetheless affirms the role for ABA:

ABA is often attacked today – unjustly, we think – as being overly rigid, disciplinary, “normalizing” in the pejorative sense. We would like to demonstrate, therefore, its intimate and enduring affinities with the radical and progressive side of normalization. (2010, p. 122)

(See also (2010, pp. 122–126) for Eyal et al.’s further explanation of this view.)

2.3. Reflections on case study

The case study has rehearsed several of the bioethical arguments that were introduced when discussing pre-birth interventions (Chapter 4). I have again adopted arguments about welfare balancing, harms and benefits. Questions of autonomy and consent, linked with questions about autistic narrative identity, have once again been relevant, while the disability rights perspective has significance in how we view different notions of “recovery” and “normalisation”. Questions of parental virtue emerge in relation to what kind of interventions parents choose for their children and why. It is sometimes alleged that those who choose ABA are unable to accept their children’s...
autism while parents respond that they are merely trying to help their children survive in the world.

Thus, debates about EIBI often take the form of arguments between (1) those who see any equation between reduction in autism symptoms and a good outcome as ablist and oppressive, and (2) those who view “acceptance” or celebration of autistic behaviours as an excuse for doing nothing to help autistic people. The controversy therefore sheds light on the essential elements of disagreement about how best to intervene in autism, polarised as treatment vs acceptance. In particular, the discourse around recovery illustrates ambiguity as to whether outcomes are – or should be – judged in terms of achieving individual change or societal change, and – within individuals – whether the relevant change is organic or merely behavioural.

Yet I have also hinted that contrasting views on the ethics of aiming to reduce autistic symptoms may actually disguise shared views, among apparent opponents, about what are important, broader long-term outcomes. I have further argued that in the case of “recovery” and “normalisation” one term can be used to cover a range of markedly different goals. My concern is that if “recovery” and/or “normalisation” mean different things to different people, then equally they may be welcomed or rejected wholesale without appreciation of the nuances that in turn will reveal whether or not people do actually share the same goals, or have fundamental differences, about optimal outcomes for autistic people. Such ambiguities may lead to polarisation – as exemplified in the treatment vs acceptance debate – when actually the underlying beliefs about what is a good outcome could be quite close.
With this in mind, it is now time to engage in further analysis of the differences, and potential overlaps, in the three categories of post-birth intervention I outlined previously in this chapter. In so doing, I wish to expose the areas of conflict that reflect fundamental moral differences, and also the areas of imagined conflict where underlying normative positions are actually congruent. Some polarities may be more apparent than real, once they are deconstructed, although other points of controversy with respect to autism interventions remain, once this deconstruction has taken place.

3. The relationship between the three categories of post-birth intervention – revisiting the “treatment vs acceptance” polarity

I have demonstrated that choices of interventions may relate at least in part to views on what is empirically possible, rather than to what they reflect about attitudes to autism overall.

This is important because the framing of the “treatment vs acceptance” debate ignores the nuances and creates a polarity of positions about autism itself that may not be accurate. To recap from my introduction (see above p.2), those on the “treatment” side of the debate are perceived by critics as overproblematising autism, and in so doing undermining and ignoring the personhood, strengths and rights of autistic people to be different-but-equal. In contrast, those on the “acceptance” side of the debate are perceived by critics as ignoring or understating the real problems that autistic people and those around them experience, and as such they are accused of inappropriately celebrating a condition that is, in the absence of helpful interventions,
antithetical to flourishing – that is, for using “acceptance” as an excuse for “doing nothing to help”.

If we plug these positions into the post-birth intervention categories I have outlined, we can see that the treatment vs acceptance debate is positioned, in effect, as a P-1 vs P-3 debate, and one in which there is no common ground. Yet in actuality, not only does this ignore P-2 but also it ignores the potential for overlap and interdependence between the categories.

In an attempt to clarify both the distinctions and the interdependencies, I will now set out five propositions.

3.1. Five propositions regarding the three categories of post-birth intervention

1. P-3 interventions can stand alone

One does not have to believe that any kinds of P-1 or P-2 interventions are necessary in order to call for P-3 interventions. Some P-3 interventions can stand alone – examples being changes in the built environment to reduce sensory overload for autistic individuals, the anti-bullying campaign referred to above (p. 216), or procedural adaptations that fit with the notion of “reasonable adjustments” as outlined in UK equality legislation. This is not the same thing as saying P-3 interventions alone are sufficient (though some might argue that they are). But rather, and in contrast, P-3 may be necessary to ensure the availability of P-1 and P-2 interventions.
2. P-3 interventions may be necessary for P-1 and P-2 interventions

Regardless of the relative weight we give to the merits of P-1 and P-2, they are to a considerable degree contingent upon the wider environment in which interventions are made available.

If one believes that interventions focused on the individual are necessary or beneficial, then it follows that they should be available and accessible, and questions of resource allocation are central to this. If interventions can only be purchased privately, there are equity implications. If they are publicly funded, then there are wider resource questions about relative weighting of investment in contrasting interventions.

Thus, arguments about the relative merits of P-1 and P-2 interventions may divert attention from a wider set of issues about justice, and lead to a bigger question about what overall level of support and education autistic people can call upon from wider society. A political campaign to increase the support for autistic people may therefore be a prima facie good goal. It is firmly a P-3 intervention, but with its roots in believing that P-1 and/or P-2 interventions are useful and significant.

I believe this reflects the reality. Frustration and indignation about the limits placed on services for autistic people, as well as the lack of strategic planning and central initiatives that contribute to their availability at a local level, are issues upon which most stakeholders and professionals will agree. So, the polarisation of “treatment vs acceptance” is in danger of hiding the fact that P-3 interventions are not antithetical to
P-1 and P-2, but rather they may be crucial. As such, one would expect P-3 interventions to gain the greatest amount of support from across the stakeholder community.

3. P-3 interventions may nonetheless require downstream decisions about P-1 and P-2 interventions

Another example of the interrelationship between P-3 and P-1/ P-2 interventions is in relation to initiatives to set up new services and ventures, such as new autism units attached to mainstream colleges or schools and new social enterprises for autistic people. These developments constitute a change in the wider institutional environment, even though the work of the new units will be of the nature of P-1 or P-2 interventions. In this sense, a construct in which interventions devoted to wider change are viewed as in direct opposition to interventions targeted at individual change is a false dichotomy, and it is in danger of polarising a “treatment vs acceptance” argument that is more imagined than real. This echoes the points made by Shakespeare (2006) about the need to reconcile and integrate both social and impairment-based models of disability.

What I am suggesting is that, although some P-3 interventions stand alone, other P-3 interventions will rapidly collapse into necessary decisions about P-2 and P-1. Although P-3 interventions may be the interventions that generate broadest support and, further, they may be the least ethically problematic, this may only obtain when they are framed at a highly general and impersonal level. The ethical imperative to respond to autism at level P-3 is less contentious the more broadly it is framed as a
goal, but the challenges and the ethical debates magnify the more one drills down into specifics.

4. P-2 interventions could benefit from greater dialogue amongst stakeholders as to their nature, purpose, and emphasis

Most autism advocates are not opposed to individual interventions to assist with areas of difficulty, although they may vary in the language they use to describe P-2 interventions. Thus “Ne’eman and others strongly support treatments that improve communication and help people develop cognitive, social and independent-living skills” (Padawer, 2014). As such, while autistic advocates may be suspicious of the underlying ideological stance of practitioners – that is, one that unthinkingly equates reduction in autism symptoms with a positive outcome – they are not opposed to targeted ways of helping individuals, where these ways embrace a pro-diversity perspective.

So, while the emphasis of advocates’ focus is on P-3, they are not arguing that P-2-type interventions should be unavailable. The possible benefits in principle of reconfigured P-2 interventions that are respectful and reciprocal are not in dispute. This reflects the point made by Broderick quoted above, that a focus on the social contexts of recovery is not in place of a focus on symptom reduction but is, rather, the central context within which efforts towards symptom reduction take place. The goals or mechanisms for P-2 and P-3 are not in opposition. Rather, we need to be mindful of broader issues when addressing individual interventions.
What is key in these cases is that the goals of the intervention, and the measures used to evaluate outcome, focus on issues that are felt to be relevant for and by autistic people themselves and those around them – and are not simply reduced to a change in the core symptoms of autism - since these may turn out not to be the key areas of difficulty for the individual.

5. Among postnatal interventions, P-1 interventions pose the greatest ethical problem

P-1 interventions are often opposed in principle by autism advocates and here the polarisation may indeed reflect a conceptually irreconcilable difference.

This is because P-1 interventions – be these couched in terms of achieving organic change (P-1 (a) or loss of diagnosis (P-1 (b)) – would seek to remove autism, “and therefore autistic people” (Dawson, 2004), in toto.

Some might argue that there is a relevant distinction between P-1 (a) (organic change) and P-1 (b) (loss of diagnosis), since – as the case study revealed – some of the controversy around ABA relied on claims and counterclaims according to this distinction. But if we hold on to P-1 (b) as a good goal, we are still seeking a world in which people do not behave as if they are autistic and/or a world in which the diagnosis of autism is abandoned. Those who advocate for post-birth prevention/cure are not simply calling for diagnosis to cease; they want there to be behaviour change in autistic people. In effect, to call for P-1 is tantamount to saying to existing autistic people, “the world would be a better place if there were no more people like you in it”.

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Advocates of P-1 therefore fall foul of the expressivist concern – one that (as I discussed in Chapter 4) many ethicists take particularly seriously. As with other areas of discussion, whether or not P-1 advocates intend to make such a sweeping point does not detract from the semantic properties of the message. For example, by making it clear that the implication of P-1 is that there should be no more autistic people in the world, I may be going further than some people who call for cure and prevention really want to go. If those who call for P-1 actually baulk at making such a statement – for example to Temple Grandin, or to their autistic relatives – then they need to reflect on whether they are squeamish out of politeness or because they have encountered a position of dissonance. It may be that when faced with this reductio, they opt to move away from P-1 and say that they favour effective and respectful interventions within P-2 and P-3 – measures that can enable autistic people to flourish and to fulfil their full potential.

Alternatively, rather than calling for a future world in which there are no more autistic individuals, they may be calling for a future world in which people can choose, or not, whether to opt for treatment/prevention measures. The problem with this second position is that the choice is unlikely to be that of autistic people themselves, since in virtually all the scenarios referred to – pre birth or in infancy – the potentially autistic person does not make the choice. It is made for them, by parents and professionals, before the individual in question has a chance for an autistic narrative identity to emerge. This means that people other than autistic people are making judgements about the quality of life of autistic people, something that has elicited wide criticism in other areas of disability and difference. More will be said about this in Part 3.
4. **Taking stock**

At this point I want to take stock and highlight some of the implications of what I have argued so far in this chapter. The exposition above has led to some important conclusions.

The first is that P-3 interventions should, logically, elicit the broadest level of support, while P-1 interventions are ethically the most problematic.

I have also argued that P-3 interventions are not only compatible with individually focused interventions, but may be necessary for them to be available, and that the polarisation of P-3 versus P-1 (ignoring P-2) is inappropriate. The issue is not one of either/or alternatives so much as of emphasis. In this way, what autism advocates have criticised to date is the *dominance* of the individual-based-behaviour-change approach, where the onus for adaptation has been entirely one way – that is, all the pressures for the change apply to autistic people, with no reciprocal adaptation from NTs. In response, broader measures in the environment are put forward not only for their practical impact but for their symbolic significance in recognition that adaptation needs to be two way.

My second observation is therefore this: that semantic ambiguities – such as using one term (e.g. “recovery”, “normalisation”, “treatment” and “acceptance”) to mean more than one thing – may exacerbate polar perspectives, whereas attempts to be more
precise about concepts and terminology may allow for fruitful discussion about ethical issues.

Third, the discussion has shown that the polarity of belief has two distinct components of controversy: one is disagreement about the desirability of removing autism *in toto*, and the second is disagreement about whether, in any case, this is a realisable aim. But beliefs about goal and achievability are actually distinct, and as such the moral positions are more complex. For example:

- As I hinted above, within P-2 there may be professionals, parents and academics who hold the goal of eliminating autism as desirable, but nonetheless think this is impossible, and so they have to settle for promoting certain kinds of adaptation and/or skill acquisition within autistic people. They would like to see P-1 but have to settle for P-2.

Conversely:

- There are many parents, practitioners and some autistic people who feel that societal change is a highly desirable goal, and yet believe that society will never change, or not in their lifetime. Because of this negative view of the prospects of social change, they consider the best way to help autistic people at present is to teach them skills of adaptation and accommodation. They long for P-3 but have to settle for P-2.

And moreover:
• There may be people who use the language of P-1 when actually, if pressed to see the implications of their words, their position is one of P-2. What they are calling for is P-2 interventions that have substantial impact for making autistic lives better, rather than for interventions that eliminate autism.

A nuanced approach is therefore necessary to disentangle the broader contextual realities from the micro choices facing individuals. Working towards societal change is a massive, complex and long-term project. Meanwhile, people are faced with local and more short-term choices about how best to live as, or be supportive to, autistic individuals. In the short term, and in some situations, providing support, skills and compensating strategies – including behaviour modification – may be crucial, in order for them to participate in the ordinary spheres of life.

Views on how best to serve the interests of autistic people therefore embrace wider views on what kind of world we live in, not just views on autism itself. It is for this reason that questions of justice and equity and the organisation of the political community enter the realm of bioethical discourse in relation to questions of disability. A key text in this area is the work of Buchanan et al. (2000) but there are several others, some of which I will be referring to in the next chapter. For now it suffices to point out that, by separating the empirical possibility issues from the desirable goal issues, I am demonstrating how closely linked they are to wider perspectives: they feed into views on how the individual is to thrive within a wider community and also how, if at all, changes to that wider community can or should be made. This theme has echoes of the “great conundrum” idea put forward in Chapter 4, whereby there is
a confused relationship between the local choices that are made within a particular
countext, and the wider society in which they are made and on which they may impact,
and also the wider society one might aspire to.

A further theme that has been iterated previously is the question of how autism is to
be conceptualised – the analogy challenge. When exploring what we might mean by a
good outcome, I have discussed the distinction between (a) increasing participation
and success in ordinary spheres of life, and (b) the attainment of neurological and/or
behavioural “normality”. If autism is nearer to being a serious disease and further
away from being a difference, then the best outcome is biological/behavioural
normalisation through measures that fit within a goal of prevention and/or cure. If the
analogy is more appropriately that of disability or difference, then individual and
environmental adaptations are likely to be interrelated and mutually influencing. In
the second case, a quest to eliminate autism in toto would be seen as a massive
overreaction to the real-life problems autistic people face.

I intend to unwrap these two big issues – the big conundrum and the analogy
challenge – in the next chapter of the thesis, which will discuss those areas of my
enquiry that have been implicated in preceding chapters but not yet scrutinised.
Part 3

Discussion and recommendations
Chapter 6 Discussion

Introduction

The purpose of Part 3 is to take a step back and interrogate the key themes that have been referred to in previous chapters, and then to make recommendations on the basis of any conclusions reached.

In order to contextualise these themes, I will first summarise what has been addressed in preceding chapters.

I have proposed a framework for analysing the ethical issues that are relevant with regard to autism, according to six categories of intervention. These categories between them explore actual or potential scenarios in which interventions might be made – from pre-conceptual measures through to interventions on fetuses, from individual-based interventions from babyhood through to adulthood, and including wider measures to affect the broader societal and institutional environment. What has been apparent throughout all the scenarios is that the ethical issues are complex – a complexity to which simple statements about cure or prevention do not do justice. All the ethical issues presented have been sensitive to contrasting perspectives on autism – perspectives that I introduced in Part 1 when exploring how ideas about autism have evolved, how knowledge around it has developed, how contrasting ways of experiencing and understanding it have been portrayed, and how it has been addressed in the ethics literature.
From the exploration in Parts 1 and 2, there emerged some key areas that were flagged as requiring further analysis. These were:

**Perspectives on “the good life”**

With regard to pre-birth interventions, as discussed in Chapter 4, it was recognised that many of the ethical issues around selection entail predictions about the quality of life a person will have once they are born, set against some baseline criteria for assessing quality of life. What these criteria consist of was left open-ended and noted as requiring further examination. Similar issues were encountered in Chapter 5 in terms of how to evaluate a positive outcome for autistic people.

Given that many of the ways in which prevention and cure have been discussed in the literature and within contemporary practice relate to interventions before an autistic person has acquired capacity to make informed choices, the morality of such interventions is closely bound up with how parents are to judge best interests on behalf of their children. This means that in addition to exploration of the components of the good life, an ethical exploration also leads us to the domain of parental virtues.

**Parental virtues and values**

Parental virtues and values – alongside rights and obligations – were considered to be of fundamental relevance with regard to pre-birth decisions in Chapter 4 and reappeared as a theme in Chapter 5 with regard to choices post birth. The question of how we determine the right balance of parental love and aspiration, acceptance and challenge with regard to autism has underscored much of the discussion throughout
the thesis, and it is time to go further than I have done so far to look at some of the ethical issues that are implicated.

“*The big conundrum*”

This is the term I have used to encapsulate the possible disconnect between the moral issues affecting local choice and the wider consequences of that choice in terms of the impact on general states of affairs. This local/societal distinction mirrors the contrast between approaches to disability, in which it is regarded either in terms of a (medicalised) problem within an individual or as a broad category of oppression arising from forces within society as a whole. I now propose to tease out the implications of this disconnect – which underpinned many of the issues discussed in Chapter 5 with regard to autism – and to highlight the dilemmas it presents for making moral judgements.

**The analogy challenge**

Finally, the abiding theme throughout the whole thesis has been the challenge of pinning down what, if anything, autism consists of – be this conceptually, biologically, behaviourally or experientially. I have also argued throughout that much of the moral content of different types of intervention – particularly around prevention and cure – rests on how autism is viewed. In addition to examining how autism impacts on notions of the good life, it is important to appreciate how contrasting ideas of autism as disease/disability/difference substantially influence the language used, and assumptions made, about what “should be done about autism”. I have alluded to possible contrasts in how autism is viewed already, but below I intend to go further in stating my own position.
The combination of these discussions will then inform the conclusions and recommendations that will make up the final Chapter 7.

1. Perspectives on “the good life”

Many of the arguments presented throughout this thesis have opened up questions about how we are to evaluate a good life, requiring us to probe what a good or bad intervention is, and to reflect on what we might mean when interpreting the overall traditional bioethical requirements for beneficence and non-maleficence. Different interpretations of concepts like “recovery” and “normalisation”, and the conflict around them, sometimes cloud the issue and generate conflict, but in searching for new language for what is meant beneath these terms, do we know what a good outcome looks like for autistic people and those around them? Will it be possible to work towards a shared understanding about the components of a good quality of life for autistic people? Or does the heterogeneity within autism, like the heterogeneity of humanity, require a diversity of criteria by which to judge flourishing?

My key task in this section is therefore to review what has been said in the wider literature about ways of evaluating and measuring quality of life / good lives / flourishing, in order to see if – or how and in what ways – autism affects whether or not they can be attained. This is an enormous territory and it is not possible to cover all of the ground here. My more narrow purpose is to explore how different notions can illuminate or hinder us when asking about the ethical principles at stake in seeking to prevent or cure autism.
Contrasting ways of addressing the question of quality of life within ethics are covered in the next four sections. The first addresses the idea of suffering within a consequentialist/welfare framework; the second addresses enquiries into moral status and entitlements viewed through the prism of deontology; the third explores the realm of virtues; and the fourth introduces the ethics of caring.

1.1. The welfare calculus – perspectives on suffering with regard to autism

I have argued – when evaluating the morality of contrasting interventions at pre- and post-birth stage (Chapters 4 and 5) – that bioethics draws heavily on a welfare calculus, taking on board ideas of harm and benefit, and that the process of calculation derives from a consequentialist approach to morality with an emphasis on avoiding or alleviating suffering.

With regard to autism, even if the word “suffering” is not always used, much of the discourse in both academic and lay communities implicitly or explicitly relates to the relationship between autism and suffering or autism and reduced well-being, relative to a neurotypical (NT) “norm”. Reasons for this included the medicalisation of autism as pathology, the long-term outcomes studies, and the climate of parental and professional advocacy (see Chapter 2, which introduced these themes). Although in Chapter 4 I have referred to the rephrasing of the concepts of suffering and well-being in some of the reproductive-choice literature – for example to “life worth living”, “best possible chance of”, and “ordinary chance of a desirable existence” – the
underlying sense is an equation of a particular condition with its impact on the individual; that is, in terms of well-being / the absence of suffering, in a utilitarian sense.

Murray (2012, pp. 20–23) suggests that the conflation of autism and suffering exists even amongst those who affirm the strengths that come with the condition. Thus he points to Baron-Cohen’s assertion that “a diagnosis is only given if a person is suffering to some degree” (Baron-Cohen, 2008, p. 29, italics in the original). Murray is critical of such a conflation: “the fact that for Baron-Cohen the presupposition of suffering is a structural part of the evaluative process of autism produces a working version of the condition that has an assumed negativity and a normalized value-judgment built into its medical/diagnostic baseline” (Murray, 2012, p. 21, italics in the original). The medicalisation of autism clearly, and almost by definition, makes Murray’s point true. Yet an alternative way of viewing the autism/suffering conflation is later offered by Baron-Cohen (2008), who by implication asserts that the diagnosis equates with “need for support” rather than “suffering”. Referring in particular to Asperger Syndrome he says:

A person who receives a diagnosis will not necessarily need that diagnosis all their lives. A diagnosis is made at a particular snapshot in time, at a point in that person’s life when things had got so difficult that they needed the diagnosis in order to access support and help.

… By adulthood, that same person might have found a niche in which they not only feel they fit, but in which they are thriving, and feel they no longer need the diagnosis. (Baron-Cohen, 2008, p. 44)

Baron-Cohen therefore places a distance between being autistic and contented, and being autistic and needing support. He is suggesting that any equation of autism and suffering need not be a permanent state, even if autism is a permanent state. He is 266
therefore highlighting the contextual and wider environmental influences at work – not only those that contribute to seeking a diagnosis, but also those that contribute to well-being as an autistic person. He still echoes the equation of “autism” with “problem” in some situations, but an important qualifier is that this problem is at least in part an externally influenced one and may not be permanent.

What this introductory discussion demonstrates is the need to go deeper in exploring what are the components of any relationship between autism and suffering. I propose to do this via a series of questions that need to be examined within the bioethical domains of benevolence and non-maleficence. These are germane to any final conclusion about the morality or otherwise of preventing and/or curing autism, and they also contribute to the later discussion around the analogy challenge. I consider the following questions all to be relevant within a consequentialist welfare framework:

- At the level of individuals, to what extent will having autism predict a diminished chance of a desirable existence?
- What, if any, are the implications of co-morbidities on how we assess the impact of autism on individuals?
- Are there different welfare issues in relation to the welfare of autistic people themselves and of those around them?
- If we address welfare in global, non-personal-affecting terms, what can we say about the impact of autism on wider states of affairs?
1.1.1. At the level of individuals, to what extent will having autism predict a diminished chance of a desirable existence?

Assumptions of beneficence and non-maleficence underpin much of the scientific literature addressing prevention and treatment of autism. While few deem it necessary to explain their thinking, it is probably fair to offer the following interpretations of how many clinical research scientists, and some families and professionals, perceive the relationship between autism and suffering. The first is that autism is disease and disease equates with suffering and should be prevented, full stop. The second, more elaborate rationale, is that it is felt to be in an individual’s best interests not to be autistic, because autism is on the whole equated with particular difficulties that lead to an impaired chance of a decent life. Either way, and aside from discussions of the criteria for membership of the moral community (see Section 2 below), the main belief is that autism equates with a harmed state / greater than average suffering for the individual.

This clinically oriented perspective cites not only overall outcome indicators over the long term but also the day-to-day difficulties that many autistic people are seen to experience. Such observers have emphasised communication difficulties and social impairment, with rigid and unusual behaviours, all of which are seen as problems that inhibit the individual’s ability to succeed academically, professionally, socially or – particularly for those with learning disabilities – in terms of acquiring independence. And for some, the very fact that autism represents a departure from the norm is, apparently, reason to pathologise it.
While many who hold a clinical perspective on autism, as well as some parents and voluntary organisations, would view this gloomy picture as an integral feature of the condition, there is an acknowledgement among some that the poor outcomes for autistic people may relate in part to lack of adequate societal support – where this may be due to the absence of ongoing specialist input or failure to access services (see for example Howlin et al. (2013)).

Autistic writers tend to offer a contrasting emphasis when speaking about their own lives. Increasing emphasis is being given to sensory processing issues which mean that many environments are difficult (fluorescent lighting, showers, sudden noises) and to feeling like an “alien” in social situations, both of which become sources of profound anxiety and panic attacks (see for example Sainsbury (2000) and Murray (2012, p. 35)). These difficulties are about the individual’s interaction with their environment, which suggests that the medical model – i.e. “disability as individual trouble” – is too crude to address at least some of what makes it hard to be autistic.

If we adopt a social model of disability, and/or are sympathetic to the neurodiversity movement, then the negative responses to autistic people from NTs as individuals, and societal structures more broadly, place strain on a crude and unambiguous assumption that to prevent autism is good because people with autism suffer – even if it is true that they (or some) do suffer. This is for the reasons explored in Chapter 5 – namely that many of the appropriate interventions are external to the autistic person, just as many of the causes of suffering are external.
The additional point from a social-model/neurodiversity paradigm, corroborated by some autistic individuals, is that they do not in any case suffer more than anyone else and/or that any suffering is worth it because of the compensating enhanced pleasures and perceptions, and/or because their lives are worthwhile regardless of attempts to measure suffering. Many are emphatic about the particular strengths and pleasures that autism can bring with it. This is not just about having super-talents in discrete areas, but more broadly about the insights, perspectives and sensory experiences that autism brings, across the range of abilities. In addition it relates to caring less about the things that NTs find so important and thus disagreeing that lack of access to these things signifies deprivation. Finally, for those who do claim that their autism entails difficulties, many or perhaps most would argue that this is not such a problem as to justify taking away their autism, nor to have prevented their birth. (See for example Robison (2007; 2013).)

It would be wrong to claim that the above views are – or indeed are not – representative of the entire autistic population. First, those who are able to express views do not all agree and there are thousands who remain silent on the issue because they have not been asked or because they do not have access to the forums that would enable their views to be elicited. Further, there are some with no access to adequate communication tools, whose inner perceptions and reflections on their own lives remain inaccessible, and we cannot just presume what they hold to be valuable and what they find difficult about their lives.

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70 This summary is based on the autobiographies cited previously and I am also particularly grateful to Larry Arnold for several conversations on these topics.
However, what this sheer heterogeneity of perspectives does already do is rule against a blanket equation of autism and suffering, if we are to take seriously what we are told. There is a further question then of whether we should take some views more seriously than others. Who should command greater attention and be taken more seriously? One group might encourage research into prevention, while another would strongly argue that this is tantamount to genocide (see above p.105). Taking account of what autistic people do and do not value about their lives is crucial, but the question of something as fundamental as whether autism should be prevented and cured cannot come down to a simple headcount of “for” and “against” (even if this were possible). A lot is at stake, and majority rule does not usually permit measures to bring about the extinction of a part of the population, even if a majority of that population has voted for it. Likewise, phenomenological and community-based participation research, while necessary and potentially transformative and informative (see above p.70), would not itself be sufficient as a basis for judgement; ethical work by its nature deals with principles and values that are additional to data, notwithstanding the necessity of being empirically grounded (see Ashcroft (2003)).

With regard to the second case, where autistic people have no access to language, an individual’s behaviour – interpreted by people close to the individual, and assisted by the perspectives of able autistics – can supply a rich source of information. But, for the reasons cited above, it is probably neither possible nor appropriate to extrapolate from this what a “majority view” or a “representative view” might be. At the level of biography and anecdote one can point to many who appear happy and contented, and many others who appear to have difficult lives. In the latter case, at least some of the
difficulties are externally caused, and – as I have argued elsewhere – command an external intervention rather than attempts to alter the affected population.

I will be saying more about all of this in due course, but there are further questions in relation to autism and suffering that need to be explored first.

1.1.2. What, if any, are the implications of co-morbidities on how we assess the impact of autism on individuals?

Increasing acknowledgement is given to the existence of additional conditions that are more likely to be experienced by autistic people than by NTs (NICE, 2013, p. 20). Some of the co-morbidities fall within the overall umbrella of neurodiversity – for example attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD). Others are more traditionally understood as medical illnesses – for example epilepsy and gastro-intestinal disease. Even within gastro-intestinal problems, there is a range of symptomatology and, it may be, aetiology (Buie, 2011; Kohane et al., 2012; Gorrindo et al., 2011). And the overall label of “learning disability” remains perhaps the most elusive of all in terms of the quest for biomarkers.

Given that autism often co-occurs with other conditions, how does this impact on the question of how, if at all, it relates to “suffering” and to the ensuing attempts to prevent and/or cure it?

72 The anthology edited by Amaral, Dawson and Geschwind (2011) offers 12 chapters under the heading of “Psychiatric and medical comorbidities” (and see also Bauman (2011)).
Medical co-morbidities

Even if some of these co-morbidities (such as ADHD and dyspraxia) come within the realm of neurodiversity – by which I mean they may be deemed to be “difference” rather than “disease” – some of them are more indisputably medical in their nature and impact. The chances of both epilepsy and gastro-intestinal illness are raised in autism, both of which can debilitate at best and lower life-expectancy at worst.

The moral implications of this are different according to the pre-birth/post-birth distinction. I will first address post-birth scenarios, where I have suggested that addressing autism in toto is problematic. In contrast, I consider that addressing medical co-morbidities is not only a morally legitimate endeavour but – further – that it is an imperative. Inasmuch as the “curebic” group (see above p.196) may be populated in particular by those parents whose children exhibit additional medical problems, including gastro-intestinal problems and food intolerances, then the desire to “cure” these additional problems should be respected and taken seriously. I say this because first, they can be life-threatening and physically debilitating in a traditional disease-model sense, and second because of the intrinsic (“individual trouble”) nature of these problems – which marks them out as distinct from difficulties that exist primarily due to and/or only within the wider social context. I will carry forward this point later in relation to the analogy challenge.

I have suggested elsewhere (Murch and Bovell, 2014) that addressing these potentially painful and debilitating conditions may in turn enable the autistic

73 This is what Starr referred to with his Robinson Crusoe analogy (see above p.80): by definition, a social-communication disorder cannot be experienced by an individual on their own, whereas the disease-based physiological phenomena of the co-morbidities I mention are independent of context.
individual to be more motivated to engage in social and learning situations, and diminish the presentation of autistic stereotypical behaviours insofar as these may have been coping strategies to deal with pain and discomfort. In these cases, because the individual was originally in pain or discomfort, then the removal of this may lead to some behaviour change, which in turn may lead to a belief that the biomedical treatment has “treated” autism itself. Yet insofar as these treatments do not affect autism symptoms in all autistic people, then it is not accurate to argue that they offer a blanket response to autism, any more than it is the case that their rationale is to address autism itself.

Meanwhile, how does the existence of co-morbidities impact on the morality of attempts to prevent autism pre birth? Given what I have said about the raised possibility of epilepsy and gastro-intestinal (G-I) problems, then – in our current state of knowledge – to knowingly enable the birth of an autistic person is to knowingly raise the chances of someone experiencing some painful and occasionally life-threatening co-occurring conditions.

Once again the argument falls back on how autism is viewed – the analogy challenge. If it is categorised in terms of a distinct group of people with a legitimate way of being, then to prevent autism in order to reduce the incidence of epilepsy would be like preventing the birth of African-Caribbeans in order to prevent sickle-cell anaemia. Because some groups are more prone or vulnerable to certain conditions does not usually justify eliminating the group. Here we are back to the fundamental question of whether proneness to these illnesses equates with other groups’ proneness to

74 The Treating Autism co-morbidity report (Treating Autism, 2014) makes a similar point.
particular illnesses, or whether a more accurate conceptualisation is that we are looking at one disease that carries with it the risk of additional diseases. If we view co-morbidities in the former way, then the moral and practical challenge is to address the debilitating medical conditions through investing in relevant medical research with a view to pioneering treatments. This is not the same as addressing autism itself.

Despite the significance of the semantic distinction, it is one that is frequently overlooked. For example in the treatment vs acceptance debate, much of the defence of the pro-treatment group rested on their emphasis on co-morbidities that could/should be treated, and their rejection of the idea that painful co-morbidities should be “accepted” rather than challenged. But there would be few autistic advocates who would disagree with this. If one looks more closely at the messages of the “pro-treatment” groups, they are often in fact calling for effective medical treatment for autistic people when their (frequently unrecognised) health needs are overlooked. This less controversial goal is not a handy title for an advocacy organisation. Sadly, though, the handy title – “Treating Autism” – implies something that carries markedly different ethical implications.

*Non-medical “co-morbidities”*

In asserting that there are several co-occurring conditions that fall under the autism umbrella, commentators such as Gillberg consider them all to be medical:

> Only rarely, if at all, is autism looked at from the point of view of general clinical medicine, which is quite surprising, given the great amount of data that exist to suggest that autism is a collection of medical disorders rather than a specific disorder in its own right. (2011, p. 445)
In contrast to viewing all such conditions as medical – and for reasons explained above – I have separated them into conditions that reflect neurodiversity on the one hand, and the more “traditional” medical co-morbidities on the other. This section deals with the former, but rather than address them individually, I am going to focus on the issue of learning disability, which has the greatest co-occurrence and which raises what I believe to be the most profound ethical questions.

It is broadly acknowledged within the field of bioethics, and in disability studies, that the domain of intellectual disability is underdiscussed (Swain et al., 2004; Thomas, 2007; Nussbaum, 2007; Carlson, 2010a; Carlson, 2010b). When it is discussed, it is usually in overwhelmingly negative terms, a point that Carlson (2010a, pp. 107–113) has drawn attention to.\(^{75}\) Where learning disabilities are addressed within ethics, this is often with the implication of lower moral status, or lower chances of attaining a minimum threshold of capabilities – topics that I will be exploring below (sections 1.2.1 and 1.2.2). My present reference to learning disability is in relation to exploring any link there may or may not be with “suffering”, particularly for autistic people with learning disability.

As discussed in Chapter 2, intellectual disability was considered to be a key feature of autism according to Kanner. It was the input of Asperger’s work and subsequent empirical research that led to a broadening of the autism spectrum to incorporate the intellectually able. But despite the fact that intellectual diversity is now encompassed

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\(^{75}\) She suggests that this is to such an extent that bioethics has lagged behind the outside world – citing social improvements in attitude and support since the 1960s, in contrast with outdated attitudes and perspectives offered by most philosophers.
within the definition of autism, it remains the case that frequent attention is given to the divide between those autistic people who are intellectually able and those with learning disabilities. Chapter 2 (see pp. 75-77) explored the way this divide has been referred to in relation to demarcating “types” of autism that should be prevented or preserved, in terms of disputes around who owns the autism “brand” and about who has the mandate to speak on behalf of autistic people and advocate for them.

One manifestation of this divide, voiced by stakeholders who are in other regards wide apart in their views (e.g. Ozonoff cited on p. 76 vs Timimi, Gardner and McCabe (2011)), is the implication that those with high-functioning autism (HFA) are capable of having a good life, while those with severe learning difficulties (LDs) will be consigned to life on the margins and – by implication – have less worthwhile lives. Alongside this view is the suggestion that “high functioning” autistics have something to contribute to the world, whereas those with learning disabilities do not. Examples of the contrasts often used are: the possibility of finding life partners, having children, accessing employment, versus being institutionalised, utterly dependent on others 24/7 and with little functional communication. I also referred to the fact that such profound differences have led to challenges concerning the validity of autism as a diagnostic category capable of uniting the breadth of manifestations.

And yet there are some problems with differentiating quality of life in terms of a straightforward high-functioning (HF) vs low-functioning (LF) divide. The first problem is that in practice a straightforward IQ cut-off (e.g. 70) does not reflect the realities of autism, where “spiky profiles” are a common feature. As discussed in Chapter 2 and Chapter 4, individuals can be extremely able in some areas of
functioning and cognitive processing, and yet have major difficulties in others. At an 
individual level, therefore, ability and disability may be inextricably 
linked/interdependent. Thus, able autistics have asserted that it is not possible to 
separate what constitutes their autism from what constitutes their singular abilities and 
their singular difficulties. And some autistic people most famous for their talents, 
such as the artist Stephen Wiltshire and the pianist Derek Paravicini, are generally 
considered to have severe learning disabilities.

The HF/LF divide is therefore a very crude simplification of a picture of much greater 
complexity. However, even if we stick for now with this arbitrary “shorthand” 
distinction, it is really not clear at an empirical level that those with LD suffer more 
overall. The possibilities for meaningful and informative generalisations are few 
because of the highly nuanced and context-specific nature of people’s lives; there is 
both ambiguity and ambivalence, and people’s lives also go through good and bad 
phases. While on the one hand the argument for the positive value of autism is often 
made by and about those with strong abilities in a range of areas, it is also the case 
that higher intellectual ability may correlate with greater levels of distress and lower 
levels of contentment among autistics. The following issues will illustrate this last 
point.

Parents who feel that the severely intellectually disabled (ID) have different and 
escalated difficulties relative to those with greater abilities often cite the twin issues of
first, lack of functional communication, and – hence – greater dependency and 
vulnerability long term. I will take these in turn.76

In terms of limitations placed on communication opportunities for those with autism 
and profound LD, it is true that this makes the individuals vulnerable: if they cannot 
articulate basic requirements such as telling us that they are in pain; if their 
preferences and needs are misinterpreted; if they do not understand the contingencies 
of wider life – from danger awareness to the requirements of hygiene – and if they are 
as a result more likely to be victims of abuse. And among many of those autistic 
individuals who have acquired functional receptive and expressive language – either 
verbal or through augmented communication devices – there is a sense of life having 
improved. Thus Solomon has said of Temple Grandin: “Temple believes firmly that 
the higher-functioning you can make someone, the happier he is likely to be.” 
(Solomon, 2013, p. 273)

And yet the presumption of equating improved functioning with reduced suffering / 
improved well-being is not as straightforward as it seems: during a discussion on 
autism and ethics (Anon, 2011), one able member of the group said, “I was happier 
when I couldn’t communicate.” That is not to say that she regrets having acquired this 
faculty (she is a gifted speaker and writer), but it does go to the heart of how we 
identify well-being and how we interpret beneficence and non-maleficence. 
“Happiness” is here presented at odds with improved communication skills, and in 
gaining skills in one area, she is aware that there was nonetheless a cost. This seeming 

76 A third issue – that of challenging behaviour – will be discussed below. Whether or not it is a 
problem for the individual, or just for those around them, will be referred to.
paradox reflects the suggestion offered by Glover (2006, p. 88) that “the best account of the good life comes somewhere in the overlap between some versions of human flourishing and some versions of happiness” – if we take communication ability as a feature of human flourishing.

My main point here is that none of this is straightforward. With regard to autism, it is evident that more work needs to be done in order to identify which outcomes should be targeted in beneficent autism interventions, and also the degree to which some outcomes that are viewed as particularly important might justify interventions that involve a reduction in “happiness” (as identified by the above speaker). And this in turn echoes the discussion of Chapter 5 about how we evaluate intervention practices as well as goals. Engaging with the community of people who are most affected and able to reflect on this is likely to be essential, given the sorry history of autism having been drastically misunderstood by “outsiders” in the past (see Chapter 2).

The second point that parents tend to make in terms of the added problems of having LD alongside autism is that it makes the individuals more dependent on others long term. First, and in the tradition of much of the disability studies literature, we need to unpack the presumption that dependency itself should always be viewed as negative. For example, Thomas (2007) challenges the negative associations with dependency and the link between this association and a capitalist society. She illustrates her point as follows:

If one thinks in terms of scales of need – leaving aside for the moment the social exclusions and socially constructed “needs” exacted by disablism – being an adult with an impairment(s) may mean that one has a greater than average need for assistance with daily tasks such as dressing, washing, cooking and travelling to the shops. But a non-disabled businessman needs the assistance of others to a far greater
degree in the course of regularly criss-crossing the globe in aeroplanes, “living” in hotels and restaurants for much of the year, and returning home from time-to-time to see his wife who runs the house and brings up the children. Despite this, our culture attributes “neediness” and “dependency” – devalued, sometimes stigmatized, states of being – to the person with impairment, and celebrates the businessman’s “self-sufficiency” and “independence”. “Needs” in the abstract are rendered meaningless, and “having needs” becomes a negatively valued quality attributed only to particular social groups. (2007, p. 88)

Referencing others (for example Giddens (1991)) she says that we live in a society “in which the universality of need and individuals’ mutual interdependency is eclipsed, and ‘independence’ and ‘self-sufficiency’ have grown in value over the decades” (Thomas, 2007, p. 89).

Making a similar point, Scully (2008) has said:

contemporary Western societies respond badly to reduced independence. Loss of independence is … accompanied by levels of fear and disgust that betray a less rational, infantile fear of the dissolution of interpersonal boundaries. Hence the need to deny or cover up dependence has enormous force. (2008, p. 163)

and

It is clearly not the case that some people are dependent and others independent, but rather that some dependencies are permitted and other, disallowed ones are marked out as anomalous. (2008, p. 164)

From feminist ethics and the ethics of care we also find a questioning of the positive value placed on independence. I will be exploring these ideas further below, but a taster of the points that are made is offered in the following quotations from Kittay (1999):

No one escapes dependency in a lifetime (1999, p. xiii)
Dependency is inescapable in the life history of each individual. (1999, p. 29)

And of her daughter Sesha she says:

I fear that the stress on independence reinstates Sesha as less than fully human. With every embrace, I know her humanity. And it has no more to do with independence than it has to do with being able to read Spinoza. … Development for Sesha means the enhancement of her capacities to experience joy. (1999, p. 173)

Where adequate love and support are provided, then for the individual him- or herself the disadvantages/stigma of being “dependent” may be far outweighed by the security and protectedness that being supported can bring. In offering the following, personal example, I am also reflecting the views of several others with whom I have talked over the years. The example relates to my own son, who, when not suffering physical pain, is observed to be exceptionally cheerful and – as his NT stepbrothers wistfully observe – free from worries about careers and money, less bowed down with responsibilities, and able to enjoy each experience “in the now”, seemingly blissfully unaware of stigma and seemingly unworried by what other people think of him. For people who are close to individuals with profound learning difficulties, Kittay’s observation that such people may have a greater “capacity for joy” rings true, and – I would add – to influence those around them in a similar spirit. Alongside that, and as the testimony of more verbal autistics confirms, their sensory perceptions give them access to beneficial experiences about which many/most NTs may be oblivious and which may equate with a greater capacity to experience “mindfulness” (a key concept in positive mental-health promotion). The film produced by autistic people (Something About Us, 2008) is particularly effective in conveying this quality. If we are aiming for happiness or contentment, then some amongst the intellectually disabled autistics may be capable of achieving the highest quality of life. Yet in the
wider “narratives”, let alone the standard information about autism, very little attention is paid to the positive experiences and lives that are lived amongst the learning-disabled autistic population and how this can “rub off” on those around them.

I do not wish to claim that the above is a picture that relates to everyone. There are other autistic people with severe learning difficulties whose lives appear to be filled with much greater levels of distress than the above picture portrays. For outsiders, it is hard to view behaviours such as screaming, crying, extreme self-injury and violence as signs of a high quality of life. It would be dishonest to ignore the fact that these behaviours reflect the reality of some autistic-learning-disabled lives, even though it is also inaccurate and misleading to universalise such behaviours as portraying autism with learning disability, let alone the whole spectrum, in its entirety.

There are two things to say about this. First, it reflects the challenge I discussed above in relation to those with greater intellectual abilities: given the massive diversity of experience within autism, whose views and experiences “count” more, when it comes to the all-important issue of assessing the impact of autism as a whole on quality of life – that is, making a crude equation of autism and suffering?

Second, pursuing my negative example of the autistic-learning-disabled life, we do need to delve more deeply into what may be causing or contributing to the signs of severe distress that I have described some individuals as showing, before reaching a conclusion about the impact of autism on quality of life more generally. The point

77 There is a separate ethical issue in relation to the extent to which autistic individuals should be free to self-injure as they choose, which reflects broader ethical debates about all kinds of self-injuring behaviour. I find this an interesting area but it would be too great a digression to enter into it in this thesis.
here is – as confirmed by many experts in relation to challenging behaviour and by autistic individuals who write about their own behaviours – the outsider needs to appreciate the several potential contributors to such behaviour. Individuals may be in physical pain, they may not have access to adequate communication aids, there may well be a constellation of issues that need to be addressed and – correspondingly – there may be an array of responses to the individual and practical strategies that can mitigate their distress. It is far too early to write off a group of autistic people as being incapable of a good life on the basis of current knowledge, given that what we know about autism and learning disability – in particular knowledge about interventions – is in its infancy.

By suggesting that the provision of appropriate responses to autism is in its infancy, I am once again suggesting that at least some of the things that equate to “suffering” for autistic people with learning disabilities should be appropriately addressed in the external domain of P-3 – beyond the individual themselves. It is surely not controversial to assert that life could be better for many such people if more was invested in intervention research, if support workers and families had more knowledge and more time to understand and work with individuals, and so on.

Again, if we look at vulnerability – to bullying, poverty, hate crimes, neglect (see for example Quarmby (2011)) – we are taken back to how the wider environment responds to the individuals. Locating their problems as entirely internal misses the point – as discussed more fully in Chapter 5 above. So, reflecting the social model of disability, intellectual disability when seen in this way is not so much a co-morbidity according to disease models, as it is a further marker of social marginalisation. As
such it leads us to look at measures for evaluating flourishing in terms of rights, justice and capabilities.

I will explore this below in Section 1.2 but for now I wish to stay within a welfare-balancing ethical framework, reflecting what I suggested is a mechanism for exploring both pre-birth and post-birth interventions (Chapters 4 and 5).

1.1.3. Are there different welfare issues in relation to the welfare of autistic people themselves and of those around them?

I argued above that there is no direct positive correlation between what kind of well-being, flourishing or suffering an autistic person will experience and the level of their intellectual functioning, which is in keeping with the standpoint of Edwards (2003) that “there is no necessary connection between ID and suffering” (p. 526).

But, moving beyond what autism may entail for the individual (both positively and negatively), there is a further argument that suggests that despite the evident pleasures that the autistic individual might gain from their condition (e.g. the stimming and experiences described above p. 217), the impact of autism on the family is so negative that the overall welfare calculus is diminished by the presence of autism in a family. Here, the suggestion is that even if an autistic person is not suffering, s/he might be causing a reduction in the welfare of those around them. Families cite examples of wrecked furniture, curtailed lifestyles, sleep deprivation (see for example Solomon (2013, pp. 223–229) and Rankin (2000)).
If we refer to the published literature, or to the ubiquitous parental perspectives on autism on the internet, we find a picture of extremes, in terms of contrasting experiences and but also in terms of contrasting responses to similar experiences. At one extreme, there is no denying the heartfelt difficulties that some parents refer to (see for example Terminiello (2013)). These range from repeated exposure to challenging behaviour and injury (e.g. of siblings), through to the agony of fear for the long-term future, and from the wearying impact of continual sleep deprivation to the shared experience of being an isolated and stigmatised family. For some, there is the pain of having to give up direct care for the child, while for others there is the opposite challenge of unremitting care with no external support.

The fact of parental and sibling stress is recognised in official and unofficial sources (see NICE (2013, Chapter 8)). Even amongst disability rights academics there is recognition that some features of disability place particular burdens on parents – specifically lack of sleep and violent behaviour (Ferguson, Gartner and Lipsky, 2000). Insofar as these issues affect some families with autism to a greater extent than other forms of difference and disability, it is important to recognise that some more general observations around the social model of disability may be less applicable with regard to autism. So I believe we do need to recognise that families in which NTs and autistics coexist may entail a culture clash, or a challenge on both sides for mutual accommodation. An autistic child may want to smear faeces, or stay awake or night, and we cannot romanticise or preach this away by saying it is not or should not be a problem for other family members.
I certainly do not wish to imply that this picture is true for all autistic children or their families. But the broader point about the need for mutual accommodations is relevant I believe. From a position of equality, reflecting the “double empathy” and “reciprocity” emphasis that pro-neurodiversity writers such as Milton (2012) and Morton Gernsbacher (2006) present, it is important to attend equally to the rights and needs of all family members. In this context, interventions targeted at the behaviour of autistic family members may have ethical justification alongside interventions to assist the rest of the family to adjust their behaviour. In asking, “who are interventions for?”, Ashcroft (2014) is making an important point that some P-2 interventions towards an autistic family member might be generated in order to assist the NTs around the autistic person. Whether or not this is ethical depends on the degree of balance, mutuality, reciprocity and “reasonableness” of the intervention goals and practice that, consciously or unconsciously, are required for each member of the family.

In encouraging and enabling an autistic person to grow up in a world dominated by NTs, inevitable adjustments are continually required of them (as self-advocates point out), so that for autistic people and NTs alike it is a work in progress to ascertain which adjustments are possible, and also which are reasonable. The family will not be able to function long term if accommodation cannot be reached through mutual reasonable adjustments, and – crucially in some cases – the provision of external advice and assistance to achieve this. The individual will not be able to survive long term if his/her interests are at loggerheads with those of their family and/or if society

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78 I am deliberately reflecting the language of UK equality legislation with regard to “reasonable adjustments” (Great Britain, 2010).
does not provide an alternative environment in which their preferences, needs, choices can be met more easily.

Notwithstanding these realities, it is also the case that the above picture does not tell the whole story. Given the heterogeneity of autism, and indeed of families, there are multiple different narratives in which problems including challenging behaviour and sleep deprivation either do not feature, or feature only at a particular point in time, and which in any case are perceived as being compensated for by some of the benefits that an autistic family member will bring (see for example Moore (2012), Chew (2013) and Hastings (2014b)). It is also the case that while for some families the presence of an autistic individual is felt as a major and ongoing loss, there are many others who feel and describe the experience in positive and grateful terms. (See Solomon (2013, Chapter V) and below.)

Just as I argued that autism brings positives and negatives for individuals themselves, so it is the case that vicarious experience of these qualities impacts on family members.

The following quotations both come from conversations I have had with parents of autistic children who have severe learning difficulties (SLD), who do not wish to be named.

On the one hand, he is more vulnerable and frustrated at times, but on the other he experiences greater unalloyed joy. When he’s happy he lights up the room for us all.
This quotation echoes Kittay’s assertion that certain capacities possessed by at least some people with intellectual disabilities are often overlooked. In this case, regarding joy, we are talking about a capacity for something that is profound and wonderful for those around the individual as well as for the individual herself, and far more so than the cosmetic issues, such as eye colour, that seem to preoccupy some bioethical discussions around reproductive selection.

A further way in which impact on others is overlooked is the fact that often those with greatest impairment may do least damage to others:

I know he’s never going to achieve economic independence or get married, but on the other hand he’s unlikely to get a drug habit, rob a bank, bully anyone or break a girl’s heart.

This quotation is in keeping with total-welfare approaches, insofar as it looks not only at positive contributions to welfare through active achievements, but also at contributions to total welfare through a diminished capacity to harm others.

What these quotations illustrate is the fact that the welfare calculus incorporates a far more complex and subtle set of factors than the crude “disabled vs non-disabled” discussions of much of the literature, and that this is true not just for the individuals themselves, but in relation to the impact on those around them.

They also suggest that we need to be paying attention to the personal qualities that individuals have, and the contribution this makes to well-being. I will take this point further below when discussing virtue ethics. Further, they suggest that we need to look not just at capacities contained within one individual, but on the “externalities” –
a significant and profound impact on people surrounding the individual in question (see Section 1.1.5 below).

In saying this, I am not unaware that such a positive perspective has come under fire from critics who suggest that the learning disabled are being sentimentalised or instrumentalised as “soul makers” for the benefit of the typical population (Barnbaum, 2008, p. 103). I believe however that these criticisms miss the point. While what they say might be true if “enlightening” typical people was the only value of the intellectually disabled and autistic person, the crucial point is that those around the person benefit \textit{when and because} their loved one is flourishing. The significance really lies in the fact that \textit{not only} can the lives of the intellectually disabled be far less associated with suffering and damage than is generally believed, \textit{but also} they can bring to those around them a highly positive and transformative influence.

This is not captured in a crude equation of autism and suffering. Furthermore, in challenging the crude equation, we are being invited to explore new or different criteria by which to judge flourishing compared with those adopted by other individuals and other families. If for example “capacity for joy” is felt to be of profound significance by those who experience it directly or vicariously, then we learn something more about the relevant components of a life of flourishing for everyone.

In contrast, and in extreme situations when it seems that accommodation between the conflicting needs of autistic and other family members is not possible, the situation has to undergo more radical change. Sometimes this is because the family
environment is simply not sustainable for the autistic individual, where s/he needs and
wants a level of consistency, space or structure that is incompatible with the
requirements of their family. Nidotherapy – in which all the adjustment is made
around the person – is a way of summing up what needs to happen here (Tyrer, 2013).
If the family cannot, with the best will in the world, adjust sufficiently – perhaps
because their legitimate rights not to be at physical risk are being threatened – then
the individual will need to live in a setting more suitable for him or her. Residential
settings away from the family are sometimes vilified as being about segregation or
familial rejection, but sometimes they are actually a place where the individual is
most likely to thrive on their own terms. But the key feature of such settings, if they
are truly to address the needs of the individual and not be merely a segregated setting
in order to contain the person, is that they need to be of a high quality. And this will
be a composite of the skills, attitudes and competencies and attitudes of the workers,
and – in turn – the level of resourcing.

An important message, then, is that the diverse realities of lives should not be swept
aside in the attempt to provide a uniform message about how autism impacts on
families. Some autistic people – and their families – are more resilient than others;
some are more constrained than others in terms of the size of their homes, and so on.
And some people – autistic and NT – are more contented than others – autistic and
NT – almost regardless of circumstances or levels of functioning.

What I am suggesting is that – either within a family home or elsewhere – with
greater practical support, and in an atmosphere that is less stigmatising, and with
values that celebrate diversity, individuals and families can achieve significant levels
of flourishing. And this comes back to the significance of P-3 and P-2 interventions as discussed in Chapter 5. The issue is not to deny that families experience difficulties, but rather to explore the most moral way of intervening to improve the quality of people’s lives – both autistic and NT. As with the issues facing autistic individuals, many of the problems families face are linked to the wider environment. “It’s not X’s autism that’s the problem, it’s the battle for services” (Anon, 2001, pers. comm.) is how one mother of an autistic child described it. This is a common feeling that, were I to supply all the references I have accessed to illustrate it, would occupy a volume in its own right. It is an experience that transcends different types of disability, and is encapsulated in the following quotation from Kittay:

There is a loss – of capacities and possibilities. The disaster, however, is not the disability per se, but the callousness and insensitivity, the sheer miserliness of the response to it. Must it be so? Is it inevitable? The sorrow may be, but not the inequality, not the injustice. …

Parents could readily accept a rhetoric of universalism and equality if what was being distributed equally was high quality care and services and if that care and those resources were in fact universally available. Instead, parents are asked to accept injustice and shoddy treatment as “conditions” as inevitable as their children’s disability. (Kittay, 1999, pp. 174–175)

Socio-cultural obstacles currently include the battleground atmosphere in which many families have to conduct their claims on external support (manifested in litigation, bitterness or just neglect). External measures that could drastically improve the experience for families include: greater willingness to fund adequate early intervention, education, social care, supported employment and so on, reinforced by investment in research and practice (intervention and social) to improve the quality of life of future generations. The emphasis for intervention here is firmly in the category of P-3.
The fact that all of this has resource implications cannot be overlooked, and it is here that autism is often viewed in terms of its wider impact.

1.1.4. If we address welfare in global, non-person-affecting terms, what can we say about the impact of autism on wider states of affairs?

Having discussed the impact of autism on individuals and their families, I have argued so far that there may not be a linear spectrum of possibilities for any potential person, with disease/impairment and suffering at one end, and “enhancement” and happiness at the other. I have further suggested that, once we prise open the welfare calculus, we find a set of very complex and interlinked influences that leave it wide open as to what precisely are the things that might confer welfare and also make it hard to separate the individual from others in any kind of calculation. It is time now to look at what happens to the moral questions if we extend our field of concern beyond individuals and their families, to wider society – by which I mean more general “states of affairs”. The picture I have painted, which is already complex enough, gets even more complex when we move the analysis away from individuals and their immediate families, and look at the “macro” picture in terms of possible states of affairs in which autism exists.

The impact of cure/prevention on autistic people in general

The possibility that individual choices and generalised attempts to prevent or cure autism might have negative consequences for autistic people more generally, by virtue of the devaluing message that is sent out, falls within the expressivist argument that might be put forward to argue against prevention/cure (discussed previously in Chapters 4 and 5). A state of affairs in which the welfare of existing autistic people is
worsened because of attempts to cure and prevent is also a possibility if such attempts (particularly if successful) lead to a falling-off of support available to the remaining autistic population. As discussed in Chapter 4, these points, in relation to disabled people more broadly, are taken seriously by writers such as Wilkinson (2010) and even those in favour of procreative beneficence (PB), such as Harris (2007) – although Harris does not see these arguments as so powerful as to overwhelm other reasons for preventing disability.

As I suggested in relation to P-1 in Chapter 5, at its most extreme, prevention and cure would, long term, mean there were no more autistic people at all. In this sense both the expressivist argument, and concerns about a reduction in support to autistic people, would only be relevant for the period in which prevention and cure are not achieved wholesale. The point then is whether – for those who feel that the long-term absence of autism from the world represents a good state of affairs – the harm to autistic people, short term, is outweighed by a perceived increase in welfare from a state of affairs in which autism is eradicated.

Such a “hard-line” position is compatible only with a very strong consequentialist approach combined with a firm perception of autism as profoundly counter to welfare, which I have already argued does not stand up to scrutiny. But there are other ways of interpreting autism, and indeed the consequences of prevention and cure, that lead to different assessments of the ultimate impact on generalised/impersonal welfare. And these – which I will now discuss – include a calculus based on the interests not just of autistic people themselves, but also the interests of the wider population of NTs.
The impact of cure/prevention on the wider population

In defence of autistic people’s positive contribution to the world, much is often made of the special talents possessed by some individuals. The extraordinary powers of calculation possessed by Daniel Tammet, the notable contribution to quantum physics by teenager Jacob Barnett (BBC News, 2013), the efficient and humane contribution to agricultural engineering by Grandin are just some examples. Less famous, but also seen as making positive contributions, are those with particular talents in information technology, other types of engineering, the army of librarians and others with remarkable attention to detail who populate our society (a point made eloquently by Wendy Lawson (2011). The contribution of autistic people in the creative and expressive arts is also gaining increasing recognition, and some well-known individuals are “coming out” as autistic (for example the actress Daryl Hannah and musician Susan Boyle).

This way of referring to autistic people moves us away from equating it with a state of damage or suffering, and also brings us into the wider arena beyond the individual or family. The point is that these talents and contributions are things that have the potential to confer a blessing on others, perhaps even more than on the individual him-/herself – benefits that the whole NT community can also appreciate. The potential to confer benefit is not restricted to families or immediate communities but can extend globally – hence the trend of “outing” historical figures such as Einstein and Mozart (Murray, 2012, p. 41).

We need to be careful in how we use these facts. On the one hand, such examples serve the purpose of negating negative stereotypes of autism and reminding the world
that difference carries with it the potential for talent and creativity from which everyone can benefit. But on the other hand they create another kind of unhelpful stereotype in which all autistics are expected to have special talents. This places a heavy weight of expectation on those autistics who fall within the “average” range of talent – a burden of justification that is not similarly carried by NTs. It further devalues those autistics whose abilities fall below the average, or whose abilities are so unusual as to not confer wider appreciation. Autistic people with profound learning disabilities dominate this latter group.

Ari Ne’eman, quoted in (Solomon, 2012, p. 276), has said:

“As a public relations point, it’s nice to have Vernon Smith, who has Asperger’s and won the Nobel in economics, or Tim Page, who has Asperger’s and won a Pulitzer. It’s a point in favour of respecting and recognising the legitimacy of human neurological diversity. But it would be a deep mistake to say that people should have their differences respected only if they can deliver some special talent.”

The implication that we value people because of their special talents or abilities to fulfil economic or inspiring cultural roles within our society carries a converse message that those who do not offer something in the way of talent or monetary potential have no value. This links with negative views on dependency, which consider that the disabled person requires more from others than they contribute. Thus, the implication is often made that disabled people represent a burden. The problem is summed up by Asch and Wasserman (2005, p. 179) when speaking of disability more broadly:

The child with an impairment is seen merely as a drain on her parents and society, with little or nothing to contribute; the child prodigy is seen as having the potential for great contributions.
Bioethical texts about the burden of disability in wider resourcing terms consider that this is a legitimate terrain of ethical enquiry. For example Brock suggests that members of society have a legitimate, broader interest in preventing the birth of people who will add to the cost of care and services (2005, p. 92). Wilkinson (2010, pp. 100–107) addresses this “cost-of-care argument” and takes a pragmatic view insofar as he points out that data are unavailable, and that if they were to become available, then those who use the costs of care as their main argument in favour of preventing disability may become hostages to fortune.

If we are to take seriously a proposition that some autistic lives are more valuable than others on the basis of talent or economic contribution, then it follows that we should take seriously the proposition that all potential and actual lives – i.e. of NTs – can and should be evaluated in this way. Assessing the justification for antenatal and postnatal intervention on such grounds would then, logically, permit or even require us to make reproductive choices on the basis of potential earnings and talent. But, as argued previously (see Chapter 4 p. 135), such an approach may be self-defeating, based purely on positional goods that by definition enable only the minority to succeed. And besides, evaluating lives purely in terms of potential contribution and burden comes very close to the “ugly attitudes” to which Glover (2006, pp. 29–36) has referred, and which – if one accepts a slippery-slope view – lead into unacceptable applications of eugenics. Wilkinson further suggests that it could lead to unpalatable conclusions such as deliberately creating people who will for example smoke, die young and avoid the need for protracted and costly care (2010, pp. 105–107).
However, if we still forge ahead and believe it is legitimate to address costs of care, then it has to be acknowledged that – concerning autism – some data are available. “Autism costs the US and UK economies $175bn … and £32bn a year respectively” is the first sentence of a recent front-page article in a national UK broadsheet (Siddique, 2014). The study in question was that of Buescher at al. (2014), building on previous UK-only data (Knapp, Romeo and Beecham, 2009).

The article clearly adopts a disease model of autism. It is headed “Study says cost of autism more than cancer, strokes and heart disease”, and the text laments an underinvestment in research and treatment of autism compared to the major diseases of the headline. Put this way, the information can be used to command greater investment, rather than less, to help autistic people through P-2 interventions, as well as P-1 interventions. But even a disease model raises some questions about the appropriateness of the comparison, because autism is not in itself a potentially fatal illness like those with which it is compared.

In contrast, a difference model of autism alters the tone and message significantly. The article would in effect be saying “autistic people cost the US and UK economies billions of pounds/dollars”. Crudely put, the conclusion to be drawn is that autistic people are expensive and cost the NT population a lot of money. This is even though singling out a group of people in terms of the burden they represent is usually felt to be pernicious (Glover, 2006).
The way neutral data can be corralled into bolstering ideological messages has been the subject of critical interpretations and analysis elsewhere, and is not something I can dwell on here. There are just a few points I would like to make.

First, I refer to the disability movement’s critique of the bias implicit in singling out the disabled when making public-expenditure arguments (we do not question the provision of street lighting even though it is an avoidable expense for blind people; the investment in public spending on sports facilities and treating sports injuries doesn’t trigger a public outcry concerning the economic burden of physical activity). The choice of what are considered to be necessary and “normal” areas of public expenditure, as opposed to avoidable and burdensome areas, is a political one that reflects underlying power structures and priorities about who are legitimate participants in our economy – and who are not.

Second, if we pursue economic evaluation then strictly speaking we should be using full economic cost-benefit analysis, which extends beyond immediate financial costs and attempts to assign values to the more intangible social impacts – positive and negative – on people’s lives. So, if we are to take into account individuals’ offerings to others, as well as their chances of themselves having a good life, then we need to address more factors than talent or economic productiveness alone. Some of these intangible issues have been referred to previously. Importantly, we need to account for potential to do harm. The possibility that those who represent the greatest economic “burden” may also be those who inflict least harm on others is generally overlooked, even though in a total-welfare calculus it is an important consideration.

Thanks to Larry Arnold for discussions on this topic.
Moreover, and still within the field of economics, the cost data would need to be augmented with a macro-economic appreciation of the role of social and health-care spending more broadly, and the sums allocated to autism within this. It is not irrelevant that the bulk of so-called “costs” are largely allocated via employment of people who in turn pay taxes and/or spend their earnings and stimulate aggregate monetary demand. The funding allocated to autistic people operates within the circular flow of income, rather than being an extraneous black hole that merely swallows up money and puts nothing back.

Moving beyond economics but staying within the idea of how autism may impact on wider states of affairs, another way of viewing autism is to see it as contributing positively to diversity, where diversity itself is seen as inherently advantageous to us all. Disability studies writers have pointed out that a diverse genetic pool is generally conducive to evolution and progress. Using the analogy of Dutch elm disease, which killed off all the trees in a neighbourhood because diversity of tree species was lacking, Solomon has said:

> selflessness is not the sole engine in honouring diversity, as is clear when the term indicates a balanced investment strategy or refers to the multiplicity of species in our forests, seas, and wetlands. (2013, p.625)

Even if diversity arises from mutations and seeming errors, he points out that to prohibit error would be to end evolution. Error lifted us out of the primordial slime. (2013, p. 30)
He also suggests that the benefits are not solely to be found in biological evolution, but in the domain of morality, particularly related to virtues:

just as species diversity is crucial to sustain the planet, this (family/horizontal) diversity strengthens the ecosphere of kindness. (2013, p. 698)

and

Yet if parents often end up grateful for their problematical children, then so, in the end, can we all be grateful for the courage such people may embody, the generosity they may teach us, even the ways they complicate the world. (2013, p. 685)

Scully also affirms the value of diversity, while acknowledging the problems for individuals that it can bring:

Is phenotypic variation beyond a certain point inherently undesirable, something that we ought always to prevent or remove if we can? Or does phenotypic variation bring enough (or any) benefits to our lives, individually and socially, that a positive response is feasible?

Expecting the problem of disability to be solved by preventing impairment appearing in the first place assumes that phenotypic variation is, as a rule, unwanted. I’ve been indicating that the reality is much more complicated (and more interesting) than that. It is true that the consequences of extensive phenotypic variation are often profoundly disadvantageous. There are impairments which are lethal in infancy, cause unbearable physical pain, or in other ways seem incompatible with a life anyone would choose to live. We can acknowledge all that and still not reject the intuition of many disabled and nondisabled people that eradicating all disadvantageous phenotypic variation would entail losses as well as gains. (2008, p. 171)

Wilkinson (2010, pp. 41–44) takes a neutral stance about the use of the diversity argument to justify positive selection. He suggests that there is no necessary connection between promoting diversity and a beneficial state of affairs, any more than there is a necessary connection between beneficial wider states and restrictions on diversity. In other words, diversity per se is not a good or a bad goal, but rather, we
need to be clear which human attributes are to be encouraged to evolve through promoting diversity, and which ones are to be inhibited.

The implication throughout all of this is that we cannot judge on diversity on its own, but need further to address the issues of what aspects of humanity are conducive to wider welfare – as such, we are touching on virtue ethics, which will be discussed below.

1.1.5. The intangibles: extending the argument beyond “suffering” and “welfare”

The overall welfare calculus has tended to put suffering and its absence, or benefits and costs, on a single continuum, but actually, as I have indicated, the picture is more complicated than this. Although I have argued that an implicit welfare calculus operates amongst individuals when weighing up options, few parents adopt a cost/benefit calculation when actually setting or articulating their goals. They do not choose to have a child in order to minimise suffering or indeed to maximise levels of impersonal welfare. Rather, their reasons for having children are likely to be many-layered. Likewise, the benefits conferred are likely to be complex and, I believe, not routinely captured within bioethical analysis to date.

There are a series of points to be made here. The first point expands what I have stated previously: suffering and flourishing may be inextricably linked/interdependent rather than in opposition. This point is stressed by Parker (2010), in his criticism of the notion of procreative beneficence (PB) because of its paradoxical implications:
Both strengths and weaknesses of character, and of our lives more broadly, are essential and interdependent elements of the good life. … The best possible life is not necessarily and indeed could not be one in which all goes well. The best possible life is not necessarily, indeed, could not be, one lived by a person with no flaws of character, or of biology. (2010, p. 70)

He also points out that in any case PB may be self-defeating: the very pursuit of perfection may undermine achieving the good life.

My second point is about the impact of time. I suggested above that we cannot know which aspects of diversity are likely to be beneficial and which aspects less so for future human states of affairs as a whole. A similar point operates at a local level in which individual decisions are being made, because our notions of what is beneficial may shift with time. In the case both of pre-birth and post-birth choices, this renders an *ex ante* choice a position of ignorance and also raises the fundamental point of how and when we can, on balance, arrive at the most appropriate or accurate balance-of-welfare judgement. If we suppose that assessments may well shift between time periods, and among different individuals and their families across a lifespan, which point in time shall we say confers the point of greatest enlightenment for ascertaining the overall-welfare calculus? [I will return to this point below in Section 1.4.1].

1.1.6. Conclusion to this section

I have argued that simple assertions that autism reduces welfare – for individuals, for those connected to them or in wider society – cannot be justified. I have also suggested that, although the welfare calculus, based on maximising principles derived from utilitarianism, may assist us as a mechanism for making local choices, it struggles to handle the broader complexities of ethical significance that need to be addressed if the questions of my thesis are to be explored in depth.
Because of this, I believe it is important to extend this exploration of alternative ways of addressing “the good life” beyond the traditional terrain of bioethics, with its emphasis on harm and benefit linked to welfare maximisation, or the minimisation of suffering. Moral philosophy offers a rich literature about how we should evaluate a good life aside from questions of suffering and welfare maximisation. Alternative appraisals address notions of personhood and a possible link between flourishing and personal capacities and endowments on the one hand, and wider notions of justice, rights and dignity on the other. These concepts offer ways of appraising autism and the good life without reliance on the concepts of welfare and suffering.

1.2. Alternative measures of a good life

Alternative measures of the good life that do not rely on welfare and suffering are offered from both deontology and virtue ethics (including the ethics of care).

The principles of moral status, justice, rights and dignity are largely drawn from deontology, and in particular Kantian ideas of dignity and rationality (see Nussbaum (2009) and Kittay and Carlson (2010, p. 4)), while an emphasis on specific human capacities slides into ideas of human virtues.

There is little in the literature regarding the good life with respect to autism specifically, although Edwards (2003) discusses the link between intellectual disability and the conception of a good life. He refers to three theories labelled by Brock (1993) as hedonistic (focusing on subjective experience), preference
satisfaction (where subjective experience is augmented with achieving certain hopes/desires) and ideal (achieving a set of objective goods). He argues that there is no incompatibility between intellectual disability and any of these three. I wish to go a little further in this section by exploring some of the main themes that I consider to be of greatest relevance in relation to autism. First amongst these is the preoccupation with moral status, since it is what Barnbaum has used as a disqualifier of autistic people from the moral community.

1.2.1. Membership of the moral community – Capacities and qualities inherent in the individual

*Normal species functioning*

Discussion of the categories of postnatal intervention in Chapter 5 kept returning to ideas of the “normal” and “normalisation”. Different ways of interpreting this latter concept were seen to lead to markedly different conclusions in terms of whether it denotes a positive or negative outcome for autistic people. I referred to the idea of “normal species functioning” which has been used in bioethics when seeking a shared understanding of a “minimum” quality of life that applies in equal terms across humanity (e.g. Daniels (1985), Boorse (1975)). While egalitarian in aspiration, the difficulty with this is the dominance it gives to notions of “normality”. Yet there is no prima facie argument for assuming that departures from the norm are necessarily incompatible with a good outcome.
Indeed, some departures from the norm confer advantage (see Scully (2008, pp. 36–32)), and the possibility of enhancement has generated a large literature. While some departures from the norm appear to be uncontroversially “harmful” insofar as they denote injury and incapacity arising from a misfortune such as a car accident, other departures from the norm are stigmatised or seen as less desirable simply because they depart from the norm. This has been extensively examined by autistic writers (e.g. Lawson (2008)) and more broadly within the sociologies of disability and illness (see for example Thomas (2007)). Particular attention has been given to the whole area of stigma, perhaps most famously addressed by Goffman (1968).

Commentators such as Silvers (1998) have questioned the equation of species-typicality as a standard of biological optimality. Silvers has also pointed out that measuring outcomes in a broader way taking seemingly objective quality of life (QOL) measures may overlook the interests of minorities: “Systems that identify effective health with species-typicality advance the interests of the species-typical, but beg questions of justice for anomalous individuals” (2005, p. 51).

Dan Brock has made the same point about broader outcome measures:

> It is important not to construe these categories in an unduly narrow way that merely reflects the dominant preferences and way of life of the society at the expense of both disabled persons and others who pursue unusual plans of life. (2005, p. 69)

This highlights how the attempt to find shared standards may be thwarted by human variations. A life that is good for one person may be deeply unsatisfactory for another. Examples of possible departures from the norm for autistic people include a lower emphasis given to friendship (some want friends but some don’t), and – for those with

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80 Reference was made in Chapter 4 above p. 142 at note 43, and below at note 81.
more profound intellectual impairments – there may be no sense of linkage between self-worth and a state of independence from others in day-to-day life. (See above pp. 278-281). Lawson (2008) has questioned the damage that an emphasis on “normality” can do for those who are neurologically “different”, and Ari Ne’eman has made the point that in strict statistical terms, normal merely means “average” and further that the midpoint on the bell curve signifies nothing more than “mediocrity” (Solomon, 2013, p.275).

*Cognitive capacity*

While normal species functioning has been used as a basis against which levels of human well-being or quality of life are evaluated, cognitive capacity has been used not just as a marker for quality of life but as a minimum requirement to achieve full moral status. Most controversial is the notion that only a certain level of cognitive functioning is commensurate with personhood (see Singer (1995), whose criticism of “speciesism” involves comparing those with limited cognitive capacity and other mammals, and McMahan (2003), who considers, for similar reasons, that “killing animals, and allowing them to die, are morally far more serious matters than we have supposed. But allowing severely retarded human beings to die, and perhaps even killing them, are correspondingly less serious matters than we have believed” (2003, p. 230)).

This emphasis on cognitive functioning continues to have resonance in discussions about enhancement, for example in pursuing the thought experiment (and subsequent debate) about the issues raised by a future species of supra-persons – those with
enhanced cognitive capacity.\textsuperscript{81} This is important for two reasons. First, cognitive capacity has been used as a qualifier through which to judge the morality of antenatal selection and hence prevention. Second, it has been used to explore the principles by which we evaluate treatments/interventions for individuals after their birth – in terms of their goals and measures of impact. I am thinking here of those studies that have used IQ as a proxy for good outcome when comparing contrasting post-birth interventions (including the original Lovaas experiment cited in Chapters 2 and 5).

Autism offers an interesting test case in relation to the equation of cognitive abilities and membership of the moral community. On the one hand, as previously discussed (pp. 295-296) we see “savants” – those with exceptional cognitive faculties who on this basis might qualify as supra-persons. On the other hand, we find people whose cognitive capacities are at the other end of the bell curve in relation to standard measures of intellectual functioning. And frequently we see an elision of ability and impairment \textit{in the same person}. So even if we supported McMahan and Singer in elevating cognitive functioning as the key quality through which personhood is gauged, this would be of little help in judging whether or not autistic people overall are members, or outsiders.

Critics of the emphasis on cognitive capacity as the key factor in judgements about moral status have made several points. They question whether cognitive capacity is valid because it is rarely fixed over a lifetime. For example Kittay (2010) and others suggest that even amongst those of profound disability there is still the capacity to

develop, and they do not consider why it – as opposed to other qualities – should have overwhelming significance.

The possibility that it is other qualities that have greater moral relevance than cognitive capacity points us in the direction of virtue ethics, moving us away from the Kantian emphasis on rationality. I will be saying more about virtue ethics below, but what I am about to say keeps us within the topic of ideas about moral status.

**Capacity to care**

In offering alternative criteria to cognitive capacity, Agnieszka Jaworska (2009) proposes that “capacity to care” should replace reason as a condition for full moral standing. Similarly, James Harris (2010) suggests that, “moral development must be considered as it relates to socialization and empathy, not to reasoning alone” (2010, p. 67). Michael Slote goes further and requires more than general caring – he emphasises the role of a particular type of empathy and empathetic caring (2007).

Thus, the emphasis on care has led to the evolution of the ethics of care as an ethical framework in its own right, and I will say more about this below (Section 1.4). My purpose in this section is more limited, in highlighting the way individual capacities have been identified by some philosophers as the criteria by which to denote membership of the moral community.

These alternative suggestions for innate abilities as qualifiers for personhood do not fit well with traditional notions of autism. If we are wedded to species-typical ways of expressing socialisation and empathy, then autistic people might fare as badly under these criteria as they did under Barnbaum’s emphasis on theory of mind (see Chapter
3). But – as I more fully outlined in Chapter 3 – we need to be clear about the difference between atypical behaviour on the one hand, and underlying sentiment and capacities on the other. Differences in expression of socialisation and empathy are not the same as being anti-social and uncaring.

Another point to make here is the distinction between minimum thresholds for moral status, versus higher-level attainments by which active flourishing is achieved. With regard to empathy, Slote (2007, pp. 34-45) implies that supererogation (for example extreme empathy bordering on total self-abnegation) is not a requirement, but that there is a basic minimum capacity that is essential. Yet with regard to autism and learning disability in particular, there may be other capacities in which autistic people may actually excel over NTs and which contribute if not to moral status then certainly to an idea of flourishing. I am thinking in particular of the capacity to experience joy identified by Kittay (see above p. 282), whereby at least some individuals on the spectrum may have a greater capacity than NTs.

So, our judgements about people’s capacities – be they for eligibility for moral-community membership or to denote higher-level attainment for achieving flourishing – are highly sensitive to which capacities we believe to be of most importance. In light of this, some come from a perspective that minimum thresholds equate with being a human being, and eschew the moral relevance of any emphasis on capacities.
1.2.2. “Automatic” membership of the moral community – human worth, human dignity

Responding to the idea that membership of the moral community is dependent upon individual capacities, Kittay (2010) says: “I reject the idea that you [should] base moral standing on a list of cognitive capacities, or psychological capacities, or any kind of capacities. Because what it is to be human is not a bundle of capacities.” (2010, p. 408). She further develops the significance of a common bond of humanity — in all its expressions — as being a sufficient condition for membership of the moral community, in her famous phrase, “we are all some mother’s child” (2010, p. 412). She is here suggesting that humanity itself confers moral status, rather than any capacities that some humans (but not others) may have. This does not require any sentiment or consciousness of there being such a bond between humans, but rather constitutes a categorical “objective” position about membership of the moral community.

Similarly, Carlson (2010b) emphasises the essentially human nature of people with intellectual disabilities, drawing on the work of several philosophers who emphasise the significance of humanity. And Wong (2010) has said: “the boundary between moral persons and nonpersons is indistinct and difficult to judge; we should therefore include all human beings without trying to determine exactly where they are on the spectrum of cognitive functioning” (2010, p. 142).

The emphasis on humanity reflects the big question asked by Glover (2006, pp. 81–99): “Should we defend a central core of human nature?” The elevation of human worth as something of inherent value is also associated with notions of human dignity,
a concept that underpins much of Nussbaum’s wider work in political theory and her particular focus on cognitive disability (Nussbaum, 2007; 2009; 2010). For her, these issues are inextricably linked with theories of justice. She offers a rich analysis of how the intellectual foundations of prominent notions of political and redistributive justice, built on liberal social-contract theories around mutual advantage, and based on the idea of rationality, are inadequate in addressing the interests of three excluded groups, one of which is people with severe cognitive disabilities. She proposes a “capabilities approach”, which relies on an intuitive idea of human dignity: “what people are actually able to do and to be, in a way informed by an intuitive idea of a life that is worthy of the dignity of the human being” (Nussbaum, 2007, p. 70). On this basis she has identified a list of ten central human capabilities, all of which she argues are implicit in the idea of a life worthy of human dignity. The goal is then to get everyone above a threshold level of each of the capabilities if minimum accounts of social justice are to be achieved; implying that the threshold levels are therefore an appropriate target for individual and social intervention.

Even here, though, it seems that it is necessary to qualify the minimum threshold in some ways to accommodate those with the most profound cognitive disabilities. For example, number 4 – senses, imagination and thought – includes being able to imagine, think and reason, in a way informed and cultivated by an adequate education including literacy and basic mathematical and scientific training. Number 6 – practical reason – requires ability to engage in critical reflection about the planning of

82 Chiefly derived from John Rawls. His work is often used as a reference point, even though it has been subjected to several critiques (e.g. by Robert Nozick). It would be a digression to outline these issues in this thesis.
one’s life, and number 7 – affiliation – is “to be able to imagine the situation of another”.

The fact that her list sets a high capability threshold for people with severe learning difficulties is addressed by Nussbaum when referring to Eva Kittay’s daughter Sesha.

It seems implausible to say that even the best care will produce all the capabilities on this list, up to the socially appropriate threshold level. Should we then introduce a different list for her, as our social goal? And should we introduce a different threshold for the items on the list, as our political goal for what she should attain? (2007, p. 188)

She then suggests this is dangerous, since it lowers expectations and a sense of what someone is entitled to. Instead, one should insist on the importance of the central capabilities for all citizens, and thus maintain that they are worth the expenditure that may have to be made on those with unusual impairments. She is clearly arguing for generous measures to empower those with profound disabilities, but there is also an implication that she does not link this with an aversion to preventing the birth of people with conditions like Sesha’s. She explicitly takes Sesha’s impairments to be more severe (providing less opportunity to access the capabilities threshold) than other examples – Jamie (with Down Syndrome) and Arthur (with Asperger Syndrome). And thus she says of Sesha:

if we could cure her condition and bring her up to the capabilities threshold, that is what we would do, because it is good, indeed important, for a human being to be able to function in these ways. If such a treatment should become available, society would be obliged to pay for it, and would not be able to offer the excuse that she is impaired “by nature”. And further, if we could engineer the genetic aspects of it in the womb, so that she would not be born with impairments so severe, that, again, is what a decent society would do. Notice we do not say this about Jamie or Arthur, precisely because there is a realistic prospect that they will attain the capabilities that we have evaluated as humanly central. Thus the view does not entail engineering Down
Following Nussbaum in relation to autism, one would instantly come up against the challenge of heterogeneity, particularly now that Asperger Syndrome (AS) falls within the overall diagnostic criteria of Autism Spectrum Disorder (ASD). If Nussbaum’s position is valid, then it will be necessary to disaggregate autism as a whole, so that Arthur can be responded to in a very different way from an autistic person whose life with severe impairments corresponds more closely to what Sesha experiences. I have already discussed the challenges of separating out “types” of autism in terms of what they predict about suffering or capacities. But I have additional concerns about Nussbaum’s approach.

On the one hand she is setting a minimum threshold of capabilities to justify adequate expenditure on someone with impairments as profound as Sesha’s, and yet she is also implying that she does not really consider that Sesha can attain a life worthy of human dignity.

Moreover, Nussbaum then proceeds to distinguish between a minimum threshold on the one hand, and active flourishing on the other. She suggests that, having identified the extreme threshold – a life worthy of dignity – people should proceed to seek a higher threshold – “the level above which not just mere human life, but good life, becomes possible” (2007, p. 181, italics in original). Given her doubts as to whether Sesha can reach the minimum threshold, the implication is that Sesha can never achieve a good life, according to Nussbaum’s criteria.
It seems then that an attempt to combine approaches to evaluating justice in society as a whole, with criteria by which to judge flourishing in individual cases, is hard to achieve even though Nussbaum’s approach attempts to do just this: to identify minimum thresholds for acquiring a life worthy of human dignity, and simultaneously to set out the criteria by which we can evaluate a just society, including the nature of its political institutions.

She does hint that there is need for greater flexibility of interpretation within the tight criteria she has set out in the capabilities:

> The job of a decent society is to give all citizens the (social conditions of the) capabilities up to an appropriate threshold level … Insofar as a highly general idea of human flourishing and its possibilities does figure in the approach, it is not a single idea of flourishing, as in Aristotle’s own normative theory, but rather an idea of a space for diverse possibilities of flourishing. (2007, p. 182)

However, I am not sure that one set of criteria can do both jobs adequately, and others too have found problems with the concept of human dignity as a single concept, for similar reasons.

**Minimum thresholds versus achieving flourishing**

Different interpretations of “human dignity”, and the emphasis that is placed on it, mean that recourse to “human dignity” alone is not entirely helpful in trying to draw out how membership of the moral community is to be interpreted, nor what is then meant by flourishing. For example Kass (2009) articulates two “equally important but sometimes competing ideas of human dignity: the basic dignity of human being and the full dignity of being (actively) human, of human flourishing” (2009, p. 299, italics in the original).
With respect to political entitlements, Paul Weithman identifies two distinct features of how human dignity is an underpinning principle: first, there are minimum standards in terms of how humans are treated, and second, there are threshold capacities without which human beings cannot live lives worthy of a human being (Weitham, 2009). This seems to echo the problem Nussbaum encountered when trying to reconcile her minimum threshold capabilities with the possibility that for some people, the threshold may need to be lower. (For a fuller discussion around the concepts of human dignity and bioethics, see Pellegrino, Schulman and Merrill (2009) and Brownsword (2013).)

Justice and rights

Having said this, one of the strengths of Nussbaum’s approach is in its elision of philosophical and political principles, recognising that judgements as to people’s value/worth, and hence the treatment they might receive from others, are inextricably linked with how society is configured in terms of relative power held by different groups. Echoing the concerns expressed above in relation to normal species functioning – that it excludes the perspectives of “anomalous individuals” and minority groups – many autistic advocates have given primary emphasis to their cause as being one of human rights more broadly. “Autistic rights are human rights” is the phrase that the Autism Rights Group Highland (ARGH) chose for the T-shirts at a recent conference (ARGH, 2014). “Intensely and incurably human” was a phrase that
Dinah Murray chose to convey an important message about the condition of autism at this conference (Murray, 2014).

A further interpretation of principles of entitlements and rights is offered by Feinberg’s notion of the right to an open future (RTOF) (Feinberg, 1980), referred to previously in Chapters 3 (p. 93) and 5 (p. 232). The RTOF has been adopted by Davis (2001) in relation to positive selection and Barnbaum (2008) in relation to autism. By way of recap: Feinberg argues that parents are obliged to promote this right by acting in such a way as to keep the most number of doors of possibility open for their children, in order to enable them to lead the fullest human life (in quantitative and qualitative terms) once they have matured to achieving full autonomy.

There are several problems with this approach in general, aside from how it has been used in relation to autism. As a basis for selecting children, or bringing them up, the right to an open future is not without its critics, for a range of reasons (for example see Scully (2008, pp. 61–64); Wilkinson (2010, pp. 44–47)). The point to make here is one that applies to other ways of viewing reproductive choice also (for example procreative beneficence), and this is a problem about the interface between those opportunities that lie within the scope of local choice, and those that are a product of wider conditions. Being born in poverty may curtail someone’s open future more than being born with an impairment, yet the emphasis that moral philosophy has given to the RTOF has confined itself only to this micro bioethical context. This is the point that Nussbaum addresses, in arguing that the capabilities are a basic minimum for all.

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83 Murray acknowledged Micheline Mason (2005) as the originator of the phrase “incurably human”.
84 See above p. 93 where Barnbaum’s view that “it is a violation of the right to an open future for a child to be born autistic” (Barnbaum, 2008, p. 162) is discussed.
in terms of access to certain “goods”, and as such incorporate wider entitlements/conditions.

I do not want to be sidetracked into a forensic analysis of the commonalities and distinctions among these different interpretations, nor the critiques and counter-critiques of Nussbaum’s approach (though see for example Bérubé (2009), Stark (2009) and Jaworska (2009)). But it is important to recognise that, once again, the work of exploring possible stances on the morality of types of intervention, and indeed the most relevant way of interpreting a good autistic life, is complex and leads us into areas of intellectual endeavour beyond the traditional domains of bioethics. Suffice to say that however localised discussions about individual treatments appear to be, addressing the wider context in which these take place turns out to be unavoidable.

1.2.3. Membership of the political community – overlaps between individual flourishing and the wider environment

I have argued that one important reason for viewing flourishing more broadly than a focus on individual endowments allows is the fact that individuals and their potential cannot be judged without reference to broader context. This echoes Parker (2010) who has said of the goal he feels we should look towards – “an ordinary chance of a desirable existence”:

This also usefully reminds us that the conditions conducive to the possibility of a good life are at least as much to do with the broader social, political, economic, and environmental contexts in which people live as they are to do with their biological make-up (2010, p. 69)
The suggestion that the problems people face consist less in their own particular endowments, and more in their interaction with wider society, is the enduring message of the social model of disability, reflected in the neurodiversity movement, and is at the heart of the distinction I explored in Chapter 5 between the categories of intervention. The perspective is summed in the following statement:

A poor record of intervention is inevitable, whatever the intervention, since society is the other half of the autism equation and society needs fixing. (Murray, 2014)

If the things that cause disabled people to have a less than good life are externally caused, then we have to look beyond the individual to establish what kind of interventions are going to improve quality of life. I configured this as P-3-type interventions, as opposed to P-1 or P-2 interventions, in Chapter 5. It is for this reason that the social model of disability embraces political awareness and activism, with the implicit notion of the good life as one in which there are no barriers to participation and no stigmatisation of those with differences. The emphasis on participation is a feature of the “Strong” version of the social model (see p. 65), and, reflecting this emphasis on full participation in political and institutional life, Nussbaum interestingly suggests that her capabilities approach would entail “trustees” having voting and jury rights on behalf of those with significant cognitive disability. But even a “softer” social model, which allows the problems to lie in the interactional space between individual and environment, places emphasis on the necessarily environmental component of any ameliorative adaptation – and commentators such as Bérubé (2009) feel that these types of intervention, focusing on practical ways of facilitating everyday life, are more pressing than the issues of voting and jury service.
A further feature of the social model is that it requires greater attention to be paid to the perspective of disabled people, beyond the stigma and stereotypes characteristic of externally generated narratives about the lives of disabled people (see for example Scully (2008, pp. 109–130)). I have referred in Chapter 2 to objections to the external imposition of primarily medical-model value judgements about the quality of disabled people’s lives. Even within the oppressive constraints of our current society, the point is made that disabled people’s lives are much better than imagined by the rest of the population.

It is suggested that a reflex equation of disability with suffering or lower capacity to flourish is based on misinformation or prejudice or both. This is a particular concern within bioethics insofar as it purports to make moral claims about the rightness and wrongness of interventions that affect the future of disabled people.

Serious bioethical engagement with disability issues should raise fundamental questions about the kind of knowledge that is needed to make moral decisions concerning people with different embodiments from our own. (Scully, 2008, p. 40)

Ethics … must have some grounding in fact, if the values and norms it prescribes are to have any meaning for the practices of the real world. (Scully, 2008, p. 41)

Some might respond that actually outsiders just do know better than the autistic people whose lives they are judging, and further that they can be confident in this knowledge because (1) the outsider perspective derived from imagination and thought experiment is sufficiently robust not to require empirical referencing, and (2), in contrast, the autistic population cannot imagine the state of being “typical” and therefore don’t know what they’re missing. This suggestion that non-autistics know best has been discussed in relation to Frith and Happé’s questioning of autistics’ ability to reflect accurately on their own internal states (1999, p. 7). The implication is
that *by definition*, autistic people will not have an accurate or adequate take on their own life and will also not be able to make informed judgements about other, alternative (and by implication preferable) lives. If this is true for autistic people of average or above-average intellectual abilities, the argument goes, a fortiori those with learning disabilities are not able to assess the quality of their own life.

And yet the discussion in Chapter 3 about Milton’s “double-empathy” problem – in which it is the *mutual* failure of understanding between autistics and NTs that is postulated – offers a cautionary note to such a view. The possibility that the typical onlooker is unquestioningly imbibing the “toxic narratives about disability” that circulate culturally can be a real cause for “moral damage” according to Scully (2008, p. 114). She says:

> It is a moral choice to respect (though not uncritically) a disabled person’s accounting of her own life.

Given the lack of empirical work, Scully goes on to say:

> Although I can’t offer more solid evidence than personal knowledge and the stories of other disabled people, it does seem that a major element in the overall quality of life of many phenotypically variant people is whether they are constantly regarded as anomalous by their community, or conversely, are accepted as part of that community’s normality. (2008, p. 174)

There is an ironically circular dimension to this. Scully is in effect arguing that a key contributor to a lowered quality of life for disabled people is the very fact that

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85 This reflects a point made by Kittay at the Autism, Ethics and the Good Life Conference, in which she called for an expansion of what we consider to be “normal” (Kittay, 2012).
outsiders, including moral philosophers, are willing to make generalised statements about the poor quality of life of disabled people.

Making a similar point, Amundson (2005, p. 102) holds that prominent discussions of the QOL of disabled people reveal “an unjustified and unexamined commitment to the Medical Model of disability, and for that reason a bias against the interests of disabled people”. The emphasis on impairments disguises the extent to which it is not these, but rather wider social forces that contribute to a reduction in welfare. (For more in-depth discussions of these issues see for example Thomas (2007), Amundson (2005), Shakespeare (2005), Saxton (2000), Parens and Asch (2000).)

This does not negate the way that impairments pose problems for individuals, but it does place many of the problems within a wider context. Interventions to improve people’s welfare need, therefore, to focus at least in part on addressing these wider conditions. Thus Kittay (2010) has said of her role in being mother to Sesha, “socialization for acceptance means that you have both to help the child make her way in the world given her disabilities and to help shape a world that will accept her” (2010, p. 398, italics in the original).

For disabled individuals, then, and those that champion their rights, membership of the moral community is inextricably linked with wider political concerns – both in terms of how to interpret the difficulties that disabled people face, and in terms of the most appropriate way to intervene.
The question then is, given the heterogeneity within the disabled population, which Scully and others (see in particular Shakespeare (2006)) recognise, do these general observations offer enough granularity with respect to autism? If it is vital to look at what autistic people are telling us about their lives, then how do we go about doing this, and what kind of questions do we ask? I suggested above that this is not straightforward from the prism of a welfare framework, and I do not see that the deontological framework has offered any further insights in this regard.

1.2.4. Conclusion to this section

I suggested in Section 1.1 above that there is little chance of arriving at neat or generalisable conclusions about how we can assess “the good life” for autistic people when adopting estimates of welfare within a consequentialist framework, either for individuals or in the broader community, particularly with reference to the idea of “suffering”.

In this section I have therefore explored alternative ways that lives are evaluated within the ethical literature, but have fared little better in finding a single interpretative framework for addressing either baseline criteria for moral-community membership or approaches to defining “the good life” in relation to the autistic population.

Throughout, my purpose has not been to come down in favour of any single interpretation but rather to demonstrate the challenges that such an endeavour poses in general, and in relation to autism in particular. In light of this extremely complex area, caution is needed in coming to hasty judgements about the quality-of-life chances of
autistic people given the lack of clarity of criteria by which to make such judgements. What does seem likely is that those who call for prevention and/or cure of autism do not take full account of the potential layers of evaluation that are morally relevant.

Further, I have indicated that at least some of the ways of framing quality of life carry the danger of excluding the perspectives of unusual people / minority groups – including autistic people. Some at least also fail to address the potential relevance of external forces, being preoccupied with qualities within an individual, rather than addressing chances of a good life in terms of the wider conditions in which people live.

I consider therefore that – despite the limitations that I have suggested apply regarding the ways quality of life, flourishing and well-being have been addressed so far – the direction in which we should be headed requires a critical examination of the role played by the wider environment in turning disability/difference – and autism in particular – into an individual’s problem.

In addition, I would like to extend my enquiry to a further examination of emergent approaches to ethics that have tended to play a less dominant role in discussions around interventions in the broader bioethical literature to date, but to which my discussion has frequently pointed. I have referred in particular to the potential role of virtue ethics, and I wish now to say more about this, and about its “offshoot” (though some argue it is a separate approach) – the ethics of care.

86 See for example p.72; p.102; chapter 4 section 1.1.1(i); pp. 247-248.
1.3. Virtue ethics

The question of “what kind of people we want in the world” arose above in relation to whether or not diversity per se is a good goal (pp. 300-302). Within traditional bioethics, the focus has been almost entirely on the absence of illness/disability and the pursuit of “enhancement” within a chiefly “medical-model” framework. I discussed previously the limitations of using cognitive capacity as the defining qualifier for full moral status or as an indicator of greater states of welfare and well-being. I also observed that very little attention is paid in the bioethical discussions around procreative decision-making to a future person’s capacity to harm others. On this point, it is worth citing Alan Thornhill (2009) who pointed out that the Unabomber had a higher IQ than Watson. An equivalent observation is that weapons of mass destruction are not designed by those with cognitive impairment. In focusing on what potential persons are likely to achieve and the attributes (which are often in any case positional goods) around which the enhancement/treatment intervention debate takes place, there is little space given to people’s potential to do harm.

The apparent obsession with cognitive capacity on the one hand, and on the other hand apparently trivial (“morally neutral”) issues such as eye and hair colour (Harris, 2007, Chapter 9), is matched with an absence of attention to other beneficial qualities that may contribute to a good life for individuals and those around them. Within ethical discourse, this places us firmly in the terrain of virtue ethics, both in terms of the virtues but also in terms of the absence of “vices”.
Virtue ethicists ask, “how should one live?” in order to achieve the good life, holding a fundamental connection between human well-being and virtue (Crisp and Slote, 1997, pp. 13–16). Thus, as Hursthouse discusses, virtue theory creates a link between eudaimonia (or happiness / flourishing / living well) and certain personal qualities or character traits – virtues – that enable eudaimonia to be attained (Hursthouse, 1997, pp. 217–219). This approach offers criteria other than cognitive capacity by which membership of the moral community is judged, and it also extends beyond a baseline idea of membership of the moral community to achieving a state of well-being.

Within this framework, attention needs to be paid to the qualities that, as autistic advocates have pointed out, may be more applicable to autistic people than to NTs. Given the impairment focus of the diagnostic criteria for autism, autistic virtues have been under-recognised. I referred to this in Chapter 3 (Section 3.2) when discussing observations of bias in research. The NT observers interpreted as deviant certain behaviours and qualities that the autistic observers felt were in fact superior to “typical” behaviour. The following is Michelle Dawson’s humorous but hard-hitting critique of the conclusions drawn by Andari et al.’s research experiment about the effects of oxytocin:

Autistics randomly administered a nasal mist containing oxytocin, rather than a saline placebo, significantly improved. They became willing to work with one of the players in an effort to shun and discriminate against the other two, and thereby get more than their fair share of money and attention. They became willing to see the player who shared with them as good and trustworthy, and the player who shared with someone else as bad and untrustworthy. They learned and displayed selfishness and hypocrisy and us-vs-them thinking. Their objectivity, fairness, and altruism were – temporarily – cured. (Dawson, 2010)

In this vein, some autistic people hold themselves up as less capable of manipulative and self-serving behaviour, more likely to be honest and trustworthy, less suspicious
of other people’s motives, and so on: “You need us to keep you honest, actually” (Wendy Lawson, in *Something About Us* (2008)) is a point that has particular resonance in light of the startling content of an ethics paper by Jaarsma, Gelhaus and Welin (2012). They suggest that “‘morally educating’ children and adolescents with autism to become socially skilled empathic ‘liars’” may be necessary, in order to overcome the fact that “remarkably, lying is not a common phenomenon amongst normally intelligent human beings who are on the autism spectrum” (2012, p. 1).

Virtues are not the sole terrain of the more able or verbal autistic advocates. Similar observations are applicable across the range of autistic people, including those with profound learning disabilities. Of these people, Solomon has said:

> Given how much less these children are likely to attain than typical children, however, to universalize intelligence and achievement as a measure of worth is in some ways to deny who they are. They are not so bright and can’t accomplish so much by general standards, but have real virtues and are capable of personal fulfillment. (Solomon, 2013, p. 202)

Solomon is offering two observations here. His reference to real virtues echoes what I have been suggesting about the significance of addressing autism through the prism of virtue ethics. In addition, he is suggesting something important about the idea of identity: he is implicitly critical of traditional ways of evaluating the worth of learning-disabled people’s lives, insofar as these traditional ways tend to “deny who [autistic people] are”.

Ideas around autistic identity will be discussed below, but before that there is an additional area of virtue ethics that is relevant to the discussion – the issue of parental virtues and how these may overlap with the desire to prevent or cure autism.
1.3.1. Parental virtues and the parent-child relationship

The possibility that some parents might seek to prevent the birth of an autistic child, were a test to become available, and/or then seek to “cure” the child after they are born, raises several issues around parental virtues and what standards of parenting, and what attitudes, are morally legitimate. I introduced this theme in Chapter 4 (with regard to the virtue of parental acceptance). It reappeared in Chapter 5 in the context of parental approaches to intervention. “Treatment vs acceptance”, when viewed through ideas of parental virtue, can translate both into contrasting vices (for example parental perfectionism vs defeatism) – and also contrasting virtues (for example hopeful aspiration vs patient acceptance).

I believe this is a rich area, the significance of which has only become apparent in the process of writing this thesis. Like so many of the other themes I have introduced, I cannot do justice to it here, but there are some particular issues I do want to develop.

Parental aversion and grief

Parents who view autism as a tragedy have been keenly challenged by some autistic advocates. Jim Sinclair’s essay “Don’t mourn for us” is famous in setting out clearly how damaging this can be. He wrote:

“When parents say, ‘I wish my child did not have autism,’ what they’re really saying is, ‘I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.’ Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.” (quoted but not referenced in Solomon (2013, p. 37))
And Amanda Baggs has written:

“Being seen in light of the ghost of who you were expected to be is a kind of emotional violence for many disabled people.” (quoted but not referenced in Solomon (2013, p. 236))

This suggests that parents who are looking for a cure, or who see their child’s condition as a grave misfortune, may be the cause of suffering for their autistic child. What Sinclair, Baggs and many others are indicating is that serious moral reflection is required by parents on the things they say about autism both to their children and to others. This echoes the expressivist argument about the wider damage that is done through negative messaging about disability in general and autism in particular. Nor can we know whether or not those with apparently limited receptive understanding are protected from such messages. They may pick up these feelings in terms of how they are treated, or because they understand more language than those around them realise.

While important, the details and real-life approaches of how parents engage with their children about their autism is not what this discussion is about. Also, the reasons why some parents grieve are bound to be far more complex and diverse than I can begin to address here. What I do want to do, though, is to draw out the various interpretations we might give to such grief where these have ethical implications. I suggest there are three types of response that have different implications for how we gauge parental responses where “grief” is a component. I distinguish between those families who do so because (i) their attitudes reflect a wider attitude that they have absorbed, from stigmatising influences including the medical/scientific/bioethical community, through to having certain views on the good life that are incompatible with having an
autistic child; (ii) those whose struggles are chiefly generated by experiencing lack of practical help in meeting the challenges that they would otherwise willingly embrace; and (iii) those whose feelings are mixed and changeable.

(i) Perfectionism, normalisation and stigma

In Chapter 4 I outlined how arguments about parental virtue can be marshalled both to oppose and to favour reproductive selection. The virtue of parental acceptance was counterpoised with a different take on parenting reflected in the idea of “procreative beneficence” (PB). While PB is advocated on overall welfare grounds, the implication is that parents are morally obliged to be perfectionist in their reproductive choices. In contrast, the point was made in Chapter 4 that such an attitude may be self-defeating, and Rosalind Hursthouse suggests that it has no place within parental virtues:

But to care too much about that dream, to demand of life that it give it to one and to act accordingly, may be both greedy and foolish, and is to run the risk of missing out on happiness entirely. Not only may fate make the dream impossible, or destroy it, but one’s own attachment to it may make it impossible. (Hursthouse, 1997, p. 234)

While many feel uncomfortable about perfectionism (Sandel’s “hyper-parenting” referred to in Chapter 4), I have demonstrated in previous chapters that widespread endorsement is given to the power of normalisation as a goal underpinning antenatal procedures and postnatal treatments. Further, it is argued that antenatal choice elevates the relevance of discernible biological differences and abnormalities over any other qualities and attributes that the potential person may have.
This view is at the root of Asch and Wasserman’s critique (2005) of parental attitudes in taking up antenatal screening with a view to termination. They offer a strong requirement that parents should not seek to prevent most forms of difference, disability or health-limiting conditions. Citing the “sin of synecdoche”, where this means “the uncritical reliance on a stigma-driven inference from a single feature to a whole future life”, they feel that it is based on an erroneous assumption “that a single known characteristic will dominate a myriad of unknown characteristics in the parent-child relationship” (2005, p. 193).

They assert that this reflects a “morally impoverished conception of parenthood and family” (2005, p. 173); and later: “A prospective parent unwilling to have a child who cannot embody her ideals appears to have a distorted view of the nature of the parent-child relationship, and of the goods of parenthood” (2005, p. 177).

They further assert that this distorted view is primarily based on stigmatising. Citing research to show that actually raising children with disabilities does live up to even “modest parental expectations”, they argue that “raising a child with an impairment is seen as a burden rather than a challenge precisely because the impairment is a stigmatized trait” (2005, p. 181, my italics).

In some cases, the experience of preferring a normal child, arising from imbibing wider stigma, may be a powerful enough explanation. But I feel that Asch and Wasserman are being very reductive in attributing everything to stigma. I feel this misconstrues some of the reasons why parents may choose not to have a disabled child.
(ii) Hostile wider environment

Once we go beyond the issue of the parent-child relationship – out into the wider world – impairment becomes more relevant in terms of what it may signify about someone’s future. And it may be that in the case of autism in particular, society’s response is currently particularly unwelcoming and inadequate. Yet Asch and Wasserman pay very little attention to the wider domain in which families conduct themselves.

In contrast, I believe that many parents do not seek children who “embody their ideals” in a misguided quest for perfection or a consumerist attitude to their children, but rather they want their children to have a chance of a decent life and are aware that wider societal conditions (including, but not exclusively, stigma) – rather than their own attitudes – may prevent this. Thus Thackeray and Eatough (2014) suggest that worry about the future for these reasons is an overwhelming preoccupation for parents, and such sentiments are stated by Beals (2003) thus:

Shortages, waiting lists, and surly, incompetent personnel also pervade services for special needs adults. And so, at least as troubling as the shortage and tenuousness of immediate help, is the triad of ultimate questions that hangs, like another sharp sword on a razor-thin thread over all parents of autistic kids. What does the future hold? Will we need to care for our child for the rest of our lives? What will happen to this most dependent and vulnerable of people once we die? (2003, p. 38)

Asch and Wasserman seem to ignore the power and significance of these external influences by focusing on the parent-child relationship, in isolation of longer-term or more societally related issues. For example they say, “What is wrong about … selectivity is not, or not principally, that it may have harmful consequences, but that it

Asch and Wasserman ask themselves later if there are any conditions that would justify parents in seeking prenatal testing and they identify potentially three: severe, comprehensive cognitive impairments; very early death; and virulently oppressive social environments. It is interesting that they include “severe, comprehensive cognitive impairments” here, since – as I have discussed above (pp. 276-285 and pp. 307-309) – this is not an uncontroversial position. Concerning “virulently oppressive social environments”, they say these “may be inimical to the goods of a parental relationship with an impaired child” (2005, p. 205). One might presume that, according to the strong social model of disability, such an environment applies for all disabilities, yet this is surely not what they intend to convey. But my point here is the same: I suggest that it is not the impact on the parent-child relationship that may be of concern to the parents, but rather the converse: what happens when/if the time comes that such a relationship of unconditional love is no longer available to the child?

I have stated elsewhere (pp. 280-283) that dependency should not always be stigmatised – as it undoubtedly is in our present society. If parental fears of dependency are based on stigma, then Asch and Wasserman are making a valid point. But if fears of dependency are actually about adverse by-products of dependency – i.e. fears of abuse and neglect – such fears are nothing to do with parental values or the parent-child relationship. What they do relate to is a realistic/pessimistic view of the world in which their children will one day become adults.
In response to this, Asch and Wasserman might put forward a counter-argument that babies go on being conceived and born in war zones and at times of famine. Surely such conditions are about as bad as it gets, and yet we do not undertake mass terminations in such situations in which a pessimistic view of the future is surely reasonable – so why is it felt to be permissible by some to select against impairments? Most situations in which prenatal testing is undertaken with a view to abortion are much less extreme – and so, the argument would continue, to terminate on account of impairment must once again be synecdochical.

But that does not end the argument. What a prospective parent might say to this is that while the conditions are equivalent to peace and plenty for the non-impaired, such are the barriers that society puts up that for those with impairments, in these cases, it truly does feel more like a war zone. If one can choose the conditions in which to raise a future child, one would surely reject the war zone – not for some self-gratifying motive concerning the parent-child relationship, but for the sake of the child.

Aside from the ongoing dilemma about person-affecting versus impersonal harm (see Chapter 4), my point here is that a parent is unlikely to be accused of synecdoche in such situations. Concerning autism, I am reminded here of the piece entitled “Welcome to Beirut” (Rzucidlo, n.d.), in which – against the frequently cited analogy of being required to live in Amsterdam instead of Paris\(^\text{87}\) – for the child and for the family as a whole, autism equates with entering war-torn Beirut. Importantly, it is not autism per se that does this, but the inability of institutions and wider society to be welcoming, supportive or in any way helpful towards people with autism.

\(^{87}\) See DfES/DH (2006, p. 6).
Moreover, I believe that autism throws up some rather different challenges in terms of the parent-child relationship. In its extreme form, there is an overblown sense that only the parent can protect and love the child. Autism is disproportionately represented in the catalogue of simultaneous child-killing and suicide tragedies that have featured in the media during the past two decades (see for example Solomon (2013, pp. 288–292) and Murray (2008, pp. 168–171)).

I would not presume to pry into the details in each case, nor to digress into an in-depth analysis of what happened or why. But what I do believe is that at least in some of these cases, the parent-child relationship has become overriding and all-consuming, because of the failure of the outside world to do the appropriate amount of wider environmental work that is necessary to enable an appropriate degree of future parent-child separation to be imaginable or achievable. This is not an assertion that is backed up by peer-reviewed literature or reputable research. Rather, it is based on a distressingly large number of conversations held in private with parents who have shared these thoughts and fears, but have – fortunately – come through the dark night of the soul in which such imaginings were on the brink of mutating into active wishes.

While murder, and possibly suicide are generally held as sinful, synecdoche is not a relevant crime in these situations. Equally, it is vital that in discussing these scenarios, it is not the child and their autism that are seen as the problem. (See for example Klar-Wolfond (2008) on the damage such accounts do to the self-esteem of autistic people.) Just as it is wildly inappropriate to imply the child has brought this tragedy upon him- or herself, so it is also inappropriate to isolate the parent without
understanding wider context. Depression, exhaustion, fear and an obsessional
certainty that no one will ever be able to understand, care for or love the child
adequately – and certainly not as the parent does – and that this makes a joint death
preferable to imagined future intolerable lives, either together or apart … I believe it
is these forces that are at work in the attitudes of such parents. Such considerations
are more relevant than the presumption of synecdoche.

If I am right about this, then this is an example of why synecdoche does not capture
the whole of the reality of parental responses, at least with autism. Rather, stigma is
just one feature of the diverse ways that external context can impact detrimentally on
the lives of disabled people and their families. I believe Asch and Wasserman have
failed to address these wider reasons why some parents grieve about having an
autistic child, and/or seek to prevent their birth. I believe that much of the answer to
this “why” comes back to wider social forces, in which parents are recipients rather
than contributors. And this in turn gives a hint as to where the major locus of ethical
intervention should be.

There is a further issue in relation to Asch and Wasserman’s important article that
*autism in particular* throws up. This is about whether autism is a small part or a big
part of a person. Their argument rests on the notion that
impairment/difference/disability is one small almost incidental feature in the totality
of a potential person’s identity. Yet in the case of autism, the point that so many
people make is that autism and the person are inseparable – which is indeed the exact
opposite message.
I will return to identity later, but first I would like to pursue the issue of parental virtue and what is required of parents of autistic children – prospective or ongoing.

(iii) Ambivalence, complexity and paradox

I referred above to the different ways in which having an autistic child impacts on families, and referred to the diversity of responses to autism in families or even within one family member. This is an issue that Solomon has explored at length, and the following is an important encapsulation of the ambivalences that often operate:

All that children can properly require of their parents is that they tolerate their own muddled spectrum – that they neither insist on the lie of perfect happiness nor lapse into the slipshod brutality of giving up. … There is no contradiction between loving someone and feeling burdened by that person: indeed, love tends to magnify the burden. These parents need space for their ambivalence, whether they can allow it for themselves or not. For those who love there should be no shame in being exhausted – even in imagining another life. (Solomon, 2013, p. 21)

And also:

“The parents may never accept what happened to them and yet accept their child. They’re two separate things, the parental loss, and the actual person they will almost always end up loving.” (Solomon, 2013, p. 183, quoting Elaine Gregoli)

These quotations suggest that parents may be permitted to feel ambivalence about their own lives, without this reflecting badly on or saying anything negative about the child, and without this ambivalence denoting some shortfall in parenting.

Somewhere between perfectionism on the one hand, and the requirement to ignore all notions of challenge in having a disabled child on the other, there lies a rich terrain of feeling and experience that abstract ethical analysis tends to overlook. Thus, virtue
ethicists have criticised the dominant schools of deontology and consequentialism because they focus on acts, obligations and states of affairs rather than qualities, and because they are barren on the issue of love, which – given its profound and complex significance in human life and despite the human focus of applied ethics – is a major omission.

For example, Stocker (1997) has referred to the importance of love beyond the romantic and sexual, as follows:

the love among members of a family, the love we have for our closest friends, and so on. Just what sort of life would people have who never “cared” for anyone else, except as a means to their own interests? And what sort of life would people have who took it that no one loved them for their own sake, but only for the way they served the other’s interest? (1997, p. 69)

And incorporating the beloved person, not just the person who loves:

The defect of these theories in regard to love … is not that they do not value love (which, often they do not) but that they do not value the beloved. Indeed, a person who values and aims at simply love, that is, love-in-general or even love-in-general-exemplified-by-this-person, “misses” the intended beloved as surely as does an adherent of the theories I have criticized. … [Such theories are] devoid of all people. …

what must also be looked at is what it does to us – taken individually and in groups as small as a couple and as large as society – to view and treat others externally, as essentially replaceable, as mere instruments or repositories of general and non-specific value; and what it does to us to be treated, or believe we are treated, in these ways.

At the very least, these ways are dehumanizing. (1997, p. 72)

These arguments, and many similar points made mainly by feminist ethicists, have in turn incubated a “young branch of the old tree of ethics” (Harper-Donnelly, 2014, pers. comm.) – the ethics of care and caring – which asserts that we cannot separate
moral imperatives about how to treat people from the question of love, caring and relationship.

This is particularly the case when we are discussing reproduction, but extends to families and ultimately communities via a less intense version of love, which is concern or solidarity (Prainsack and Buyx, 2011). I had long regarded it as the sentiment that underpins and links the desire to minimise suffering on the one hand, and the explanation – beyond capacity to reason alone – of why we should not treat people as means, on the other hand. As such, and from early on in my studies of ethics, I considered “concern” or “caring” to be the binding ingredient across consequentialism and deontology. I only came to explore more closely the emerging literature on the ethics of care, however, when the limitations of the dominant perspectives of consequentialism and deontology in answering my research question became apparent in my exploration of the issues at stake, and when I found that writers such as Held and Slote had written extensively on these issues. Both Held and Slote have come to consider that the ethics of care is not merely a form of virtue ethics but a moral approach distinct in its own right (see Held (2006), Chapter 3 in particular). For Held, the distinction lies in the emphasis on relations rather than solely individual qualities, and – hence – she conceptualises care as both value and actions: “practice” in her words. For Slote (2007), the fundamental quality that gives rise to this caring is a capacity for a certain kind of empathy – a “fully developed empathic concern” (2007, p. 31). The role and significance of caring, alluded to directly in some approaches to virtue ethics and in particular by some feminist
philosophers,\textsuperscript{88} therefore commands attention in its own right, in pursuing some of the strands left hanging in trying to answer my research question.

1.4. The ethics of care

There are several reasons why the ethics of care appears at first sight to offer an appropriate moral framework in which to explore some of the big questions of my thesis.

First, as argued by Held (2006), it claims as a major feature the “compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility” (2006, p. 10) and in so doing addresses the point I raised above and made by others such as Kittay about the ubiquitous presence of dependency and interdependency (see above pp. 280-283 and p. 333) – which is of particular relevance to those (majority of) autistic people who will need some kind of support throughout their lives.

Second, it makes room for emotion: “moral inquiries that rely entirely on reason and rationalistic deductions or calculations are seen as deficient” (Held, 2006, p. 10). This echoes Stocker’s emphasis on love, as argued above and about which I have more to say below.

\textsuperscript{88} Carol Gilligan (1982) argued that men tend to conceive morality in terms of rights, justice and autonomy, whereas women more frequently think of the moral in terms of caring, responsibility, and interrelation with others. Nel Noddings (1984) also articulated a feminine morality centred around the idea of caring.
A third persuasive feature of the ethics of care is its claim that care – or concern – underpins other moral approaches rather than acts as a mere adjunct. This is an assertion that, as stated above, has always seemed to me to be appealing both conceptually and empirically. For example: “Care seems the most basic moral value. As a practice, we know that without care we cannot have anything else, since life requires it” (Held, 2006, p. 71).

Both Slote and Held carry the emphasis on care into wider societal and political practice, though Held’s discussion is more extensive in this regard. She argues that societies will simply not cohere in the absence of caring. For example: “Rights … presume a background of social connectedness. … At the very least, human beings can and ought to care enough about other human beings to sustain the relations between them within which rights can be respected.” (2006, p. 137). She is not claiming that care alone is a necessary condition for societal cohesion, since she argues strongly for a legal and institutional framework built on the principles of justice within the public sphere, and also endorses the idea of justice as being of relevance within the private and domestic sphere (see pp. 62–66 and 90–104). But she is claiming that we cannot even start to address questions of justice if there is no sense of concern or connection with others, and that this view of humans’ fundamental state differs strongly from a Hobbesian version of competing self-interested individuals, which has persisted into more recent liberal social-contract theorists: “The illusion that society is composed of free, equal, independent individuals who can choose to be associated with one another or not obscures the reality that social cooperation is required as a precondition of autonomy.” (Held, 2006, p. 86).
The suggestion therefore is that the ethics of care is an important moral approach that provides a guide as to what it is to be moral, and to act morally, both in the private and the wider societal domain. The resonant features for my thesis are first, the linkage between the local and the societal, and second, the centrality of the idea of care/concern/solidarity\(^{89}\) in making sense of how we evaluate other people in general, and the different dimensions against which we can assess “the good life” – dimensions that are necessarily often intangible and unforeseeable. I take forward these points below, in the sections about moving love up the agenda, and in tackling “the big conundrum”.

What I am less clear about is whether the ethics of care needs to set itself up as a distinct approach, rather than a further elucidation of the principles offered within virtue ethics and feminist philosophy. Crucially, virtue ethics does not exclude issues of practice, despite its emphasis on individual qualities. Indeed, the significance of practical wisdom to enable the enactment of morality in the conduct of relations is central in the literature.

However, I feel that caring in itself – while necessary – will not be sufficient to answer the moral question of my thesis. This is because, as indicated in Chapters 4 and 5, widely differing actions in regard to autism may all stem from a presumed same place of caring. Attitudes of beneficence and non-maleficence were seen to underpin radically different goals and choices, according to views about autism, and about the state of the world in which we live. Slote’s response to this problem is to assert that it is empathy that will provide the guide in specific situations, but that may

\(^{89}\) Held sometimes uses these terms interchangeably.
not help in framing wider, “scaled-up”\textsuperscript{90} moral choices. In relation to autism, and in particular in relation to decisions made on behalf of children or adult autistics whose learning disabilities are severe, I am not certain that empathy alone will be a sufficient guide with which to judge best interests. And in this situation, there is a circularity of argument, because it seems that what is necessary is then a view of the good life, or of the things that will contribute to it, set against a view of what is achievable in our current world.

Notwithstanding these reservations, I consider that the most significant offering that emerges from the ethics of care – as with the feminist philosophy from which it has emerged and the insights offered within virtue ethics – is this:

\begin{quote}
\textit{It is not only permissible but also necessary to incorporate into our moral thinking (i) the significance of feelings and sentiments including love, and (ii) to address the linkage between private/domestic domains and wider societal conditions.}
\end{quote}

1.4.1. The implications of moving love up the ethical agenda

If we elevate the significance of love in ethical analysis, then this gives even greater power to the point made above (p. 303) in relation to the limitations around making an \textit{ex ante} reproductive selection choice.

An example of this is the following passage from the book about her autistic daughter by Clara Claiborne Park (1967):  

\begin{flushright}
90 This term is central to Parker’s argument about the requirement that moral craft needs to be able to address local and more large-scale moral choices (Parker, 2014).
\end{flushright}
I write now what 15 years past I would still not have thought possible to write: that if today I were given the choice to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands – because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love.

What this demonstrates is that experience may overturn what one might otherwise have valued. In this sense, then, *ex ante* choices, as advocated by Harris and others referred to in Chapter 4, come from a position of ignorance both about all the qualities that the child will possess and how their condition will impact on their life, and about how the experience of parenting that particular child will impact on the parents (and families), and bring about change in what they hold to be important.

A similar point is made by Solomon (2013), when writing about “horizontal identities” – those ways of being, including autism, that confer a dramatic and significant difference between children and their parents:

> For some parents of children with horizontal identities, acceptance reaches its apogee when parents conclude that while they supposed that they were pinioned by a great and catastrophic loss of hope, they were in fact falling in love with someone they didn’t yet know enough to want. … This book’s conundrum is that most of the families described here have ended up grateful for experiences they would have done anything to avoid. (Solomon, 2013, p. 47)

Another way of looking at this is to say that, *ex ante*, parents are in ignorance about the nature and components of what will contribute to flourishing. The things they believe might contribute to the good life at one point may turn out to be altered with experience and hindsight. McMahan refers to this as a shift in values arising from having a disabled child, and he further suggests that a subsequent affirmation of
disability arises with the process of attachment in the case of having a second disabled child (McMahan, 2005).

Because people develop and change over time – including their values – how are we to say at which point they are most able to make the rational or informed or loving judgement?

Speaking of this, Solomon has said:

prospective parents are dealing in the abstract with something that could become tangible, and that’s never an informed way to make a choice: the idea of a child or a disability is extremely different from the reality. (2013, p. 29)

and

With access to reproductive technologies, we are conjecturing what kind of children will make us happy, and what kind we will make happy. It may be irresponsible to avoid this guesswork, but it is naïve to think it is anything more. Hypothetical love has little in common with love. (2013, p. 682)

Herissone-Kelly (2011) has argued on similar grounds that “real” love comprises features of the unexpected, rather than adherence to a menu of preferences. He spoke of “happening upon” as an essential ingredient for love, in suggesting that sex selection may not chime with the “happening upon” nature of unconditional parental love (or, indeed, love between partners). One can make the same point in relation to disability or other types of difference.

What is interesting about this emphasis on love is that it does not offer a clear moral steer about asserting the rightness and wrongness of reproductive choices either for or
away from autism. Instead of summoning up elaborate distinctions about harm and benefit, identity-affecting distinctions and so on in order to marshal arguments for or against selection, one is actually in effect saying this to prospective parents:

"I cannot say if you're right or wrong to try to prevent having an autistic child. What I do know is that if you choose against it, you may be missing out on a great adventure of love."

Conversely – and this is something I have pointed out so much that I presume it is clear where I stand – the strongest arguments against having an autistic child are in relation to the wider environment and not to the inherent qualities the child will possess:

"I cannot say if you're right or wrong to try to prevent having an autistic child. What I do know is that if you choose against it, the argument that stands up most strongly is that society isn't yet ready to welcome your child as fully as it would welcome an NT child."

A crucial question for applied ethics then becomes: to what extent is the morality of local reproductive choice dependent on wider states of affairs? And this takes us straight into the next area I wish to explore – the ethical content of local decisions when in actuality they are located within a wider societal context. My penultimate task, therefore, is to bring together some of the themes I have explored so far in this chapter, in addressing what I have previously referred to as the big conundrum.
2. **Linking local choices and broader “states of affairs”: the big conundrum**

The big conundrum relates to the fact that local decisions may have broader consequences, so that what is felt to be morally permissible in the local context may nonetheless contribute to a worsened state of affairs more generally. It has been a theme that has been touched upon frequently in the thesis (see for example pp.152-153 and p. 263), and requires a fuller discussion now.

In the context of reproductive selection the conundrum plays itself out most clearly in discussions around the expressivist argument: do private decisions to select against disability carry a damaging message about disabled people into wider society? Does a private choice to prevent an autistic person being born damage the wider interests of autistic people and NTs, and if so, is this sufficient reason to override the autonomy of the potential parent to be the one who chooses?

A similar set of issues arose in Chapter 5 in relation to discussions about the moral questions posed by different kinds of intervention once an autistic person has been born. A view of society as irredeemably hostile to autism would, for the sake of their child, impel parents to make greater efforts to “cure” their child’s autism, or to encourage them to “pass” as NT, than an alternative view of society as willing and able to adapt to and welcome autistic people. If the process of social change takes decades, individual parents may decide that change will come too late for their child and therefore, despite their celebration of autism in their child and desire to see a more autistic-friendly world, work hard to encourage their child to “pass” as NT.
To what extent are private choices about reproduction and child-rearing compelled to take into consideration views as to what kind of a world we should all be living in? And, if there is a conflict between local actions and wider consequences, how do we arbitrate as to the morally appropriate course of action? This question has been raised in several contexts, for example by MacLeod (2010) when discussing the incentives that exist to privilege one’s own children, and he frames this dilemma as a “potentially tragic normative conflict between justice and legitimate parental responsibilities” (2010, p. 130). He feels that justice – taking account of the wider social environment and making choices that relate to a better state of affairs more broadly than one’s own child’s betterment – should be given considerable weight: “we should not confuse good luck with entitlement” (2010, p. 150). In the case of autism and decisions about prevention/treatment, the implication would be that private choices should pay considerable attention to broader states of affairs, and not focus exclusively on what is felt to be the best outcome for the child.

But even here, as has been shown earlier in this chapter, the question of what is a good outcome for autistic people is still up for discussion, as indeed is the question of whether autism contributes to or detracts from a good state of affairs more generally. Once again, we are left with a question about how autism should be viewed – the analogy challenge – and that will be my final task in this chapter. But first, I wish to demonstrate that holding a social model of disability does not assist us in resolving the conundrum.
2.1. The big conundrum: social vs medical models

Much has been written about the pressures and atmosphere in which antenatal choice is conducted, in a highly medicalised arena in which disability is a negative departure from the norm (see Jennings (2000); Shakespeare (2005)). In this regard it is suggested that the so-called autonomy of the parent who is making the decision is already infringed by unbalanced and partial information, and by a system that channels people towards selection almost before they realise what is happening. Thus Jennings has said that we need to face up to “the illusion of freedom that is created when we underestimate the reality-shaping power of biomedical technology and its implications for the kind of parents, citizens, and human beings we are” (2000, p. 130) and further: “It is breathtakingly implausible, as a matter of fact, to characterize the use of genetic testing in obstetric practice in our society as a ‘private’ act in any case.” (2000, p. 131).

Nonetheless, let us imagine, for a moment, a prospective parent who thinks independently of the medical model; she has a positive attitude towards neurodiversity and may indeed be well-versed in the social model of disability. Even she may have powerful reasons for deciding to prevent the birth of an autistic child, however sad she feels about it. Because of all the problems that arise from a less-than-supportive wider environment, as discussed above, she may feel that she and her future child are just not strong enough to face the societally constructed brick wall inhibiting the lives of autistic people and their families.

From this scenario it is clear that adopting a social model of disability may not in itself lead to a more positive parental attitude to the prospect of a disabled child. For
people faced with this choice, the decision to prevent the birth of an autistic child is not so far from the choice prospective parents make about how many children to have, or whether to have a family at all, or at a particular stage in their life – all these choices are about context, both familial and external. It is important to stress this: it is about viewing the choice of the prospective parent in the context both of their own life and that of other actual or potential siblings, and also in the context of the society around them, rather than solely in relation to the welfare of the child to be born or the type of child to be born. Where there is a difference it relates to the fact that the other choices are made about any child, whereas in the case of autism it is about the particular kind of child. Yet I argued above (p. 331-336) that it is not always valid to assume that a decision to prevent the birth of such a child is necessarily reflective of a stigmatising attitude. If we recognise that the reasons may be due to the nature of the wider environment, rather than to the virtues or values of the individual parent, then this does not end the story in terms of moral responses to the issue. There are additional considerations.

A significant argument against selecting against a child with autism is in relation to expressivist argument. For example, some have argued that even the scenario I presented above conveys a negative message – in effect the mother is saying about any potentially autistic child that they “aren’t worth the time and trouble that they require” (Nelson, 2000, p. 203). There is a counter-argument to this, however. I would suggest that an alternative message about the potentially autistic child is this: “S/he is entitled to more (extra) effort than I, in my current situation, can provide, and currently the world out there is not able to provide it either.” We can examine this
through deontological or virtue ethics lenses and find that such an attitude may well hold up as morally acceptable.

The problem, though, relates to the wider consequences if similar choices are being made everywhere, by everyone. Irrespective of the motives and considerations of the individual parents, the outcome is that the lives of potential autistics have been prevented, so that the macro consequences may be unintended but dramatic – there will be far fewer or even no more autistic people in the world. As argued in Chapter 5, the same applies if the literal implication of “cure” were achieved, once autistic people have been born.

But whether a situation in which the absence of autistic people is felt to be beneficial or repugnant rests, finally, on how we view autism.

3. Autism – culture, identity and the analogy challenge

In the first section of this chapter, I explored the ways in which autism does or does not predict “suffering” both for autistic individuals and NTs at a local and societal level. I then examined how alternative approaches to “the good life” might illuminate my research question in terms of what overriding criteria should be adopted to assess moral qualities, values and actions. I demonstrated that a crude equation of autism and suffering is unsustainable, and further that the interconnected relations both of people and of micro/macro contexts pose massive challenges to a straightforward conclusion about what should be the goals of any kind of autism intervention.
As if the several approaches to ethics weren’t complicated enough, I have indicated throughout this thesis that we can’t provide a firm answer to my research question without coming down firmly on a view about autism itself. But, at the risk of circularity, I demonstrated in Chapter 2 that there is still no shared perspective on the existence and/or essence and/or idea of autism.

I don’t want to give up at this point, however, because there is still a little more work to do in exploring the disease vs difference concepts of autism.

If we argue that autistic people share a horizontal identity, and can indeed claim to be a distinct and legitimate minority group, then this requires a different ethical position from one based on a view that autistic people are a disparate group of individuals who have all fallen foul of a specific disease.

Suggestions that there is no distinct autistic community have been made by a range of commentators. Barnbaum (2008, pp. 156–161) argues that, by its very nature, autism precludes the existence of a community. And Solomon offers a distinction between autism on the one hand, and the deaf world on the other – where “deaf culture” is a positive collective identity in a way that he feels autism is not. Thus he observes that, unlike deaf culture, there is no formal language of autism, no university with a long history of educating autistic people, no cultural institutions such as theatres, clubs and so on (2013, p. 282).

However, I believe there are strong indications of a real autism community. Beyond the academic references to it (Bagatell, 2010; Sinclair, 2005), an emerging sense of
collective autistic identity is evident in groups such as the Autistic Self Advocacy Network (ASAN) in the USA and Autreach in the UK, and in the range of online communities for autistic people. Increasingly, cinemas and theatres are offering autism-friendly viewings, while the creation of specific social groups for autistic people in many areas indicates that there is an emergence of autistic community and culture. Also, the fact that autism culture falls behind deaf culture cannot be understood without appreciating that it has only been recognised as a distinct condition since the mid-twentieth century – long after Martha’s Vineyard had demonstrated how deafness could be interpreted as difference rather than disability within a community, in the late-nineteenth century (Gross, 1985).

However, the idea of autism as difference rather than disease does not require us to identify a distinct culture so much as recognise, first, that people with the label have shared interests, and second, that at an individual level, for many, autism is intrinsic to “who they are”.

“Community” can mean many things (it would be too big a task to review the literature on this), but in terms of shared interests, I would suggest that it is in any case not necessary to try to point to an existing community or culture (though I think there are signs of this) in order to point out that autistic people have at least some shared interests. The minimum shared interest is that all with the diagnosis are carrying a label that has negative connotations in many quarters, such that the desire to prevent or cure autism is a stated goal among some researchers, parents and charities. But beyond this, the more fundamental question is whether and in what way autism is perceived as intrinsic to someone’s identity.
Jim Sinclair has set out a clear view on this:

“Autism isn’t something a person has, or a ‘shell’ that a person is trapped inside. There’s no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion and encounter, every aspect of existence. It is not possible to separate the autism from the person – and if it were possible, the person you’d have left would not be the same person you started with.” (quoted but not referenced in Solomon (2013, p. 276))

According to this view, then, autism is integral to someone’s identity-essence (see p.112). Additional quotations reflecting this self-perception abound, for example Grandin’s assertion:

If I could snap my fingers and be nonautistic, I would not – because then I wouldn’t be me. (Sacks, 1995, p. 291).

This view also explains the rejection of the person-first nomenclature around autism referred to above (p.11 and see Sinclair (1999)). Such a view of autism contrasts strongly with a disease model, where person-first descriptions are the norm.

Not everyone holds on to an idea of integral autistic personhood. Many parents express the view that autism is a separate thing from the person with autism, as illustrated by the following remark by a father about his autistic daughter: “There is her as a person and then there is her with her handicap” (IMI and the EU-AIMS project (2014)). Some autistic individuals would welcome something that would take away their autism without seeming to worry that this would mean they became a different person (Ros Blackburn (2010)). Even here, though, there are questions raised about how to generalise these personal beliefs and desires. Scully (2008, pp. 172–173) has made a similar point with reference to disability more broadly. In discussing the thought experiment of offering a “magic pill” to remove a particular condition, she has shown that private choices do not and should not be extrapolated to
be saying anything more broadly. In other words, just because (1) some disabled people rue their own condition, it doesn’t mean that they also believe (2) that their impairment in general should be prevented / completely repaired and further (3) that it would be better if all such phenotypic variation were prevented.

Scully says that we are not ready to answer (2) and (3). We don’t know in many cases how much inherent disadvantage would be left once the social and economic disadvantages surrounding the condition had been removed. We need more empirical information about what experience is like both under current social arrangements and what it could be like if measures were taken in the wider social arena to make the environment more autism-friendly. This is equivalent to saying that until we have exhausted the possibilities of P-3 and P-2 interventions, we are not in a position to decide about the justification of antenatal prevention or of post-birth P-1 interventions.

Against this, some observers suggest that the above quotations and level of consciousness, not to mention communication skills, of those who maintain that autism is intrinsic to who they are apply in any case to only a minority of autistic individuals. As such, they are not convinced that it is a relevant consideration for others whose autism is accompanied with severe or profound learning disabilities – around 50%. Yet as I have demonstrated through the quotations previously cited in Chapter 3, there is no consensus in this regard. Some parents of autistic children with profound learning disabilities still believe that if the autism were taken away, this would be like taking their child away, echoing Sinclair’s assertion that “the person you’d have left would not be the same person you started with”. In contrast, other parents make a separation between their child’s essence and their autism.
So I am not persuaded by the moral relevance of a perceived distinction between how the so-called high-functioning and low-functioning autistics feel. While the ability to express autistic identity undoubtedly requires self-awareness and expressive language skills, this does not itself invalidate the proposition that autism and identity are inseparable even amongst those with no language and fewer resources for self-reflection.

In saying this, I am aware that the whole question of what constitutes and contributes to “identity” opens up another vast area of enquiry and debate – not just within autism but within philosophy, psychology, sociology and more. Questions of what makes up an essential part of an individual (Kripke, 1980) and whether identity is ever intrinsic as opposed to independent of the social relations that help form it (Lawler, 2014) will influence how seriously we take the idea of autism being crucial to someone’s essence. Given all I have said in Chapter 2, including the suggestion by Hacking (1999) that autistic identity is fluid; and the views of Timimi, Gardner and McCabe (2011) that autism doesn’t really exist at all; and given that much of identity is socially constructed, I realise I am not on solid ground in arguing in favour of autism as intrinsic to identity. Nonetheless, I wish to persist! This is for three key reasons.

First, I am not sure that these disagreements about something so intangible can be resolved either in an a priori discussion or by looking for empirical proof. With regard to the latter, clearly the quest for biomarkers is linked to a hope of identifying some biological essence to autism. Yet I am not persuaded that even the arrival of biomarkers at some future point would prove that autism is disease rather than
difference. Biological difference is not automatically the same thing as illness or deficiency (the struggles of successive equality rights movements demonstrated and ultimately vindicated this simple point). In addition, there is a very long “stretch” between what a gene or molecule or physiological process may be like and the ultimate expression and experience in a lived life (see Scully (2008, pp. 31–32) for a fuller discussion of this).

Second, the idea of autism as being integral to identity is powerful, even if “merely” as a narrative construct, and is a driver for many people’s view of themselves and others. (See Scully (2008, Chapters 6 and 7) for an in-depth discussion of identity and disability.) This confers on autism the idea of it constituting a minority group, rather than a disease, in keeping with Solomon’s view of “horizontal identity”. And I am supported in this perspective by a growing sense among some autistic advocates that we should “stop using the word autism, and start talking about autistic people – it’s not the ‘it’, it’s the ‘us’” (Stronach, 2014, pers. comm.).

Third, all I can offer by way of a personal standpoint is my conclusion emerging from self-reflection, in trying to explore what I consider to be a person’s “essence” and what I consider to be extraneous. I offer it up in the knowledge that it is only my perspective and that it is something that is open for counter-argument. But what I have done is to examine what it is I love about various people, taking forward the important message – discussed in relation to virtue ethics and the ethics of care in particular – about the significance of love in general, and the people who are loved in

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91 In contrast to vertical identity, whereby people’s sense of who they are is derived from inheriting or acquiring properties from their parents, horizontal identity relates to “someone who has an inherent or acquired trait that is foreign to his or her parents and must therefore acquire identity from a peer group” (Solomon, 2013, p. 2).
particular (see above p. 338). I feel more confident about using this reference point as an arbitrator for my personal standpoint having studied writers such as Kittay and Held, who do not hold back from using these emotions within scholarly philosophical works – indeed, they argue forcefully that such emotions are an essential component in addressing moral questions.

When I think about the autistic people I love, I cannot separate the people from their autism. It is not that I love them because they are autistic, but rather that their autism is an essential component of what I love about them. To imagine them without their autism is to conjure up a new, different, imagined-only person. This feels qualitatively different from the ill people I love. I love them, but their illnesses are not an essential ingredient in the love I feel; in imagining them without their illness I do not have to conjure up an idea of a new, different individual. The idea of continuity of a person’s identity with and without an illness seems therefore to be untroubling. To visualise a person moving from being autistic to neurotypical, in contrast, requires at the very least a break in that continuity. It would be as if I would have to start loving a new person.

There are at least two key counter-arguments that might be made here. First, people with acquired illnesses can have a shared sense of identity based on the common experience of that illness – for example those in the HIV/AIDS community. So I need to go further in pressing for the intrinsic nature of autism as distinct, particular and singular, and the identity as more fundamental than one that arises from others’ experience of sharing a condition. Here it is worth reasserting Jim Sinclair’s assertion above (p. 354): “Autism is a way of being. It is pervasive; it colors every experience,
every sensation, perception, thought, emotion and encounter, every aspect of existence.” I would tentatively suggest that, for example, individuals from the HIV/AIDS community would not describe their condition in quite such all-encompassing terms? For example, would an individual with HIV/AIDS be able to make the following claim: “if you take away my [autism] you take away me” (Ustaszewski, quoted in Jardine (2008)).

A second counter-argument is the possibility that actually what I am distinguishing is people with lifelong conditions from those who acquire a condition during their lives – a distinction that Scully suggests has been shown empirically to be significant (2008, pp. 119–131). In the latter case, the continuity of the individual builds on a pre-illness way of being such that the illness is superimposed on an already-existing personal narrative. In contrast, the former case relates to people – including autistic people – who have never been any different in terms of the condition with which they were born, and for them the linkage of their condition and their identity seems intrinsic due to the continuity and inseparability of each. Their condition is therefore incorporated in all that the person is – it is part of what makes them loved for who they are.

This second possibility may provide assistance in recognising the harm that can be done to someone in trying to cure them of being who they are. There are parallels across types of disability (see for example Micheline Mason (2000)). It supports the caution of trying to change autistic people into behaving as if they were NT. But, the case of antenatal prevention is different. That is, as has been argued by Harris (2001), Buchanan (2000) and others, loving person X does not require us to seek the
perpetuation of their condition in future generations, nor, therefore, to oppose attempts to prevent the condition.

And yet, in the case of autism, I do extend the proposition. I have made the point previously that the logical implication of prevention, or cure, is a future world without autistic people in it. For me, this is not a good state of affairs. Not only is autism part of what I love about the autistic people I know and love now, but also, I would be sad if there were no more autistic people in the world in the future and I believe it would be a loss for everyone. So I need to go further and make a positive pro-diversity statement in the case of autism about what kind of people I would want to inhabit the world in the future. I hope there will be more people with the qualities of the autistic people I love – where these qualities are components of autism specifically, and render them distinct from most NTs in key, “autistic” ways. By saying this I refer back to the suggestion that was couched within the terrain of virtue ethics and in the account of challenges to the bias of an NT majority, and also the accounts of what may be entailed in having severe learning difficulties – qualities of authenticity, greater than average ability to withstand some of the damaging aspects of peer-group pressure, a reduced capacity to manipulate others, and often a reduced potential to be cynical about others’ motives. This is a very truncated list, and in offering it I am of course aware of the pitfalls of generalisation. I am hinting towards the need for greater reflection, and greater willingness to consider a level playing field between autistic people and NTs, in terms of what qualities are considered to be good and bad, advantageous and disadvantageous, to be encouraged versus to be discouraged. Many of the qualities of the autistic people I love offer clues as to what human qualities are to be encouraged amongst all of us – autistic and NT.
In saying this, I seem to be integrating the ethical standpoints that focus on individual virtue and on the practice of caring, with wider consequentialist notions of general states of affairs. And finally, to satisfy the deontologist, I should also point out that there are not, as far as I am aware, any instances in which it has been deemed rational or ethical to seek the extinction of a group of people – which is what, unless we adopt a strict disease model of autism, the quest for prevention and cure boils down to.

4. Final comments

Moral cases cannot rest entirely on individual sentiment, even though philosophers such as Slote (2007) and Williams (1973) have argued powerfully that personal attachments do make up part of how we judge the moral content of actions. But beyond my personal feelings about this, I believe that there are sufficient arguments, even aside from the significant issues of love and caring, to make us wary of calling for a wholesale cure or prevention of autism, as argued in previous chapters.

In particular, because of what I feel to be the significance and necessity of P-3 interventions, and the broad consensus in favour of P-2 from very diverse standpoints (as outlined in Chapter 5), and echoing Scully (2008), I do not see that we are ready to seek prevention and cure as overall and generalisable goals, unless – notwithstanding all the P-3 and P-2 interventions that might be pursued in the future – there emerges at some future date robust and uncontested evidence that autism drastically impairs chances of a tolerable life, from the point of view not just of outsiders but of autistic
people themselves. We are nowhere near this state of affairs, and my hunch is that we never will be.
Chapter 7 Conclusions and Recommendations

I have sought to interrogate whether or not the quest to prevent and/or cure autism is morally legitimate. This has entailed an exploration of contrasting standpoints on what autism is, ranging from evolving scientific knowledge to more recent socio-cultural and stakeholder perspectives, and a review of how autism has been addressed so far within the field of ethics. I have suggested that the limitation of this ethical work to date relates to its failure to incorporate empirical knowledge about autism, including the social context in which autistic people and their families live.

In Part 2, I unpacked the ethical content of different intervention scenarios, according to my framework of six categories of intervention, which demarcated as morally significant the timing (ante-/postnatal) and target (towards individual or environment) of the intervention. Exploration of issues around suffering, the good life, the individual in social context and the “essence” of autism were all implicated, and discussed further in Chapter 6. On the basis of all that I have written, I am ready to assert some broad conclusions, and also set out what these might mean in terms of the “next steps”.

1. Broad conclusions

1.1. Prevention and/or cure of autism as overall goals

If nothing else, I hope I have persuaded the reader that behind calls to prevent or cure autism there lies a highly complex web of issues, all of which carry significant and
serious implications. The weight and extent of this complexity alone should make
people pause before offering simple mission statements.

The first complexity relates to autism itself. I have argued, particularly in Chapters 2
and 6, that it is inaccurate to portray autism as a unitary, reducible condition, or as one
that allows simple predictions about what kind of life is implicated for an autistic
person or for those around them, or as one that should be viewed only in terms of
impairments. This is because, combined with the extreme heterogeneity of autism,
there is still no shared understanding of its nature, let alone its impact.

Given this, my overall conclusion is that reference to prevention and/or cure as a
desirable general goal is neither clinically/scientifically coherent nor morally
legitimate. To talk in approving terms about prevention and cure implies that a world
where there are no more autistic people would be a better world. But, as argued in
Chapter 6, aside from how offensive this is to some, it is wildly simplistic. To persist
in justifying prevention and cure as broad goals means to persist in believing not only
that such a future world would be a better place but also that it is acceptable to adopt
this terminology despite the offence it causes to at least some autistic people, and to
many who love them.

If, on the other hand, clinicians, scientists and parents are seeking to bring about
choice, rather than making any broader statement about the desirability of alternative
futures, then – to make a point that may seem pedantic but nonetheless contains
important semantic properties – their goal is, at most, to provide opportunities for
1.2. Prevention and/or cure of autism as local, context-specific choices

When confining ourselves to “opportunities” and “specific situations” there remain questions of who ought to make the choice about whether or not to seek cure/prevention, when it is made, what is involved and how the choice is framed by and to the individual affected. In other words, as outlined in Chapters 4 and 5, when one breaks down the overall goal into particular scenarios and contexts, the practical and ethical issues become once again highly complex and do not point to straightforward interpretations.

I further argued, with reference to the big conundrum, that there may be a disconnect between factors that determine the moral content of local, individual acts, and those that would pertain if these acts are generalised to apply in all cases. This disconnect means that I believe localised decisions may sometimes be ethically legitimate, even though, if the same decisions were taken by all, they would lead to repugnant consequences. The following examples relate to pre- and post-birth interventions respectively.

1.2.1. Pre-birth interventions

It is important to remember that instances of antenatal selection with regard to autism have already happened (see Chapter 4), and that the challenges facing us do not await the arrival of a screening mechanism based on a biological marker – even though if
one ever does come about it will intensify the frequency with which such choices and decisions have to be made.

In the case of pre-birth choice, despite rejecting prevention as an overall goal, I am not ready to make a blanket statement that all antenatal decisions to prevent an autistic birth are morally wrong – even though they do raise huge moral challenges when generalised and would lead to a world that I would consider the poorer.

First, as suggested in chapter 6 in discussion of parental virtues, the wider struggles experienced by autistic people, particularly when families may already be under strain from other pressures, may in a few cases make prevention of autism morally equivalent to other form of prevention for social reasons, rather than falling foul of being a specific, synecdochal issue around autism. Thus I argued that, in the context of a wider society in which life is made difficult for autistic people and their families, this wider struggle may in some cases explain – and make ethically permissible – pre-birth prevention. It may in some cases be reasonable for parents to come to a judgement that there are insufficient resources and/or social support to make it possible for them to feel confident that the autistic person will thrive and flourish.

The ‘big conundrum’ I have discussed throughout this thesis relates to a potential claim that - by allowing that these local choices may sometimes be justified – a generalization of the argument will run counter to and invalidate my broader conclusions. Because of this, it is important to stress that for the reasons in 1.1. above I do not consider that these situational caveats permit a broad overturning of my higher-level, macro position. An equivalent moral perspective is held by those who
justify abortion in specific situations in relation to the social consequences of a birth (where any resulting child is presumed to be ‘normal’). They are not arguing that all births in similar circumstances should be prevented: on the contrary, they would no doubt recoil from such a position. Further I would hope that a greater focus on wider environmental issues, including and celebrating greater diversity, would reduce the frequency with which such specific circumstances would hold up as being sufficiently powerful considerations. Localised choices running counter to the macro position would be morally permissible insofar as they remain isolated acts of prevention, such that the events, like the arguments, would not be regarded as generally applicable.

A second reason that I allow for localised choices to run counter, in some particular cases, to my overall position, is that I am not ready to override the right of the mother to be the ultimate decider about her private reproductive choices in relation to autism, and this is in line with many feminist and also disability rights advocates’ support of maternal autonomy, notwithstanding the broader messages conveyed. (See for example Shakespeare (2005)). Having said this, I follow much that has been written already in relation to disability and antenatal selection, and therefore echo its relevance with respect to autism. For example, there is scope for significant adjustments to the climate in which antenatal choices are made. Notwithstanding the generally unchallenged position of maternal autonomy, there is still a lot to be done to make the context in which reproductive decisions are made less mechanised, medicalised and geared towards producing “normal” babies (Shakespeare, 2005; Jennings, 2000). Another way of saying this is that the unspoken and invisible processes that may have a quasi-coercive impact in terms of preventing “difference” need to be reappraised, so that the mother’s choice is made on the basis of full
information. Examples that have been suggested include greater pro-diversity information available for prospective parents, a wide education of genetics professionals in the social model of disability, and – crucially – a wider cultural context celebrating diversity and exposing the often hidden forces that marginalise disabled or unusual people.

1.2.2. Post-birth interventions

With respect to post-birth interventions, I have argued throughout that at least some of the challenges that autistic people and their families face are due to wider social, cultural and institutional conditions, rather than intrinsic to autism itself. This shifts the target of ethical intervention towards wider measures – P-3 interventions. However, while I consider that P-3 interventions – those aimed at wider social and institutional change – are the least morally problematic, they are nonetheless compatible with favouring individually targeted interventions (P-2). In other words, P-3 interventions are necessary but on their own they may not be sufficient, or certainly not in the short to medium terms, in relation to individuals’ particular circumstances. Notwithstanding the possibility that parents and professionals might wish for a more autism-friendly world, the current prevailing environment may require individualised intervention to help address some of a person’s autism-related difficulties – where the intervention aims at / is effective in helping them access more opportunities to enjoy their lives and fulfil their aspirations.

But here too, I feel this needs to be couched as a need for P-2 interventions, rather than for P-1 interventions. In other words, I believe the purpose of such assistance is
only morally acceptable when conceived as a method for achieving well-being for the individual, and should not be conflated with the goal of taking away their autism.

Finally, I have therefore argued that there is an important conceptual distinction to be made between P-1 interventions – aimed at autism \textit{in toto} – and P-2 interventions – aiming to assist in particular challenges a person may face. What this means is that the goal of attempting to prevent and/or cure autism \textit{in toto}, post birth, should be abandoned.

I hope also that by introducing the three categories of post-birth intervention, I may assist practitioners, families and autistic advocates in clarifying areas of ethical controversy with regard to interventions. There is scope, for example, for applied behaviour analysis (ABA) practitioners to commit themselves openly to favouring P-3 in general, while conceptualising their own practice as P-2 for the individuals with whom they work. Separating and clarifying the macro and micro goals for any intervention will surely help illuminate an area that has been conflict-ridden for decades, and help move forward the conversations and debates that need to continue.

\section*{2. Implications for “next steps”}

Despite arguing that local (or ‘micro’) ethical considerations are highly sensitive to context and multiple nuances, which can in principle allow for the application of contrasting answers to my research question in individual cases, this does not translate into a broadly permissive ethical stance on prevention or cure. On the contrary, my
stance on arguing that the ‘macro’ goal of prevention/cure of autism cannot be morally defended is categorical, so that it translates into an in-principle rejection of all generally-stated research and practice targets that are aimed at prevention and/or cure. There are implications of this at a policy level, with regard to the type of interventions and research into autism that can be morally justified.

2.1. Interventions relating to wider social context

Greater emphasis needs to be given, in terms of research, policy and practice, to exploring the scope, nature and impact of interventions that relate to the wider social and cultural environment in which autistic people and their families live (P-3 interventions).

Broader recognition among “experts” that social, political, cultural and economic conditions militate against autistic people and their families, and a willingness to support the call for improvements in these areas rather than focusing purely on clinical and therapeutic targets, have the potential to dramatically change the climate in which autism is addressed, and to influence the scale of funding allocated to services that support autistic people and their families.

2.2. Autism research

Echoing the recommendations made by others and referred to in the thesis in chapters 2 and 3, in the field of autism research there needs to be:
1. A rebalancing of funding and activity to place greater weight on social and intervention research.

2. Adjustment of the focus within clinical and scientific research to fit with the goals of individually focused (P-2) rather than global autism-focused (P-1) interventions. Where biomedical research takes place, this should be with the purpose of finding ways to improve the lives of autistic people and not to “cure” them. This is not incompatible with ongoing biomedical research, as long as goals are differentiated according to the issues that autistic people themselves and their families identify (echoing Herbert and Anderson (2008) cited in Chapter 2). “Splitting” (according to co-morbidities) rather than “lumping” is likely to be more relevant – and possibly more fruitful – in terms of identifying clinically relevant and ethically acceptable interventions.

3. To support the above, greater involvement of autistic people and their families in the framing of research priorities, more community-based participation research and ethnographic and first-person empirical evidence (echoing Pellicano and Stears (2011); Pellicano, Dinsmore and Charman (2013) and the ethical, legal and social implications (ELSI) workshops cited in Chapter 3).

2.3. Autism interventions

In the field of autism interventions, including clinical, other “therapeutic” and education practice, there needs to be:
1. Clarification of the purpose and nature of interventions that are currently described in terms of prevention and/or cure (P-1). This is with a view to differentiating those that are in actuality aiming at particular areas of difficulty (P-2) rather than autism as a whole (P-1). Where P-1 remains the stated goal, my conclusion is that they cannot be ethically justified.

2. A broad willingness to contemplate and develop interventions that are targeted at helping individuals (P-2), subject to certain caveats. For example, given the heterogeneity of autism and the complexity of the problems facing autistic people, discrete approaches are likely to be necessary according to different individuals, experiences and lives. Where problems are identified, they should be addressed through individually relevant approaches, rather than addressed through a “lumping” approach to autism as a whole. Therefore, close attention needs to be paid to differentiate the goals of interventions: those that pathologise and address “core features” of autism are more morally problematic than those that address specific areas of difficulty that autistic individuals are experiencing. The emphasis needs to be firmly on the latter.

3. Discussion at an overarching level, in addition to localised, person-centred practice, about which broad goals and outcomes are ethically legitimate with regard to P-2 interventions in general. Such discussions require the input of autistic people and their families, in order to

   a. Establish greater consensus around those areas that are felt to be legitimate and appropriate goals for educational/clinical/practical help;
b. Ensure that approaches incorporate a spirit of reciprocity with respect to the changes that both autistic and neurotypical (NT) people may need to make for mutual accommodation;

c. Place greater emphasis on individual strengths, not just deficits, of autistic people.

2.4. Ethics

In the field of ethics, I have touched on areas that are widely acknowledged to be underexplored, chiefly ideas of the good life and flourishing with respect to learning disability and difference. I believe further work in this area would be of value for its own sake, and also because it would overlap with and augment contemporary developments within bioethics. The two big themes that strike me as particularly relevant are moral enhancement and solidarity.

The question of “what kind of people we want/need in the world” has been given considerable attention in the context of discussions around enhancement, with a particular emphasis on moral enhancement. I have hinted that further work needs to be done around what constitutes impairment and enhancement – for example the need to take into account capacity/potential to cause harm to others, to interrogate ideas around (inter)dependency and to move away from a fixation on cognitive capacity. Linked to this, I believe that if there is any value in drawing comparisons between autistics and NTs, it is not in order to identify whether or not autistic people have moral agency, but rather to explore all human qualities – both NT and autistic – that are valuable and good (virtues) and which human qualities (vices) are harmful.
Linked to all of this is a growing interest in wider “states of affairs”. The broader virtue approach reaches beyond individual agents into a collective or “macro” context – with a particularly dramatic vision that humanity is doomed unless we undertake to improve our nature (Persson and Savulescu (2012)). Other examples of this attention to “macro” ethics include recent work on solidarity and also the extension of virtue ethics, and the ethics of care, into the collective domain. In broadening the scope of enquiry and concern, bioethics necessarily overlaps with other disciplines from the social, political and economic sciences.

2.5. Specific research exercise

A specific research exercise may be needed to facilitate structured discussion around areas of ethical sensitivity in autism and in particular the issues referred to in point 3 in Section 2.3 above. The outputs of such an exercise might include both greater consensus on what constitutes “good goals / good outcomes” - taking into account the heterogeneity of autism – and/or a clearer understanding of where genuine disagreement persists, once misunderstandings have been addressed.92

Such an exercise might emulate the methodology followed by the Hastings Centre, which led to the publication of a key work on prenatal testing and disability rights (Parens and Asch, 2000). It would aim to assist all stakeholders to identify and agree

92 This follows from what many autistic writers have argued, and would take forward the tentative discussions that took place within the UK Autism Ethics Group (2011).
the targets and appropriate outcome indicators of future interventions, be these P-3 (wider environmental target) or P-2 (individually targeted).

The spirit in which such conversations take place would need to respect the facts about, and impact of, dramatic diversity within the autistic experience. The desperation and distress that some experience cannot be dismissed as a merely one-sided pathologising of autism. And neither can the strengths, enjoyments and abilities of autistic people, including the perspective of both the so-called high-functioning and those with learning disabilities, be dismissed as a one-sided and oblivious representation of others’ lives. I hope it would give time and space for the “agonizing” (p.75) to be acknowledged, for the emotions of the treatment vs acceptance debate to be appreciated, and for an emergent understanding to be grasped: that underpinning much of the discord amongst family stakeholders at least, there is a prevailing reality of love.
Appendix 1  Literature Search March 2012

The following databases were initially searched:

OvidMedline
PsychINFO
Embase Social Policy
Journals@Ovid
Psych ARTICLES
HMIC

A multi-field search was conducted for autis*, prevent* or cure, and 1331 articles were found. These were articles containing the words in the text of the article but not the abstract, and they were chiefly scientific research papers.

When the search was repeated but restricted to references to autis*, prevent* or cure specifically in the abstract, 18 articles were found. This confirmed a hypothesis that the possibility of cure or prevention is not a prioritized consideration in the research community, even though it is inserted within the body of the article as one of the implications of the research.

A repeat search of these databases was then conducted with specific reference to ethical issues related to autism. The multifield research for autis*, ethic* and moral or morality contained in the abstracts yielded just 5 articles.
Because of the limited numbers found, alternative databases were then introduced in a new search. Searching *Science Direct* with autis* and ethic* yielded 20 articles, of which several were in French. The remaining articles related to ethics in relation to research design, not prevention or cure.

Using the *Scopus* database, a search with autis* and ethic* provided a list of 240 articles. The bulk of these were about clinical practice and research design issues, but additional material concerning the moral status of autistics, and two theoretical issues in relation to conceptualization of autism and ethics were retrieved that had not been identified in previous searches.
### Appendix 2  Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ABA</td>
<td>Applied Behaviour Analysis</td>
</tr>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<tr>
<td>ADOS</td>
<td>Autism Diagnostic Observation Schedule</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AIM</td>
<td>Autism in Mind</td>
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<tr>
<td>AIT</td>
<td>Auditory Integration Training</td>
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<tr>
<td>ARGH</td>
<td>Autism Rights Group Highland</td>
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<tr>
<td>ARM</td>
<td>Autism Rights Movement</td>
</tr>
<tr>
<td>AS</td>
<td>Asperger Syndrome</td>
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<tr>
<td>ASA</td>
<td>Autism Society of America</td>
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<tr>
<td>ASAN</td>
<td>Autistic Self Advocacy Network</td>
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<tr>
<td>ASC</td>
<td>Autism Spectrum Condition</td>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>BASIS</td>
<td>British Autism Study of Infant Siblings</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary and Alternative Medicine</td>
</tr>
<tr>
<td>CAN</td>
<td>Cure Autism Now</td>
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<tr>
<td>CBPR</td>
<td>Community-Based Participation Research</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CRAE</td>
<td>Centre for Research in Autism and Education</td>
</tr>
<tr>
<td>DAN</td>
<td>Defeat Autism Now!</td>
</tr>
<tr>
<td>DfES</td>
<td>Department for Education and Science</td>
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<tr>
<td>DH</td>
<td>Department of Health</td>
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<tr>
<td>DMG</td>
<td>Dimethylglycine</td>
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<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>AEG</td>
<td>Autism Ethics Group</td>
</tr>
<tr>
<td>EIBI</td>
<td>Early Intensive Behavioural Intervention</td>
</tr>
<tr>
<td>ELSI</td>
<td>Ethical, Legal And Social Implications</td>
</tr>
<tr>
<td>EU-AIMS</td>
<td>European Autism Interventions – A Multicentre Study for Developing New Medications</td>
</tr>
<tr>
<td>G-I</td>
<td>Gastro-Intestinal</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>GPR</td>
<td>Guided Participation Relationship</td>
</tr>
<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
</tr>
<tr>
<td>HF</td>
<td>High-Functioning</td>
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<tr>
<td>HFA</td>
<td>High-Functioning Autism</td>
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<tr>
<td>HFEA</td>
<td>Human Fertilisation and Embryology Authority</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IACC</td>
<td>Interagency Autism Coordinating Committee</td>
</tr>
<tr>
<td>ICD</td>
<td>International Statistical Classification of Diseases and Related Health Problems</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual Disability or Intellectually Disabled</td>
</tr>
<tr>
<td>IMFAR</td>
<td>International Meeting for Autism Research</td>
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<tr>
<td>INSAR</td>
<td>International Society of Autism Research</td>
</tr>
<tr>
<td>IOE</td>
<td>Institute of Education</td>
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<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
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<tr>
<td>IT</td>
<td>Information Technology</td>
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<tr>
<td>IV</td>
<td>Intravenous</td>
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<tr>
<td>IVF</td>
<td>In Vitro Fertilisation</td>
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<tr>
<td>JAMA</td>
<td>Journal of the American Medical Association</td>
</tr>
<tr>
<td>LD</td>
<td>Learning Difficulty/Disability</td>
</tr>
<tr>
<td>LF</td>
<td>Low-Functioning</td>
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<tr>
<td>MIND</td>
<td>Medical Investigation of Neurodevelopmental Disorders</td>
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<tr>
<td>MMR</td>
<td>Measles, Mumps, Rubella (vaccine)</td>
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<tr>
<td>NAAR</td>
<td>National Alliance for Autism Research</td>
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<tr>
<td>NAS</td>
<td>National Autistic Society</td>
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<tr>
<td>NEC</td>
<td>Negative Eugenics Cure</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
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<tr>
<td>NT</td>
<td>Neurotypical</td>
</tr>
<tr>
<td>OCD</td>
<td>Obsessive-Compulsive Disorder</td>
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<tr>
<td>OT</td>
<td>Occupational Therapy</td>
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<tr>
<td>PACT</td>
<td>Pre-school Autism Communication Trial</td>
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<tr>
<td>PB</td>
<td>Procreative Beneficence</td>
</tr>
<tr>
<td>PDD</td>
<td>Pervasive Developmental Disorder</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>PDD-NOS</td>
<td>Pervasive Developmental Disorder Not Otherwise Specified</td>
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<tr>
<td>PECS</td>
<td>Picture Exchange Communication System</td>
</tr>
<tr>
<td>PGD</td>
<td>Pre-implantation Genetic Diagnosis</td>
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<tr>
<td>PWA</td>
<td>Person(s) With Autism</td>
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<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
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<tr>
<td>RDI</td>
<td>Relationship Development Intervention</td>
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<tr>
<td>RTC</td>
<td>Reproductive Technology Council</td>
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<tr>
<td>RTOF</td>
<td>Right To an Open Future</td>
</tr>
<tr>
<td>SAAS</td>
<td>Staffordshire Adults Autistic Society</td>
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<tr>
<td>S&amp;LT</td>
<td>Speech and Language Therapy</td>
</tr>
<tr>
<td>SALT</td>
<td>Speech and Language Therapy</td>
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<tr>
<td>SEN</td>
<td>Special Educational Needs</td>
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<tr>
<td>SFARI</td>
<td>Simons Foundation Autism Research Initiative</td>
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<tr>
<td>SLD</td>
<td>Severe Learning Difficulties/Disability</td>
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<tr>
<td>TC</td>
<td>Therapeutic Cure</td>
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<tr>
<td>TEACCH</td>
<td>Treatment and Education of Autistic and Communication-Handicapped Children</td>
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<tr>
<td>UCLA</td>
<td>University of California, Los Angeles</td>
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<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
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<tr>
<td>WCC</td>
<td>Weak Central Coherence</td>
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<tr>
<td>WEF</td>
<td>Weak Executive Function</td>
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<tr>
<td>YAP</td>
<td>Youth Autism Project</td>
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