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Disabling families: How parents experience the process of diagnosing autism spectrum disorders

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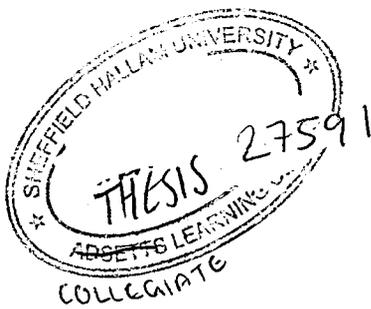
REFERENCE

Disabling Families: How Parents Experience the Process of
Diagnosing Autism Spectrum Disorders

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Abstract

This is an account of a phenomenological investigation, employing 'Lifeworld' as the methodology. The study describes how six parents experienced the process of their children being 'diagnosed' as having autism spectrum disorders (ASDs) and identifies factors which contributed to these experiences. The investigation arose out of the researcher's engagement with parents who appeared to be challenging the professional preoccupation that early diagnosis and assessment of autism is central to effective family support.

Interviews were conducted with three sets of parents over a period of one year with the researcher seeking to understand how the diagnostic process impacted upon all the 'fractions' of the lifeworld. The findings suggest that 'intervention' and 'normalisation' continue to be the dominant professional discourse but that parents find ways of rejecting and subverting these. Professional intervention, although intended to enable and empower parents was, in fact, experienced, by the parents in this study, as disabling and disempowering. It is proposed here that this was the result of professional practice being predicated on individual model principles, focused on changing the child and the family.

The evidence from this study indicates that parents of children with ASDs have a more balanced experience of parenting than the traditionally negative focus of autism research would suggest. Parenting is made problematic not so much by children's impairments but by encountering exclusionist professional practices. Guidelines are proposed for how professionals might begin to offer more effective support to parents by engaging with a social model agenda focused on celebrating achievement and enabling aspirations. 'Lifeworld' is evaluated as a methodology ideally suited to emancipatory research and as a means of enabling non-disabled researchers to offer valid contributions to the disability movement.

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Preface

Terminology in relation to impairment and disability is problematic (Oliver, 1990). Labels position people as 'other' and usually incur negative consequences for those categorised in this way and for their families (Goffman, 1963; Gillman et al., 2000). Within the current systems of distribution of resources, however, they can also be seen as a necessary evil, a pre-requisite to accessing support (Ho, 2004).

This dissertation records the impact on the lifeworlds of three sets of parents when their children were given a diagnosis of autism. It identifies parents as caught within this dilemma, resisting labels for fear of them pathologising their children (Billington, 2000) but unable to access services without that specific label. The social model of disability has traditionally rejected the apportioning of labels on the grounds that these problematise the individual, thereby disguising the real difficulties that are the disabling impacts of the environment and cultural expectations (O'Grady et al., 2004). However, there is now a call to recognise the impact of specific impairments on the individual, to acknowledge that the physical, as well as external factors, can limit opportunities (Shakespeare and Watson, 2002). Whether this will lead to some acceptance of diagnostic labels, within the Social Model, as signposts for potential impacts of impairment and strategies for support, is not yet apparent.

Within this dissertation I have used the terms children with autism and children with autism spectrum disorders as these were the 'identifiers' that professionals gave to the children and the labels that the parents were struggling with. This is not to be read as a validation of these terms however. The evidence from this study will suggest that parents do not seek to have their children placed within categories of impairment. Rather, parents desire that professionals recognise and celebrate children as individuals, identifying strengths and areas for development. The only label necessary, therefore, is a child's name.

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Background of the study

This dissertation is an account of a phenomenological enquiry into how parents experience the process of their children being diagnosed with autism spectrum disorders (ASDs). The study describes and considers the experiences of three sets of parents as they engage with the diagnostic process. Part one of this dissertation focuses on why the study was undertaken and describes how it was conducted. Part two presents the data and evaluates the potential impact of the findings on professional practice.

This first chapter establishes the background of the study, specifies the research 'problem' and considers its significance before going on to identify the methodology and methods used.

The number of children being diagnosed with ASDs appears to have increased dramatically over recent years (Fombonne, 2003). One potential explanation for this is that understanding of the syndrome has developed, thereby enabling greater recognition and diagnosis (Medical Research Council (MRC), 2001; Charman, 2002; Fombonne, 2003). Easier access to diagnosis, something parents have traditionally had to 'fight' service providers to obtain, is almost unanimously welcomed by the literature, as is the development of systems of early intervention (e.g. Robins, Fein and Barton, 2001; Charman & Baird, 2002; Butter, Wynn and Mulick, 2003). It is argued, within the literature, that prompt diagnosis and intervention is essential for parents whose children are behaving in ways that are causing considerable stress and concern to them and who are seeking explanations and support (Wing, 1996).

However, Charman and Baird (2002), while reviewing the literature on the characteristic features of ASD in pre-school children, warn that earlier and

broader diagnosis brings new challenges to diagnostic services. One of these must be evaluating the impact on children and parents when professionals attribute the label of ASD to those who, until recently, might have been thought of as eccentric, slightly odd and unusual or loners rather than 'impaired'. These are children who demonstrate intellectual ability within the expected developmental pattern for a child of that age but whose communication and social skills are noticeably different to children without ASDs.

The research problem

As a previous teacher of children with autism and now Senior Lecturer in Autism within a university, I have been involved with numerous families where parents have reported being frustrated at the lack of recognition by professionals of their children's autism and the reluctance or refusal to diagnose. Like many professionals I have argued for and welcomed the government's commitment to early identification (Department for Education and Skills (DfES), 2003; DfES and Department of Health (DH), 2004a). I have believed strongly in the maxim that early diagnosis leads to better informed parents and educators, which then results in a better prognosis for the child's development (Wing, 1996; DfES and DH, 2003). It puzzled me, therefore, to encounter, in more recent years, parents who appeared to be resisting the diagnosis of their child as having an ASD. Access to early diagnosis appeared to be experienced, by these parents, as presenting a threat to the harmony of their family and the development of their child, rather than as a source of comfort and relief.

The study's significance

This enquiry set out to identify, understand and evaluate the implications for professional practice of the experiences of three 'sets' of parents where professionals had recently raised the question of ASD in relation to the children. Although undertaken with a small number of participants, the significance of this study is that it challenges the belief that professional intervention is always necessary and helpful in relation to autism (Jordan and Powell, 1995; Howlin, 1998; Szatmari, 2004):

It almost seems to go without saying that children with autism need early and intensive intervention. It has been so frequently stated that, for many who work with young children with developmental disabilities, it is almost a mantra (Siegel, 2003: 34).

The factors identified by the parents, in this study, as sources of stress and disruption for the family were not issues resulting from their children's 'impairments' but the restrictions imposed by those professionals who were charged with supporting parents through the process of diagnosis and involved with the education of their children. The findings suggest, therefore that the individual model of disability (defined within chapter two) continues to be the dominant discourse (Foucault, 1972; Murray, 2000; Kearney and Griffin, 2001), disempowering children and their parents and contributing to the disablement of families.

Many years of listening to and reading about parents' experiences had made me aware of a range of issues and of various experiences which might concern the parents of children with autism, such as fighting to obtain a diagnosis, feeling rejected by the child, alarm at inexplicable behaviour and criticism from others in the community for the way parents manage their children's behaviour

(Wing, 1996; Howlin, 1998; Randall and Parker, 1999). The experiences of the parents in this study raised issues, however, which I had not previously considered, such as the impact on the family when their child was identified as 'impaired', disempowerment through engagement with professionals and the disablement of the family through exclusionary practices.

As will become clear, this study suggests that although the parents had accepted the nature of their children's difficulties they chose, above all, to celebrate the positives of their children's development rather than miss the pleasure of watching them develop through the early years: replacing enjoyment with anxiety because they were 'retraining' themselves to see the development of their children as 'deviant'. As we now diagnose, as impaired, groups of children, previously thought of as within the 'mainstream' or 'normal but a bit unusual' range, so we will need to adapt our thinking and procedures if we are to meet successfully the new challenges presented by these children and their parents. This is necessary to avoid pathologising families that previously considered themselves 'normal'. Some literature is beginning to recognise the danger of pathologising children within school (e.g. Billington, 2000) through labelling them as 'impaired' but this study raises the concern that this process can also pathologise the child within the home and by doing so disable the family.

This study, took three years to complete and, during this time, the methodology was transformed significantly, in order to respond to the perceived needs of the participants. The research began as an action research case study (Cohen and Manion, 1994; Freebody, 2003), based, as I now position it (detailed in chapter three), on an individual model hypothesis that parents require interventionist support in order to 'learn' how to 'manage' their children with autism. When it

began to appear that the challenges for the participants were not, in fact, around the act of parenting but engagement with the diagnostic process, the study developed into a broader and non interventionist phenomenological investigation (Moustakas, 1994), using Lifeworld (Ashworth, 2003a) as a methodology (see chapter three for a detailed account). The focus then became on identifying how the participants were experiencing this life event. Data were collected by means of interview, conducted regularly with each family over a period of one year. This too is discussed in detail in chapter three.

To summarise, this chapter has, therefore, identified the 'problem' which led to the research being undertaken, placed this within a professional context and considered the value of this undertaking. The methodology and the method of data collection have also been outlined. I have suggested that the findings of this study will show that it is the individual model of disability that continues to be the dominant discourse, within the diagnostic process. However, it was the social barriers to inclusion, rather than children's impairments, that actually disabled those parents interviewed.

The next chapter will review the literature on the experience of parenting children with ASDs. It begins by evaluating the potential impact on parents of current 'guidance literature' (i.e. literature that 'informs' on autism without necessarily being based upon research evidence) before identifying the issues for families highlighted by research. Traditionally negative accounts of the experience of parenting children with ASDs will be contrasted with the more positive reports from the field of general disability. From this, proposals will emerge as to how parents might be more effectively supported with understanding their own position towards disability. The chapter will conclude with a consideration of the social and individual models of disability.

Introduction

In Chapter One it was established that new challenges for services have arisen out of the adoption of 'earlier and broader' diagnostic practices in relation to autism (Charman and Baird, 2002). This chapter now offers a review of the literature relating to the experiences of parents of children with ASDs and is presented in two distinct but related sections.

The first section, 'Traditional Claims' centres on the parenting experience portrayed within autism specific 'guidance' literature (i.e. that which informs parents and professionals about autism but is not necessarily research based) and also those research studies which focus on the experiences of parents of children with ASDs (e.g. Randall and Parker, 1999; Tams, 2001). I argue that this literature adopts an essentially negative position, focused on the problems caused for families by the effects of impairment (Jordan and Powell, 1995; Wing, 1996; Howlin, 1998; Randall and Parker, 1999), although there is emerging some movement towards challenging established perceptions and acknowledging positive parental experiences (Tams, 2001).

The second section, 'Challenging Traditions', focuses on themes emerging from generic disability research. As my data collection progressed I became aware that the experiences of the participants, in my research, differed significantly from those recorded in the autism specific literature. I, therefore, turned to research on the experiences of parents of disabled children, but not necessarily specifically autism related, to see if I could locate there any of the experiences which had been identified by the parents in my study.

This approach of locating relevant themes in the literature, after data collection, is a well-established practice within qualitative methodologies and especially within grounded theory (Denzin and Lincoln, 1994; Punch, 1998; Silverman, 2000). In so doing I 'discovered' debates, previously unfamiliar to me, which question the value of diagnostic labels and identify the potentially stigmatising impact of these. I also located there a number of accounts which describe the positive experiences of parenting children with impairments (Case, 2000; Tunali and Power, 2002; Kelly, S., 2005). In turn, these led me to an understanding of how disability can be differently conceptualised and constructed (Oliver, 1996; Avdi et al., 2000; Kearney and Griffin, 2001; Russell, F., 2003; Sherry, 2004).

As part of this process, I came to recognise my own conception of disability as embedded within the individual model (Oliver, 1996; Barnes, 2003; Swain et al., 2003), viewing disability as a 'tragedy' to be overcome (Murray, 2000), in spite of this contradicting my own experience of positive engagement and meaningful relationships with many children with ASDs. Reflecting on respondents' views and this new literature, I came to view the individual model as a restrictive and disabling conceptualisation of disability (Avdi et al., 2000; Murray, 2000) and so question, within this chapter, whether the experiences of the participants, in this study, can be better understood within the social model of disability. I consider too whether the social model is only effective at a conceptual level or whether it offers any real, practical support for professionals as to how they might better engage with parents.

Section One: Traditional Claims

Parenting children with ASDs

I do not love Walter because he can or cannot do any particular thing. I just love Walter. His condition deepens my feelings. It keeps the love closer to the surface and makes it palpable

Richard Anderson (1991: 23), parent of Walter, who has autism

A gloomy prospect

Jordan and Powell (1995), in a text designed to offer 'help (for) all those concerned with the education and welfare of children with autism' (p. iix), identify some of the tensions that they feel might exist for parents of children with autism:

But there is still likely to be some sense of guilt and/or anger in parents in the early stages of the child's life (indeed these feelings may persist). Mothers may doubt their 'mothering abilities' on the one hand and/or resent their child's lack of responsiveness on the other. Most parents will experience physical or psychological tension at some time and many parents report a feeling at some point or other that they need 'to escape'. Clearly, this kind of feeling puts additional strain on family relationships. Brothers and sisters are affected not only by the behaviour and problems of the sibling with autism but also by the resulting increased tension in the family (Jordan and Powell, 1995: 147).

Initially, there is no mention of any contrasting, positive aspect to the parenting experience; nor is there any hope given for the future:

...families who may have weathered the storms of childhood and come to terms with their child's persisting difficulties may find that the feelings of guilt and anger resurface as they try to cope with the adulthood of their son or daughter with autism (p.147).

Although Jordan and Powell temper this bleak picture by adding that, '...the other effect of having a child with autism is to enrich the life of individuals and of families' (p.147), this is not examined in any depth. Similarly in 1996, Wing published 'The Autistic Spectrum: a guide for parents and professionals', regarded as a classic text and a frequently recommended starting point for parents and professionals when reading about autism. The chapter on the experiences of parents is entitled, 'Problems faced by Parents' (p.9). The opening lines of, 'Parents have to cope with a series of problems, some of which are practical and some of which are emotional' (p.181), are likely to suggest, to parents and professionals, that the parenting experience will necessarily be problematic. Another popular text, promoted as, 'A Guide for Practitioners and Carers', is Howlin's (1998), 'Children with Autism and Asperger Syndrome'. Again, the parenting experience is described here in mainly negative terms. One example can be found in the opening lines of the section entitled, 'The effects on families of having a child with autism', where Howlin claims that:

There can be little doubt that raising a child with autism leads to many increased pressures on families. They tend to be under greater strain than parents of children with Down's syndrome or other forms of mental handicap, and may experience even higher levels of stress than those caring for a child with a terminal illness, such as cystic fibrosis...(p.274).

Siegel (1996), an author, widely consulted by parents and professionals, also begins her discussion on the impact of autism on parents with a warning:

Before parents of an autistic child were parents of an autistic child, they were a couple. Before they met, they were individuals with their own separate identities. In the process of meeting the extraordinary demands of raising an autistic child, it is very possible for the husband and

wife to lose each other, and for each parent to begin to lose his or her identity separate from the child (p.136).

Popular texts appear, therefore, to suggest to parents and professionals that the experience of parenting a child with an ASD is likely to be extremely difficult and challenging. However, Kress (1985, cited, Ong-Dean, 2005: 156) argues that, 'any' one text may be the expression or realization of a number of sometimes competing and contradictory discourses'. Although, the focus here is on the negative aspects of accounts of the parenting experience, these fore-mentioned texts do also recognise some positive aspects to the parenting experience. These tend, however, to be less emphasised.

As such texts have been written by highly respected professionals, with many years of working with parents of children with autism, then it would seem probable that their only intention is to offer support and guidance to parents and professionals. This raises the question, therefore, of why the focus on the parenting experience, in relation to autism, might have become so negative. One speculative response might be that this is an 'unconscious' rebuttal of Kanner's and Bettelheim's claims that 'refrigerator parents' were responsible for their children's emotional withdrawal (Bettelheim, 1956; 1967; Eisenberg and Kanner, 1956); a theory which predominated throughout the 1950s and 60s. Dawson (2003: 1) argues that Bettelheim 'created an extreme'. His exceptional position in relation to parents caused an equally extreme reaction in parents and many professionals. Parents went from being the cause of autism to being seen as its 'heroic and tragic victims' (p.1). Murray (2000) suggests that this type of portrayal of parenting naturally arises from the individual model's (discussed fully later in this chapter) tragic view of disability (see also Landsman, 2005). What has been neglected in the literature on autism, and

what it is hoped that this study will help to address, is the balancing of the stresses of being a parent with the positive aspects of the experience. Siegel (2003), writing about parents of children with ASDs, identifies what she terms, 'the components of the talents of the best parents...' (p.447). The first of these is that, 'these parents have given themselves permission to really love being with their child.' (p.447). This would suggest a need for more positive accounts of the parenting experience, within the literature, to counter the individual model's negative image of disability and to 'support' parents with 'allowing' themselves this enjoyment of their child. In the history of autism, however, it is the search for a cure which has dominated the literary landscape. This has been most powerfully expressed within the image of the 'empty fortress' (Waltz, 2005).

Storming the fortress

The image of autism, as something that insidiously surrounds a child, forms a barrier between him/her and the parent and which needs to be vanquished in order to rescue the child, is strongly rooted in the history of autism. One of the earliest and most influential books about autism, first published in 1967, was written by Clara Claiborne Park (1983), a parent. It chronicles the first eight years of her daughter's life and is entitled, 'The Siege'. It is described on the cover as:

...a mother's own account of her patient, loving and ultimately successful attempts to penetrate the fortress of her abnormally withdrawn daughter's 'willed isolation.

Claiborne Park herself writes, in relation to her daughter, that, 'We would use every stratagem we could invent to assail her fortress...' (p.12). The image of

the unassailable fortress was very strong in the literature at that time. Parks was responding to Bettelheim's (1967) use of this image in a publication produced that same year (Waltz, 2005), 'The Empty Fortress', a highly influential, if now discredited, account of autism (Jordan, 1999; Ong-Dean, 2005; Waltz, 2005). The view of autism espoused in this text, and which was prevalent throughout the 1950s and 60s, was that autism was an emotional response to a hostile world; the child built up defences as a reaction to the style of parenting. Wing (1976) states that theories were put forward that the child with autism was a, 'vulnerable child in an abnormal environment' (p.79), or that, 'abnormalities in the children (were) exacerbated by parental pathology' (p.78). The role of professionals was, therefore, to take down these defences to reveal the child inside. Waterhouse (2000) echoes this imagery by stating:

...whilst we may see it (autism) as a fortress which locks us out, those who are imprisoned may have become so accustomed to the walls that they ignore them, seeing only the sanctuary. (p.305)

Waterhouse notes however that, Gunilla Gerland, a person with autism, reacted strongly against this image of people with ASDs. Gerland, according to Waterhouse, objected to the image of people with ASDs as being in need of rescuing. Gerland argued instead that people with autism can be comfortable with the way they are and to attribute this to retreating behind walls is to undermine their right to choose a way of being. This still leaves parents and the early interventionist with the problem of when and to what extent to intervene in the development of a child. If a parent is to accept that her/his child has autism and that this is an inherent part of who he/she is, then to what extent should she/he compel the child to 'fit' within a 'neuro-typical' norm? The social model, in its adamant rebuttal of impairment as a source of disability (Goodley, 2001;

Shakespeare and Watson, 2001; Thomas, 2004) appears to deny a solution to what, for disabled people, parents and professionals, is a very real dilemma.

Parents' voices

The professional guidance literature reflects the 'pessimistic' findings of much of the research on the experiences of parents of disabled children (Murray, 2000; Kearney and Griffin, 2001). Many of the 'autism specific' projects begin with an adverse hypothesis, e.g. exploring parental stress levels (Dunn et al., 2001; Hastings and Johnson, 2001; Esdaile and Greenwood, 2003; Hastings, 2003; Wood Rivers and Stoneman, 2003). One particularly influential study, which was published in book form, was that of Randall and Parker (1999). This was a survey of parental experience amongst families using a Family Support and Assessment Unit. Although the researchers describe their study as, 'broad and exploratory' (p.20), they do not state how many parents were actually interviewed, using the 'interview questionnaire' they had devised. From these interviews, the authors identify a range of parenting experiences. These all have a negative focus, with no mention made of the positive experiences of parenting. However, the negative findings may well be the result of the survey questionnaire being designed around negative aspects of parenting, with no encouragement for parents to discuss their positive experiences. For example, one question asks, 'Have you any comments to make about the time before you received the diagnosis and the difficulties you experienced?' (p.37). Parents were also asked to focus on, 'What mistakes do you feel you have made?' (p.63), without any balancing request to consider in what ways they thought they had been successful, as parents. Unsurprisingly, therefore, the responses

to the diagnosis and the experience of parenting are negative ones; not invalid responses but only part of the picture of parenting.

Randall and Parker (1999) found that reactions to diagnosis were identified as, anger, anxiety, depression, confusion, denial, grief, helplessness, guilt, self-pity, terror and sorrow. Lack of a visible impairment, in the early months of development, means that parents only become concerned about their child over time. Parents describe this as, 'It just creeps up on you' (Randall and Parker, 1999: 106), a sense of unease giving way to alarm and perhaps desperation. As parents begin to realise they have a disabled child, it feels as though their child has 'died' and that they now have a different one to care for. They experience unease and fear about the future. Lack of reciprocity to parental attempts to engage their child in baby play feels like a rejection by the child. One mother recalls:

I would stand grinning at her, like some big Cheshire cat, just praying she would smile back at me. She never did. One day I found my husband doing the same- he was smiling at her, tears rolling down his face, begging her to smile back (Randall and Parker, 1999: 107)

which leads to feelings of failure as a parent. Although parents may feel fear and alarm that their child displays inexplicable behaviour, these concerns are often dismissed by other family members and family doctors. Getting support and honest information from professionals is experienced as frustrating and difficult. Parents feel misunderstood by others outside of the family, 'People keep looking at us. They think we made her the way she is.' (Randall and Parker, 1999: 111). As a result, instead of drawing attention to their child by 'showing off' his/her achievements, as parents often do, parents of children with

autism can become desperate that no one will notice how 'odd' their child is (Randall and Parker, 1999).

While also identifying some of these same experiences, Rachel Tams' study of twelve parents of ten children in 2001, appears to take a more balanced perspective. In the interviews that she conducted, parents again demonstrated a range of reactions to the experience of parenting a child with autism. Some parents saw autism as an 'emotional disorder' with the potential for breakthrough, while others used to feel this but then came to view autism as 'pervasive and enduring'; parental attitudes changed over time. Some parents fight against autism while some accept; fighting means they are more likely to work to change their child's behaviour, to normalise; accepting means they are more likely to make allowances for behaviour, to 'let him be autistic'. Tams identifies several key themes that emerged for parents. If children are demonstrating disruptive behaviour within the community, the normality of their appearance means that others do not make allowances for the child having an 'impairment'; parents feel labelled as 'bad' or 'incompetent' parents (Tams, 2001). Those, outside of the home, who did know that the child had autism would often be insensitive or only partly informed; being asked what special talents their child had was one illustration given by parents of a question that frustrated them (Tams, 2001). The lack of social awareness and often impaired communication skills in their children, raises, for parents, issues of vulnerability, concern that they might not know if others were harming their child (Tams, 2001). Behavioural difficulties often present parents with challenges; lack of danger is seen as a particularly significant worry. Most parents felt they did not manage difficult behaviour well. Many different strategies were tried to change

behaviour while two parents preferred to allow the behaviour (and felt fine about this), as they felt it was important to let their son 'be autistic' (Tams, 2001).

Dealings with professionals were often described in terms of conflict as parents 'battled' for diagnosis and for services (Tams, 2001). Autism was experienced as a difficult and demanding condition to live with, more complex than 'retardation' and something which imposed restrictions on parents' lives. Parents felt their children were more capable than they were prepared to demonstrate. Some viewed autism as outside of their child, something that 'takes her away' but parents of older children had come to the view that there would not be a 'magic key' to recover their child (Tams, 2001). Most parents thought their child was fine and then regressed at 18 months. Parents distinguished between early onset and late-onset and there was confusion over possible cause (Tams, 2001). In Tams' study, parents also reported that they had become involved in support groups. They actively searched for answers/cures, attended conferences, read the latest research and became 'experts' in the field of autism, although some parents became less actively involved with autism over time.

Interestingly, although these parents highlight many of the 'traditional' concerns parents have had about their children with autism Tams (2001) also identifies some discrepancies between the experiences of these parents and other established literature. These parents perceived their children as more affectionate and less withdrawn than typically portrayed; all parents viewed their child as different from the typical child with autism, e.g. more loving. Tams concludes that there is a variety of parental experience and a range of attitudes towards autism. She suggests that professionals should respond to this by

determining parents' personal belief systems before suggesting strategies for change. One issue that provokes a range of parental reactions is the question of labelling. Traditionally parents of children with ASDs have had to fight for a diagnosis (Howlin, 1998). Since Kanner first identified the syndrome in the 1940s there has been much debate around the parameters of the syndrome. As autism can only be recognised through behaviour, it is often left to the opinion of an individual psychiatrist or paediatrician to assign the label, as it is the 'medics' who remain the 'gatekeepers' of diagnosis (Wing, 1996; Siegel, 2003).

Traditional discussion around the experiences of parents of children with ASDs has focused, therefore, on the stresses and disadvantages that may arise. Other aspects of the experience, such as parents enjoying meaningful relationships with their children have, to a large extent, been overlooked within autism focused literature. The next section considers the experience of parenting as revealed within a wider, 'generic disability' context.

Section Two: Challenging Traditional Claims

This section identifies themes within the literature of generic disability research that I came to while gathering the data for this study. I turned to these when many of the experiences of the participants, in my study, did not appear to be reflected in autism specific research accounts. Within generic disability research I discovered a new series of debates that I had not previously encountered. Namely, these were labelling, stigma, power relationships, and models for understanding how disability might be constructed.

The labelling debate

Gillman et al. (2000), in their study of the impact of diagnosis, question the value of a label. Whilst they recognise that it can 'open the door' to services and enable access to resources, they also warn that diagnosis can lead to a worsening of circumstance for the individual so identified. They record a number of potentially negative consequences. One of these was that professionals acted as though having a label justified intrusive treatment. Another was that parents, carers and professionals, who had been working well with people prior to diagnosis, then felt disempowered from engaging with them, without 'expert' knowledge of the 'syndrome'. A third effect, claimed by Gillman et al. (2000), was that labels lowered the expectations of others, leading to a disregard of the individual with a learning difficulty as though he/she could have no direct input into his/her own provision.

This reduction in expectations is termed, by Goodley (2001), as 'relational construction', where behaviour is interpreted in relation to diagnostic labels and some labels, such as 'learning difficulties', for example, carry with them lower expectations than others (Goodley, 2001). Gillman et al (2000), also argue that the diagnostic process results in the medical mystification of aspects of human development, leading to, 'the marginalisation, disqualification and rejection of knowledge and expertise of individuals and their family carers' (p.396), as people's own reflections on how they experience the world, or the insights of their carers, are dismissed as 'non expert'. Professionals conduct the diagnostic procedure as though it is the process by which truth and enlightenment are revealed, instead of it being merely a social construct through which the majority categorise and exclude certain sections of society. White (1997, cited Gillman et al., 2000) dismisses any diagnosis made by 'outsiders' as little more

than 'thin description'. 'Outsiders' are defined as those who observe the lives of other people without taking into account the views of those most qualified to speak, i.e. those who are living the experience and their family members/carers. Dismissal of the insights of those most affected by the diagnosis also allows professionals to locate the problem and the solution within those individuals, 'thereby ignoring structural oppression and discrimination, such as poverty, and physical and attitudinal barriers' (p.390).

Gillman et al. (2000) argue that people seek out labels, for themselves or their dependents, for a number of reasons. These can be summarised as:

1. A means of explaining symptoms of 'illness' or 'abnormal' development in order to relieve 'the stress or ambiguity of the unknown' (p.394).
2. Medical explanations are what seem appropriate in order to understand what is seen as an illness. This was especially sought after by those whose son or daughter's learning difficulty was not immediately apparent.
3. A label can be an explanatory device that can be useful to family carers in their dealings with the general public; an official diagnosis can be a powerful convincer that relieves parents of giving further explanation for their child's behaviour to others.
4. Some labels are felt to be more stigmatising than others, thereby leading to a search for a more favourable label.

Additional reasons might also be that some people believe that a label will enable access to specialist support and understanding and enhanced financial resources (Kelly, S., 2005). Avdi et al. (2000) found these positions supported within their own study, involving three sets of parents of children with autism, with the addition that their group of parents also sought diagnosis as 'official acknowledgement of the 'reality' of the problem' (p.248), evidence to demonstrate that their concerns were legitimate. Labels are not just applied to disabled children however. It is argued that through 'courtesy stigma' (Goffman, 1963; Green, 2003) families can also become thought of as 'disabled families', disempowered through association.

Courtesy stigma

As a concept courtesy stigma was first acknowledged by Erving Goffman (1963) who recognised that not only does the person, who is labelled as different in some way, have a spoiled identity and is stigmatised (Kearney and Griffin, 2001), but also those with whom she or he associates. This can then lead to social isolation and emotional distress (Russell, F., 2003). Green (2003) names this process, 'Modified labelling theory', where not only the child receives a label but also parents become known primarily for being the mother or father of the disabled child (see also Gray, 2002). Waltz (2005) identifies that this coping with their own 'spoiled social identity', the 'stigmatisation of parental identities' (p.8) becomes, in fact, the central focus for many parental narratives on raising a child with autism.

Experiencing stigma

In considering the impact of stigma, Gray (2002) distinguishes between 'felt' and 'enacted' stigma. Felt stigma occurs when parents perceive others as stigmatising them in some way whereas enacted stigma is when the stigmatisation is demonstrated through some particular act, such as overtly hostile comments or avoidance (Gray, 2002). Gray asserts that parents actually find it very difficult to distinguish between these two forms of stigma when asked to recall events. Felt and enacted stigma merge, leaving parents unable to remember if someone actually was avoiding them, for example, or whether they just anticipated avoidance. Deciding how to react to such behaviour, from other people, presents parents with a dilemma. To advocate for their children, or explain that their children have impairments, immediately identifies the children as different, as "disabled", something some parents wish to avoid. However, ignoring such acts can be very frustrating when parents really wish to make the other person understand why their children are behaving in that way.

Disabled families

Dowling and Dolan (2001) also discuss the impact of courtesy stigma. They draw on the social model of disability to illustrate how social barriers, prejudices and poorly conceived service provision condemn families of disabled children to financial hardship, stress, anxiety and prejudice. Dowling and Dolan, along with other researchers (e.g. Kelly, S., 2005) are identifying here that it is not only the child who becomes disabled but the whole family (Kelly, S., 2005).

Dowling and Dolan (2001: 22) assert that:

...it is not caring for the child with disabilities, 'the care burden', that causes this reduction in quality of family life, but rather it is a direct result of the social construction of disability.

Although they choose not to use the term, "disabled families", because they argue that this is not as common an anti-oppressive term as, "families with disabled children", "disabled families" is certainly what Dowling and Dolan describe:

In the same way that lack of funding, inflexible care arrangements and the prejudices of others disable those with impairments, it causes stress to those who are caring for disabled children and has an adverse effect on family welfare. This often leads to unequal opportunities and outcomes – in work, leisure, finance and quality of family life (p.24).

They see change as being both needed and possible but only when services can be constructed from the perspective of the disabled child and their family. If services start to be constructed from the starting point of listening to the experiences of people with impairments and their families then this will go some way to breaking down oppressive barriers. In the meantime, parents are left to devise strategies to manage the impact of stigma.

Managing stigma

Green (2003) identifies three common but different responses that individuals with impairments, and those close to them, might make to manage this stigmatised position, '...secrecy, education and withdrawal' (p.4). They may try to hide their disability from others, feel obliged to educate and manage the emotional responses of the public and/or choose to limit their social contact to

being with others in a similar position. To some extent secrecy and withdrawal may be motivated by the same desire; the wish to control information concerning their child's impairment (Gray, 2002). Gray (2002), talks about parents wishing, at times, to 'pass' as a normal family. If their child does not show any visible sign of being disabled, such as may be the case with high functioning autism, then parents may not make reference to this when out in the community. Even where their child does show clear signs of impairment parents may still 'pass' as parents of children without impairments if their child is not accompanying them. Spending time with other parents of children with impairments, perhaps through a support group, for example, may make 'passing' more difficult so parents may avoid association with such groups (Gray, 2002). Gray notes that the low visibility of high functioning autism, while allowing some families to 'pass' as 'normal' in some circumstances, exposes parents to a higher incidence of 'stigmatising reactions' as others in the community do not make the allowances for behaviour that they might if the child clearly looked different. Gray also found that mothers experienced stigma more than fathers did; this he attributed to the fact that the mothers in his study were principal carers and were out in the community with their children to a greater extent. Also some mothers felt that the responsibility for their children's behaviour rested with them as their role within the family was as primary carer (Gray, 2002). The school community was one particular location where parents experienced stigma from teachers, administrators and other parents (Gray, 2002). This took on several different forms, including being left with sole responsibility to manage the impact, on their child, of being socially isolated and/or bullied, difficult interactions with other parents and generally feeling different and 'looked down upon' (Gray, 2002: 742).

Perceptions of disability

How parents react to having a child with an impairment, Green (2003) claims, is influenced significantly by their own perception of disability. Kearney and Griffin (2001: 582) argue that the prevailing image, within society, of having a disabled child is that of a 'tragedy from which the family may never recover'. Murray (2000: 685), writing from her perspective as parent, expresses this particularly powerfully by asserting that the dominant view is of, 'our disabled children with learning difficulties as being intrinsically defective and, therefore, sub-human'. Ferguson (2001, quoted in Kelly, S., 2005: 183) claims that, 'it is not a specific set of parental reactions to disability that is inevitable but the influence of social contexts in shaping those reactions'. Disabled children will also be affected by parental perceptions of disability (Thomas, 1998, cited Kelly, B., 2005). The children of parents, who challenge the traditional 'negative' perceptions of disability and focus upon barriers to inclusion, rather than impairment, are likely to have more positive self-esteem (Thomas, 1998, cited Kelly, B., 2005). The more that parents share the view that individuals with disabilities are devalued and discriminated against by others, the more likely they are to feel, '...embarrassed, guilty, ashamed, resentful, worried, trapped and/or emotionally upset...' (Green, 2003: 8). Parents who have a more optimistic perception of how disability is perceived by society are less likely to experience these feelings to the same extent. For some parents the experience of parenting a child with an impairment alters their perception of disabled people generally and they begin to perceive them with more empathy and understanding. For those parents whose views remain negative towards disability, the child's impairment may be a source of embarrassment and, '... may evoke feelings of resentment and entrapment...' (Green, 2003: 8).

Agency

While Kearney and Griffin (2001) warn that the prevailing individual model view of disability as a tragedy is a pervasive and powerful discourse (Foucault, 1972) which continues to dominate, Murray (2000: 687) claims that, 'it is increasingly possible to find accounts in the literature by parents who hold a more positive view'. While Foucault (1972) argued the supremacy of professional discourses, he did not make clear the role of subjective agency in relation to these; individuals, according to the Foucauldian perspective, appear to be naturally submissive in the face of dominant discourses (Sarup, 1996). Goffman (1963), however, celebrated resistance to controlling conceptualisations. He argued that stigmatised individuals adopt a variety of strategies for combating dominant discourses including forming lobbying groups of similarly affected people, becoming expert in the area of the stigma to challenge professional opinion, becoming immersed in the culture of the group through reading literature which represents their experiences or reflecting on being 'different' and coming to a new understanding of what is important to them as individuals (Goffman, 1963).

Ong-Dean (2005) also sees parents of disabled children as active agents. He argues that some parents embrace the individual model as a mechanism for understanding their child's development. Ong-Dean suggests that the positive consequence of this, for parents, is that, by doing so, they release themselves from the role of 'bad' parent. Similarly, Landsman (2005) views parents' relationships with the models of disability as dynamic. Although she agrees that parents do utilise the individual model in support of their sense of themselves as effective parents Landsman argues that this is not because it is a 'parent-friendly' discourse but because it is the only public discourse on disability

available to them. It may well be that this is also the only discourse encountered by professionals.

Positioning parents

Murray (2000) argues that it is necessary to resist positioning parents of disabled children as 'other', somehow different to parents of non-disabled children and naturally having 'super abilities' which enable them to 'cope' with the 'tragedy'. The parenting relationship is complex with parents balancing conflicting emotions and attitudes; 'From the moment most couples know of the wife's pregnancy, they harbour feelings of hope and also of anxiety' (Bettelheim, 1987: 46). 'Negative feelings' are not uncommon for new parents generally. Lupton and Schmied (2002) report that some women, about to become mothers, fear that to stay at home will bring about a loss of "self-fulfilment" and "self-actualisation" which they perceive can only be achieved through work outside the home. The experience of becoming a parent leads to an adjustment of perception for new mothers. Most of the women, interviewed by Lupton and Schmied, felt that the role of mother seemed a "distorted" or "constrained" self as opposed to the "real me". Coming to terms with parenthood can be a complex, challenging and disturbing process (Whittaker and Cornthwaite, 2000; Akister and Johnson, 2002). Disability is another factor that magnifies the complexity and can also isolate parents as this is one factor outside the experience of most other new parents. In addition, it is not only their own feelings that parents of disabled children need to manage; Green (2003) notes that coping with the reactions of others to their children is yet another source of emotional turmoil, especially in the early years of the child's life.

Russell, F. (2003) argues that enabling parents of newly diagnosed children to explore their expectations of the experience of parenting, through the counselling process, would empower parents, supporting them with becoming active, rather than passive and demoralised, 'partners' with professionals. Russell also asserts that embracing the social model and focusing 'on the child's strengths, their aspirations and opportunities to involve them' (p.148) would further support this process. Adopting the individual model, with its focus on deficits, identifying 'need' rather than 'entitlement', causes a discrepancy between the parental view of the child and the professional perspective (Lake and Billingsley, 2003, cited Russell, F., 2003). Russell, F. (2003) advises that focusing on what children can do, what they hope to do and identifying what obstacles need to be overcome, in order to enable the achievement of ambition, would lead to a more unified parental-professional approach.

Evolving positions

Brown (1998, cited Case, 2000) identified that parents reported a dissatisfying and conflictive experience of professionals. Brown, like Randall and Parker (1999), also found that the most common reaction, of parents, to the diagnosis of an impairment, was a negative one. Tunali and Power (2002) identify established hardships as resulting from becoming a parent of a disabled child. These include financial hardship, strained emotional relationships within the family, forced changes to life goals and family activities, impact on social life, the burdens of medical treatment, housing adaptations, educational hardships and parental grieving. Traditionally it has been claimed that such burdens have resulted in a significantly increased risk of individual and marital distress but Tunali and Power note that more recent studies argue against there being any

significant difference here between parents of children with or without impairments. They claim that this may be due to parents of disabled children managing the stress of their experience by redefining what is important to them and also coming to value new experiences that arise from them being parents of disabled children.

Tunali and Power claim that, compared with mothers of non-disabled children, mothers of children with autism redefine their position and become more likely to believe in values, and engage in practices, that support their own position. These may include holding that mothers of young children should not work outside the home. As a result they may therefore, place less emphasis on career success and spend more leisure time with their extended family. They may also be less concerned about what others think about their children's behaviour, place more emphasis on support between spouses and parental roles and have a higher tolerance of ambiguity through coming to terms with not always understanding their children's behaviour. Tunali and Power did not find any significant difference between the overall life satisfaction of parents of children with autism and those of children without the syndrome. Moreover those parents of children with autism who had redefined their position on becoming parents of a disabled child demonstrated the greatest life satisfaction overall. The more parents can redefine their thinking to accommodate their change in circumstances, the higher the predictor for overall life satisfaction. Kelly, S. (2005) records an example of this process of redefinition. Nora, the mother of a disabled child, once she had accepted the 'reality' of her daughter's impairment, then 'remade herself' as the parent of a child with an impairment. Kelly identifies this process as a positive and empowering experience; one of, 'acceptance, personal transformation, and choice' (p.188).

Different experiences

Case (2000), in his collation of a questionnaire sent to one hundred and fourteen parents of children with impairments also found many aspects of this potential for positive experience. For example parents viewed their children as, '...attractive, happy, friendly, and interested and bright.' (p.283). While opportunities to continue pre-birth or impairment social activities might be reduced or curtailed, the parents in Case's study identify that new ones take their place, such as making new contacts through the world of disability. Case argues that part of giving parents of disabled children equal rights in society is to enable them to have these positive experiences, '...highlighted, elaborated and celebrated'(p.283).

Similarly Gray (2002) notes that for some of the parents in his study, although they had withdrawn to some extent from socialising with friends, they had then put more energy into other, less social activities, such as hiking and having family picnics. More time was spent with families who also contained a child with autism. However, this is not to suggest that there will not be challenges to be faced when parenting a child with an impairment; Gray, for example, does record that '...the resulting limitations on the abilities of the families to socialise was often felt by the parents to be a considerable loss.' (p. 741). Avdi et al. (2000) found that parents accept the idea of normal development and compare the development of their own children with others, in order to evaluate their child's progress. However, parents stated that once they have accepted that their child is following a different path then they can begin to focus on, 'how he is' rather than on 'how he should be' (p.247).

The power of redefinition of values and perspectives is also recognised by Woolfson (2004) who proposes a psychosocial model of disability-related child behaviour problems; how parents view the nature of their child's impairment will affect both parents' own sense of well being and how effective they are in supporting their child with managing his/her behaviour. Woolfson claims that parents, who are experiencing difficulty with managing their child's impairment on an emotional level, may well have a perspective on impairment that mirrors the different negative models of disability which are found in society. Woolfson identifies these as, 'disability as a medical problem', where parents attribute all behavioural issues, inevitably, to the child's impairment, 'disability as a tragedy', where parents must make it up to the child for the tragic circumstances of their condition or 'disabled people are dependent and need help from others', where parents must protect their child from any challenges. Families that adopt any of these positions, Woolfson claims, may need support to reframe their thinking, away from these dominant, medically influenced, social perspectives toward a more 'social model' view on disability.

Carol Schall (2000) in her study of the experiences of three families raising children with autism again finds many positives in the experience of parenting a child with an impairment. Although she begins in the language of the 'tragedy model' of disability: 'In the midst of a devastating condition, these families found courage and hope' (p.409), the data is rich with evidence of the positive aspects of parenting and family life, regardless of the child being disabled. One sibling describes his brother with autism as, '...a great big brother...' (p.419) and one mother's love for her child is so intense that she would, '...walk through fire for him...' (p.420). The families describe themselves as, 'growing', because of their experiences and their changing perspective. They develop a far greater

awareness and appreciation of disabled people than they would have predicted themselves doing otherwise. Having a disabled child even gave one mother, '...a sense of commitment and passion for life.' (p.420) that she did not have before, quite different from the bleak picture predicted in the early years of her son's development, '...in an institution for the rest of his life...' (p.411).

Schall's (2000) study also acknowledges that families can face challenges from trying to understand and manage their child's behaviours, such as sleeplessness, constant crying and head butting, especially before diagnosis when they could not understand why their child was behaving differently to other children. The parents described the actual diagnosis as empowering as it meant that they could then research how to 'manage' their child's condition. One parent recalled that until the moment of diagnosis, '...there was nothing I could do but wait (for a diagnosis)...' (p.411) but this is almost as though permission was required from 'experts', those on the outside, before this mother could engage effectively with her son. Once there was a diagnosis then parents become avid readers, although only of positive literature (Schall, 2000). The suggestion is made that, through this process of learning from others, families then become skilled in supporting their child in all areas of development, evidenced by their mastery of technological terms and becoming well informed on therapies and interventions (Schall, 2000).

The majority of hardships experienced, by the parents, records, Schall (2000), come from engagement with others. Many professionals seemed to disregard parents', '...experiences and opinions regarding their child...' (p.412). Parents 'battle' authorities constantly to get resources for their children and have to act as advocates and interpreters on their behalf. The effect of this is physically exhausting. Parents can find themselves and their children incorrectly accused

of wrong doing. Examples given by Schall (2000) include mothers being asked if they took drugs or drank alcohol during pregnancy and being sometimes subjected to unwelcome interventions from state agencies, such as removal of the child because of suspected abuse. Friendships change as old ones are abandoned if friends seem to lack understanding of the situation, and new ones are made with those who have more empathy. Throughout the parenting experience families develop coping strategies together to enable the family to survive and flourish (Schall, 2000).

Gray (2003) looked, in particular, at differences in how mothers and fathers cope with parenting a child with high functioning autism. He found that traditional family roles still apply with women continuing to bear the greater burden of childcare, taking part in therapy programmes, negotiating with school staff and accompanying their child on medical appointments. 'Escaping' to work, fathers felt more distanced from the daily responsibility of parenting activities, such as mediating between their child and school. If women were working or had intended to return to work they often found it necessary to reduce their working hours, change the nature of their employment or elect to remain at home. Men still had issues around having a child with autism, such as fear for their future. Although they were largely unable to identify their own coping strategies, often keeping feelings in until they came out as anger, some fathers did adopt a strategy of 'taking a philosophical perspective' (p.641), trying to keep things in perspective or make the best of things and seeing family problems as minor in relation to other world events. Mothers relied more on letting feelings out through crying or sharing with friends and taking comfort from the support of spouses or from religious faith.

A social construction perspective

Avdi et al. (2000) take the viewpoint that attitudes to autism and impairment are socially constructed:

receiving a diagnosis of autism is a complex and powerfully emotive experience for parents, which draws heavily from the social context and culturally available meanings about autism, disability, normality, deviance and difference... (p.243)

The parents in their study viewed autism as the 'enemy from within' (p.248) and saw themselves as in constant battle with it to stop their child from regressing back into an autistic state. Parents remain in a continual state of alert for signs of this. Avdi et al. (2000) see a search for a cause as an inevitable result of constructing a child as 'deviating from normality' (p.249), often leading mothers, in particular, to locate the cause of the problem within themselves or some act they had committed during pregnancy. These researchers found that securing a diagnosis resulted in children being scrutinised and analysed. Parent-child relationships then adopted a teaching or curing focus, thereby taking some of the 'fun' (p.250) out of the relationship. Once their child had been given the diagnosis of autism, then he/she could no longer, 'be constructed as normal' (p.250). Parents may then feel inhibited from interacting with their child, perceiving themselves as lacking the expert skills needed to help children with autism; parenting is felt to be instinctual in relation to 'normal' children but something that needs to be taught for parents of disabled children (Avdi et al., 2000).

Murray (2000) argues that the attitudes that parents adopt to disability will, in addition, impact upon their relationships with professionals:

the demands of parents who view their disabled child positively (Goodey, 1991; Murray & Penman, 1996) are very different from those who struggle with accepting their disabled child (Hannam, 1988; Meyer, 1995) (p.684).

Reframing understanding

Parents of children with ASDs may go through several periods of reframing their understanding of who they are and their attitudes towards disability. As autism is often not diagnosed until around the age that children begin to use language, parents often assume, first, that they have a 'normally' developing child and are therefore a 'normal' family (Siegel, 1996; Randall and Parker, 1999; Schall, 2000). If traditional methods of behaviour management have not been successful and/or their children do not seem to be responding to them emotionally, like their friends' children, then parents may perceive of themselves as 'incompetent parents' (Dunn et al., 2001). On learning that their children have impairments, parents start to re-evaluate this assessment. At the same time they become acutely aware of what being disabled means to them (Gillman et al., 2000; Murray, 2000; Waltz, 2001). Case (2000) makes several suggestions as to how parents might be supported through the reframing process. Quine & Rutter (1994, cited Case, 2000) stress the importance of professionals being, '...sympathetic, direct and approachable, empathetic and good communicators' (p.286). They should relate to parents as, '...people first, professionals second.' (p.283). Thorin & Irvin (1992, cited Orlowska, 1995), writing now thirteen years ago, described it, even then, as a matter of 'common sense' for professionals to listen to family members, '...before making assumptions about support needs.' (p.441). Case (2000) argues that what will happen in the future is an issue that actively concerns parents. Professionals, he argues, need to respond to this positively but realistically to help parents

plan ahead. Case (2000: 282) suggests that families, ‘...will respond positively to humane , skilled intervention, rather than the abrupt, uncaring and negative manner of professionals in this (Case’s) study...’ and he argues that counselling, especially after diagnosis, is one way of providing this support.

Living in the present

Fisher and Goodley (2005) emphasise the importance of being able to ‘free’ parents up from fear of the future to enable them to enjoy the here and now with their children. In a paper under development, they term this, after the work of Deleuze and Guattari (1987: 4, cited Fisher and Goodley, 2005), ‘the philosophy of the present and becoming’ and argue that when professionals support parents with enjoying the moment, valuing their children for who they are, then parent-professional relationships are experienced as being ‘enabling’ and ‘positive’ (p.17). Hastings and Johnson (2001) recommend that levels of stress in families of children with ASDs might be lessened if professionals support parents with identifying and celebrating their strengths and capabilities as a family, accepting the inevitability of some ‘negative’ events and by putting ‘a more positive spin on problems’ (p.335) to avoid discouraging family members. In valuing the positives of the parenting experience, in this way, professionals may begin to focus more on removing disabling barriers to entitlement rather than continuing to locate the ‘problem’ within the child and the family. They may experience a shift in focus from an individual model of disability towards a social one (Oliver, 2003).

The social model of disability

Reference to the social model of disability is embedded within this dissertation.

This section serves to identify the key principles that underpin this theory of disability and make clear my own position in relation to the model.

For the past thirty years disability discourse in the United Kingdom (UK) has been dominated by the emergence and refinement of the social model (Swain et al., 2003; Thomas, 2004). This means of understanding disability holds that it is not people's bodies that prevent them from engaging fully with society but 'discrimination and prejudice' (Shakespeare, 1992, cited Swain and French, 2000: 571). The barriers experienced by disabled people, 'permeate every aspect of the physical and social environment' (Swain et al., 2003: 138). A distinction is made, therefore, between impairment and disability. Impairment is defined as, 'the functional limitation within the individual caused by physical, mental or sensory impairment' (Barnes, 1991, cited Tregaskis, 2002: 458) and disability as, 'the loss or limitations of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.' (Barnes, 1991, cited Tregaskis, 2002: 458). Proponents of the social model argue that it is largely the medical establishment who pathologise individuals, by defining them through a variety of negative and disempowering labels such as 'different', 'deviant', 'abnormal' or 'invalid'.

The individual model is so termed because it locates the problem within the individual with an impairment and sees the only solution as changing that person to make them as 'normal' as possible (Oliver, 1996; Thomas, 2004). For the social model, it is society that is to blame for denying disabled people equality through a variety of practices. These include denying access to employment and thereby making disabled people dependent on charity

(Barnes, 2000), preventing physical access to social spaces and not recognising non spoken systems of communicating and segregation through specialised schooling. It is not the impairment that excludes the person from taking part in society but these restrictions imposed by society. In order for disability to be eliminated, the social model calls for an integrated approach, by service providers, to identifying and removing the barriers to inclusion (Campbell, 2002). It is claimed that this will enable people with impairments to have control over their own lives (Campbell, 2002). In order for this to be achieved, professionals, supporting people with impairments, must be committed to promoting this autonomy (Campbell, 2002). The empowerment and politicisation of disabled people is a defining principle of the social model (Oliver, 1997; Swain et al., 2003) with disabled and non-disabled people working together to achieve change (Goodley, 2001).

Recently the social model has been challenged by attempts to reassert a relationship between impairment and disability (Goodley, 2001; Shakespeare and Watson, 2001; Thomas, 2002; 2004). Proponents of the social model have been accused of refusing to acknowledge the potentially disabling impact of impairment (Humphrey, 2000; Shakespeare and Watson, 2001; Thomas, 2004) although Barnes (2002: 443) refutes this as a 'misinterpretation (of the social model) by some disability activists' (see also, Oliver, 1994; Thomas, 2002). Goodley (2001) argues that certain groups, such as people with learning difficulties and those with profound impairments (Brett, 2002), have been excluded from the social model through their perceived identity as 'unsocialisable' (Goodley, 2001). Deal (2003) also questions the homogeneity of the disability movement by exposing within it a hierarchy of impairments: those with physical impairment and the ability to work collectively dominate while

those with intellectual and/or social impairment are marginalised within the movement. Unsurprisingly, therefore, there appears to be no specific discussion around people with autism within the social model. Nor could I find, within autism-focused 'professional guidance' literature, any reference to the social model.

Autism is defined by a triad of impairments (Wing, 1996), a description which arises from a deficit focal point. However, Wing (2004) has also described autism, as being a problem of other people, in the sense that those without autism operate systems that exclude those who have the syndrome. In this description the 'problem' is located not within the individual but within systems external to them. A central tenet of the social model, which defines the disability 'movement' (Humphrey, 2000), is collective action (Goodley, 2001; Swain et al, 2003; Thomas, 2004). Lisicki (cited, Oliver, 1997: 245) defines the disability movement as, 'a set of people that have somehow made a connection with a set of ideas'. This raises the question as to what extent the 'social impairment' of autism has and will lead to the exclusion of people with ASDs from the 'movement' because of its intrinsically 'social' nature. Nor is the position of parents of disabled people made explicit within the model. Are they, 'fully paid up' members by virtue of being also disabled (Dowling and Dolan, 2001) allies of the movement (Brett, 2002), a tool of disablement themselves (Garth and Aroni, 2003; Landsman, 2005) or the enemy, fervent upholders of the individual model (Dawson, 2003)? The disability community itself is not yet inclusive (Humphrey, 2000); parents, people with learning difficulties and those with social impairment remain voiceless and disempowered even within the movement.

While the social model has been thoroughly 'theorised' and 'problematized' by researchers, there are very few practical suggestions within these papers which might support either disabled people or their 'allies' (Brett, 2002) with identifying and dismantling barriers to inclusion. We now have, amongst many others, a social model (Oliver, 1996), an alliance model (Brett, 2002), an affirmation model (Swain and French, 2000) and a psychosocial one (Woolfson, 2004). Tregaskis (2000) argues that conceptualising disability in this way has been important for disabled people in that it has helped them to make sense of their own experience and shifted the focus of blame, for exclusion, from the individual to society. Also legislation, informed by the social model has gone some way to start the process of inclusive practice (e.g. Disability Discrimination Act, 1995, Special Needs and Disability Act, 2001). In spite of this, however, disabled people continue to suffer social exclusion (O'Grady et al., 2004). Within my own local authority it is estimated that ninety five percent of people with learning difficulties are unemployed (Hesmondhalgh and Breakey, 2001) and the National Autistic Society claims that only six percent of people with autism or Asperger syndrome are in full time work (Barnard et al., 2001). Educational legislation and guidance has raised parents of disabled children to the position of 'partner'. Examples of these are The Code of Practice (Department for Education (DfE), 1994), Meeting Special Educational Needs (Department for Education and Employment (DfEE), 1998) and Every Child Matters (DfES, 2003) but these appear to create partnerships in 'name' only. Although it has been suggested that there has begun to be some improvement in professional-parent relationships, with the parent now 'cast' in the role of 'consumer' (Case, 2001), this relationship continues to be dominated by professional discourse (Gillman et al., 2000; Murray, 2000; Brett, 2002).

Although the legislation may change, it is unclear whether the attitudes and perceptions of non-disabled people are evolving alongside this (Tregaskis, 2000; Thomas, 2002).

The social model may, therefore, have radicalised the collective identity of people with physical impairments. To what extent this has occurred also for people with intellectual impairment, social impairment or the families of disabled people remains less clear. While academics have actively conceptualised disability, professionals are left with little guidance on how to identify and disassemble barriers to inclusion within their own particular field. Landsman (2005) claims that mothers of disabled children remain largely unaware of the existence of a social model of disability, although they are sensitised to the disabling impact of other people's attitudes. While the importance of reframing parental attitudes (discussed earlier) is emphasised within the literature, again there is little guidance on how to achieve this. Rather than adding to the menu of disability models I argue that it is now time for academics to emancipate the professional agenda by formulating a clearly articulated and practical agenda for change. Parents locate the problem within society but the solution within the child; on a practical level, the child is still seen, by parents and professionals, as easier to change than the attitudes of others. (Landsman, 2005).

This literature review has been presented in two parts to illustrate how my own knowledge and understanding of the experiences of parents of children with ASDs was informed and reformulated through interviewing the parents for this study. Rather than the literature informing the research question it has become part of the data, illuminating the phenomenon being studied (Glaser and Strauss, 1967; Silverman, 2000). I now consider the 'guidance' and research

literature which had informed my previous professional practice (e.g. Jordan and Powell, 1995; Wing, 1996; Howlin, 1998; Randall and Parker, 1999) to have an individual model focus on the negative aspects of the parenting experience. I argue that, although some autism specific literature is now presenting a more balanced view (e.g. Tams, 2001; Moore, 2005), reports on the experiences of children with ASDs continue to be 'firmly rooted' within the individual model of disability (Oliver, 1996; Avdi et al., 2000). Parents of disabled children continue to be presented as 'other' (Foucault, 1972; Murray, 2000), with parenting expressed either as a tragic or saintly occupation (Murray, 2000).

In order to find accounts of the parenting experience which were more 'in tune' with those revealed through my own research I turned to generic disability research. Here were found numerous reports (Murray, 2000) of the everyday, positive aspects of parenting (e.g. Anderson, 1991; Kelly, S., 2005). Although conceptual models of disability appeared to have been effectively ignored within the autism specific literature, those within generic disability studies identify the social barriers which disempower and disable families (Avdi et al., 2000; Murray, 2000; Case 2000; Dowling and Dolan, 2001; Woolfson, 2004). While it is recognised that parents of children with autism might have particular concerns, arising out of how their child is experiencing the world (Schall, 2000; Tunali and Power, 2002), this is framed as part of the 'normal' complexities of the parenting experience (Gray, 2002; 2003; Lupton and Schmied, 2002; Tunali and Power, 2002).

I argue that the literature on disability informs us that in order to support parents effectively professionals will need first to define and, if necessary, reformulate their own position towards disability (Tunali and Power, 2002; Woolfson, 2004; Kelly, S., 2005). Only then, will they be able to help parents through this same

process. To do so, professionals will need to challenge the individual model with its focus on impairment and a 'needs' led approach (Tregaskis, 2002). Instead they should embrace the social model, focusing 'on the child's strengths, their aspirations and opportunities to achieve them' (Russell, F., 2003: 148).

The themes emerging from this study, supported by those found in the recent literature, suggest that parents require a range of responses from professionals who are sensitive to the parents' positions and who recognise and value parents' positive experiences. Although families may adopt new patterns of behaviour to respond to specific support needs arising from the effects of the impairment (Goodley, 2001), these lead to different rather than lesser experiences. Also, being enabled to believe in the possibility of a positive future will support parents with living in the present (Fisher and Goodley, 2005).

This chapter has, therefore, established that there are concurrent and competitive discourses concerning the experience of parenting a child with an ASD. These debates appear to reflect the contentious conceptualisations of disability as a phenomenon, primarily through the medical and social models of disability (Hedlund, 2000). This current study was designed to inform these debates by detailing the experiences of three sets of parents. By doing so, it was intended that the structures, which potentially 'underpin' the experiences of parenting, might be elucidated. The literature review suggests that social model researchers need now to clarify the barriers to inclusive experience in order to support parents and professionals with the dismantling of these. It also guided the formulation of this study by identifying a need for more detailed accounts of how the diagnostic process is experienced. In addition, the review informed the analysis of the data by enabling the participants' experiences to be understood

within a wider context, helping to identify factors which might, potentially, have helped shaped those experiences.

The following chapter will now identify the methodology chosen to investigate the impact of these discourses on parents as 'Lifeworld' and evaluate its utility for investigating disability as a phenomenon and for providing effective and ethical disability research (Moore et al., 1998).

Introduction

This chapter identifies the methodology selected for the study as that of 'Lifeworld'. It then locates Lifeworld within methodological paradigms and explicates its essential principles. The value of Lifeworld as a means of giving voice to participants' experiences is assessed and related to the question of whether Lifeworld can be considered to be an emancipatory methodology within the traditions of disability research. A comparison is made with grounded theory, the other methodology considered for this study, and an account given of why Lifeworld was selected, because of its 'fit' with my own ethical, ontological and epistemological positions. Within the chapter the experience of being a researcher is also explored and identified as a complex, fluid and evolving process, offering up a number of alternative and sometimes competing paths. The chapter concludes with a consideration of how the research data were analysed in accordance with the phenomenological tradition.

Defining Lifeworld

All of us have a lifeworld; it is all that we are and all that we do, 'the frame of all experience' (Ashworth, 2005, personal communication). It is the sense that we have of ourselves, how we feel emotionally, what our bodies can do physically, the relationships that we have with others, our hopes and ambitions, our perceptions of time past and the future in front of us, the activities we engage with and all that we value. Although the way that we experience them will be unique for each of us, these aspects of being alive will be shared by all of us; they are the parts of the lifeworld, not bounded within themselves but

experienced fluidly with each aspect influencing and being influenced by the other. Ashworth (2003a) terms these aspects, 'fractions', to emphasise that they are not separate dimensions but that they are interconnected parts of a whole.

Ashworth (2003a) defines them as:

- **Selfhood** – this is our social identity – what power do I have in this situation? What impact can I make on what is happening to me? What does what is happening say about me?
- **Sociality** – our relationships with others - how does what I am experiencing affect my relationship with others? What language am I using to connect with others?
- **Embodiment** - what we feel physically and emotionally – how does what is happening affect me physically and emotionally?
- **Temporality** – sense of time – how is my sense of time, duration, biography affected?
- **Spatiality** – the space we occupy – is where I need to go affected?
- **Project** – the things we do which are important to us - how does what is happening to me affect the activities which I am committed to and which are central to my life?

- **Discourse** – use of language – what sort of terms, educational, social, commercial, ethical am I using to describe my lived experience?

Lifeworld as a methodology is the means by which researchers rise to the challenge of identifying the lifeworlds of others. This study focused particularly on how the experience of being told your child has autism impacts upon parents' established ways of being.

Lifeworld as a research methodology

Lifeworld refers to the perceived experience of the individual. As a method of phenomenological study its roots lie in the work of Husserl (Goulding, 1999; Wilson, 2002; Ashworth, 2003b; Bengtsson, 2004) who highlighted that 'reality' was experienced differently by individuals. Each individual is held to experience a lifeworld where there is order, as meaning is attributed to experiences. Disorder arises when events or actions occur which do not fit with the individual's established sense of order and which cannot relate to previous experience (Hammersley, 2003). Hammersley also argues that this concept of the lifeworld can be described as a Kantian view as Kant argued that the mind plays an active role in forming the 'real world' for the individual. Therefore, Hammersley (2003) states, some features of experience, in particular; spatial, temporal and causal relations are formed not by the 'things-in-themselves' but from the 'constitutive activity of the mind' (p.757); there is no reality, only people's perceptions and senses of their lived experience. Lifeworld is a phenomenological methodology and is therefore about the nature of human

experience and the meaning people attach to their experience (Wilson, 2002; Ashworth, 2003b).

Lifeworld has been developed into a methodology by academics such as, Peter Ashworth (2003a,b), based upon the writings of Husserl, Merleau-Ponty and Amedeo Giorgi (Wilson, 2002; Ashworth, 2003a). The aim of the methodology, in keeping with existential phenomenology, is to describe the varieties of human engagement (Ashworth, 2003a). Husserl's commitment to understanding individual experience remains within the methodology but there is no attempt made to extract essential, universal truths or common theories from the data. Also validity is given not only to the conscious thought of the individual but also to more basic experiences such as emotion, for the person is viewed as a 'body subject' who reacts to situations at an emotional level which might not always be conscious (Ashworth, 2003a).

The lifeworld is defined by Ashworth (2003a: 25) as, 'our individual meaning-construction of our situation'. To understand it, Ashworth argues that the researcher must first suspend or 'bracket' any notion of reality in order to focus upon elucidating the conscious experience of the research participant (Harvey et al., 2000; Ashworth, 2003a). This involves setting aside current theory about the issue being studied and being able to consider the views of the research participant outside of the influence of the researcher's personal philosophy and perspective on the issue (Ashworth, 2003a). Harre (1998) describes two ways of coming to know the social world. The first is knowledge by acquaintance, an actual living of the experience, and the second is knowledge by description. As I am not a parent of a child with autism I cannot come to understand this experience by living it and so must describe the experience instead. To do this Harre (1998) suggests that the researcher must first employ a model. Harre

(1998: 45) argues that, 'models are analogues of their subjects' and 'any subject might attract a variety of models, each revealing a different aspect of it'.

Within this research the participating parents represent the models by which I came to understand, as far as was possible, the impact of the diagnostic process. Giorgi (1985) asserts that the more participants there are in this type of research, the greater will be the variations within the experience. By identifying the differences within an experience, its essential aspects ought to become clearer. Three sets of parents took part in this research, which was the highest number that seemed practical within the resources, without compromising the experience for the participants. I wanted them to receive something positive and useful from the study: enlightenment and empowerment through the process of reflective thought and the giving of voice to experience.

Lifeworld as a tool of enlightenment

Phenomenology is concerned with the 'inner world' of participants (Harvey et al., 2000: 56), the sense that they make of the world. Within the lifeworld, meaning for the individual might be embedded in the subconscious and the body (Ashworth, 2003a). Sayer (2000: 711) defines this as the lifeworld, 'involving not only communicative interaction but non-cognitive and embodied elements'. This might be described as the 'enriching' mode of interpretation (Ashworth, 2003a) which aims at maintaining the understanding of the individual's experience but uncovering layers of the experience in order to understand it more fully. Ashworth (2003a) notes that Ricoeur (1970) distinguishes this from 'the hermeneutics of suspicion' that, Ashworth (2003a)

argues, has, as a central assumption, a belief that the surface account may be a 'cover' for much deeper-rooted beliefs and perspectives. At times, during the interviews, I felt a 'sense' that what was being said was being influenced by a thought or feeling that I had not yet come to know, that the interviewee did not, on that occasion, feel able to give voice to certain aspects of their experience. I, therefore, conducted the interviews over time, with the hope that this might give an opportunity for trust to develop, allowing me to raise my 'intuitive' perceptions, at a time when it felt, to me, to be unthreatening for the parent. The parents could then reflect upon to what extent these suggestions 'felt in tune' with their experience. I did not see this as coming to understand the participants better than they might themselves (Whittemore et al., 1986, cited Goodley and Moore, 2000) but rather as coming to know more of the complexity of their position.

My role as researcher became, therefore, one of listening attentively, reflecting back to the parents what I had heard in order to enable them to confirm, reject or clarify my summation in the light of their emotional response to hearing their thoughts again. This approach was based on the principle that observations, voiced by the researcher, which are in accordance with the core beliefs of the interviewee, will resonate within them upon hearing them expressed by the interviewer. This is a method used within Rogerian counselling (Thorne, 1992; Kvale, 1996) and I have found this to be a useful technique for disciplining myself as a listener. It also enabled me to 'challenge' the speaker, on occasion, by attempting to articulate feelings and beliefs that I felt lay behind the statements being made but which were at an emotional level which may have been less accessible for the interviewee. Through this method, I hoped it would be possible to begin to access what is described by Stelter, (2000) as the 'felt

sense'. This can be defined as the emotional response at the pre-reflective level of understanding. The speaker raises an issue; the listener attends to what is said but also attempts to intuit any other meaning which may be obscured by the words. The listener then reflects back their interpretation that the interviewee either accepts or rejects, depending upon their emotional reaction to what has been said. For example an interview might proceed as:

father – I have not contacted the consultant because I know she is very busy and I don't want to waste her time.

researcher (*thinking the parent is raising the issue of professionals not giving credence to parents' concerns*) - so you are worried that the consultant will dismiss your concerns as those of an overanxious parent?

father – I don't think it's that so much but more that I might forget what I want to say and the consultant won't know what I am talking about

researcher – so what is worrying you is that you won't be able to give the consultant a true picture of why you are concerned about your son?

father – yes, that's it exactly. I can talk to you alright but those doctors just make me forget everything

researcher (*hypothesising that the parent feels disempowered within the relationship with the consultant and looking for the parent to validate or reject this assumption*) – because

you feel doctors have all the power and it is hard to argue against them?

father – no but they use long words and I don't and that makes me sound stupid and I'm not

So through this process (of which only part is illustrated by the excerpt above) the researcher and participant can clarify, for themselves and each other, that rather than the parent being concerned about the consultant viewing him as an overanxious parent the issue for the parent here is his feeling of being personally misrepresented through discourse with doctors, appearing as less intelligent than he believes himself to be through use of a less extensive vocabulary. This raises issues, perhaps, around identity of self and conflict between the interviewee's concept of self and what he believes to be the perception of others. It is hoped, too, that this reflective process will help the interviewees to develop a greater understanding of their own situation and, in this sense, will be an emancipatory process (Kvale, 1996; Moore et al, 1998; Barnes, 2003).

Lifeworld as an emancipatory methodology

Sayer (2000: 712) argues that 'the lifeworld can be a site of domination and misrecognition'. Lifeworld, as a methodology, has been used as a means of identifying such imbalances of power (Foucault, 1980) by giving expression to those traditionally without voice, such as disabled people or patients (see for example, Ashworth and Hagan, 1993; Mulderij, 1996; Barry et. al, 2001). As such it is emerging as a useful methodology for emancipatory disability

research which has the empowerment of the research participant as a central defining characteristic (Barnes, 2003). Research with disabled people has a history of marginalisation of participants in the research process (Moore, et al., 1998; Walmsley, 2001; Barnes, 2003). Lifeworld, by its insistence that the focus of the research remains on the 'lived experience' of the participants (Giorgi, 1985; Ashworth, 1996; 2003a), places them at the centre of the process. Oliver (1996) also identifies the dilemma of the 'non-disabled' researching and writing about the issues for disabled people. The process of 'bracketing', within Lifeworld requires the researcher to become conscious of, and 'set aside', any influences and pre-conceptions that he/she may bring to the study (Wilson, 2002; Ashworth, 2003a). This works again, therefore, to maintain the position of participants as primate; the focus of research is on accurate description of the participants' experiences and not the researcher's agenda (Kvale, 1996; Wilson, 2002; Ashworth, 2003a).

Speer (2002) also positions feminist research within this emancipatory paradigm. She cites the value placed by feminist researchers on the importance of research being 'respondent-centred' (p.783), with the expectation that participants will set the research agenda according to their personal priorities, as evidence of its empowering nature. Speer argues that such principles are more respectful to women than researcher led studies and that they offer some protection to those (Speer states 'women') 'that are 'Other' to, and less privileged than ourselves' (p.784). However, Speer (2002) also warns that a feminist researcher is a political being who cannot become a 'neutral conduit' (p.785) through which the participants speak, as the feminist agenda must remain paramount.

While respecting the need for safeguarding and protecting the interests of the participants (Speer, 2002) I rejected the positioning of the political above a commitment to the recording of experience. Although I have some sympathy for the view that a critical theory approach might illuminate social and political inequities (Foster, 1996) suffered by disabled families, this research did not set out with an emancipatory agenda (Goodley & Moore, 2000). If there was a political agenda then this would emerge from the data, rather than from my own pre-formed notions of the social world. The bracketing process within phenomenology is intended to remove, as far as possible, any such assumptions (Wilson, 2002; Ashworth, 2003a,b). Foster et al. (2000) also argue that methodologies should not reflect the value judgments of the researcher. The role of the researcher, as identified by them, is to provide the facts for others to make judgments; the researcher should not assume a position of greater authority than participants (Foster et al., 2000).

The emphasis within Lifeworld of understanding the perspective of the participant thereby gives value to their being. A core belief in Rogerian, person centred psychotherapy is that human beings become 'increasingly trustworthy once they feel at a deep level that their subjective experience is both respected and progressively understood' (Thorne, 1992: 26). The hearing of the interviewer gives rise to the voice of the interviewee and enables him/her to relax enough in the trust of being valued to access their 'inner voice'. Although a researcher will have no way of knowing if participants actually believe the accounts they give, James and Warner (2005: 124) argue that the narrative researcher must rely on the expectation that 'people will tell stories that they are at least familiar with'.

Often, throughout my study, I had the impression of the parents having become 'disabled' themselves through the diagnostic process. In their interactions with some professionals and the educational system they often felt powerless and silenced, afraid to protest about what was happening to them and their children in case they suffered oppressive repercussions. Smith (2005) identifies that researchers working within a 'social constructionist philosophy' (p.102), a definition which would include phenomenology (Wilson, 2002), may be in a position to address imbalances in relation to power (Foucault, 1980). The tool of empowerment, within this study, has been the enabling of parents to make heard and understood their experiences.

Selecting Lifeworld as a methodology

I began using the methods of Lifeworld in order to investigate my research questions before knowing it as a methodology. I had been approached in my role as Senior Lecturer in Autism by a member of a family, the Jenkins, with the request that I visit the parents as they had been made highly stressed and anxious by the suggestion of autism having been raised by professionals with regard to their firstborn son. I originally began to research with the family as an action research case study (Cohen and Manion, 1994; Punch, 1998). My intention was to evaluate what they were doing with their child, negotiate together a new course of action, evaluate this and then move forward.

I felt assured that the parents would find this way of working useful. This assumption was based upon my past experience of working with families and the literature I had read around issues facing families of children with ASDs. I,

therefore, brought many pre-conceptions to the first two interviews with John and Marie Jenkins, such as the expectation that they would feel they were 'fighting' service providers *for* a diagnosis for their child and specialist support and that they would be demanding a diagnosis but would be meeting resistance from service providers who would want to delay the process (Jordan and Powell, 1995; Siegel, 1996; Howlin, 1998; Randall and Parker, 1998). However, when the responses from the parents did not match my expectations, I felt confused and unsure of how to proceed with the research. The format I had chosen did not seem to fit well with the way the family members were living their lives. All my suggestions of how to change things were, for the most part, met with what I perceived as polite refusal. I became uncertain of how to proceed now that the issues for this family seemed to be very different from those I had anticipated.

In response to this dilemma, I instinctively felt that, as far as I was able, I should suspend all expectations and immerse myself in the role of engaged, reflective listener. At the time I did not realise that to do this would be termed 'bracketing' within a methodology (Goulding, 1999; Wilson, 2002; Ashworth, 2003a,b; Ashworth and Cheung Chung, forthcoming, 2006). I simply proceeded from the position of recognising that I did not know nor understand how these parents were experiencing this event in their lives and that the most effective way of discovering this seemed to be to ask them. I decided to start from the point, as far as I was able, of no knowledge of how they might feel about the situation. Rather than asking specific questions to encourage the parents to reflect upon issues raised by the literature, which I sensed might dictate to them how they perhaps ought to be feeling, I focused on the issues that these parents raised

spontaneously. I anticipated that it would be these that would give the greatest insight into what most concerned them.

At the same time I began to consider qualitative methodologies which might facilitate the approach I was using. I wanted to employ an established methodology to help ensure that my work was 'valid' and make certain, as far as possible, that I had considered all the potential 'pitfalls'. I was also looking for guidance on how to organise and make sense of the data I was collating. It seemed important that the methodology should enable me to work in the way that 'felt' instinctively correct as the means of understanding the parents' experience, rather than trying to impose a suggested approach on the participants simply because it kept us within an established methodology.

Bengtsson (2004: 16) claims that:

It should also be obvious that we cannot adopt ready methodological recipes if we want to do justice to the complexity of reality. Instead, methodological creativity is demanded (Bengtsson 1999) that develops adequate methods from the particular field that is going to be investigated.

Goulding (1999) also emphasises the importance of a researcher finding a methodology which 'fits' with their own ontological and epistemological position.

The criteria that I set out to match within a methodology were that it:

- accepted the participants' perceptions as valid
- encouraged a spirit of discovery, accepting that we cannot always predict the path of research
- was flexible and not overly prescriptive

Two methodologies appeared to meet these criteria: Lifeworld and Grounded Theory.

Grounded theory

Grounded theory is defined by Punch (1998: 163) as a:

...research strategy whose purpose is to generate theory from the data... the objective of collecting and analysing the research data is to generate theory....the theory will be developed inductively from data.

A hypothesis, therefore emerges from the data (Coolican, 1994; Outhwaite, 1996; Selden, 2005), rather than the data being the means by which a theory is either proven or disproved in the positivist and anti positivist traditions (Cohen & Manion, 1980; Robson, 1993; Selden, 2005). This methodology emerged from the 1960s through the work of Glaser and Strauss and evolved into a specific approach for analysing data (Denzin and Lincoln, 1994). Punch (1998) describes a three-stage process involved in the formulation of theory using this method of data analysis. First the data is scrutinised for concepts, then these concepts are examined for any indication of relationships between them and thirdly the researcher looks to see if any key themes are emerging from the study which might form the theory of the work. To take the interview excerpt discussed earlier, between researcher and father, concepts are emerging of social relationships, power, language, self-doubt and vulnerability. Connections, between these concepts, might then be suggested such as, language reflecting power relationships, self-doubt resulting from problems with parenting a disabled child or feelings of vulnerability leading to lack of voice. From these

there might then emerge one or two key theories such as, 'the specialist language used by medical professionals can render parents of disabled children voiceless' or 'raising a disabled child can lead to feelings of self-doubt and loss of confidence'.

Once the theories are formulated these can be 'tested' through interviews with other participants (Silverman, 2000). In grounded theory, therefore, the interviews with participants should run consecutively rather than concurrently, with the data being analysed at the end of each interview and the theory modified and refined (Goulding, 1999; Bryman, 2001; Selden, 2005). The literature should then be reviewed after the data have been collected to see if the themes of the research can also be located there.

Lifeworld versus grounded theory

Initially I found Lifeworld, as a methodology, difficult to access and understand. Sited within the paradigm of phenomenology, Lifeworld is informed and governed by the traditions of philosophy (Goulding, 1999; Wilson, 2000; 2002), and I had no previous knowledge of this area. Terms, such as 'existentialism', at first seemed too esoteric to apply to a study that was to be grounded in the practical and emotional struggles of parents living in the everyday world. Therefore, in terms of language I engaged with grounded theory more readily. However, as I read further, aspects of grounded theory did not seem to fit well with the parameters I had set for my own investigation. The emphasis of grounded theory on the extensive testing and revision of newly formulated theory differs from Lifeworld, which is concerned less with proposing general

themes and more with giving voice to the lived experience of the individual (Goulding, 1999; Ashworth, 2003a). To this extent Lifeworld would fall within the postmodernist 'camp' of research methodologies as it is focused on describing the phenomenon without suggesting more universal themes of experience.

This does not mean, however, that researchers are not able to use exploration of the lifeworld to inform policy. For example, the work of Ashworth et al. (2003) was designed to inform university policy with regard to plagiarism. The experiences of the students interviewed, by Ashworth et al, were recognised as both unique but concomitantly suggestive of a range of potential experience, rather like Bassey's (1999) claim that individual case study can suggest possible common themes of experience, 'fuzzy generalisations' (p.12).

As my study focused on three families, using the method of grounded theory would suggest theories that could not then be tested within the scope of the study. Like many other researchers I might claim to be carrying out grounded theory but in reality would only be engaging with aspects of it (Goulding, 1999; Bryman, 2001). Certainly, parts of the methodology would be helpful. The process of 'unbreaking' the data resonated within me as the correct means of identifying the experience of the three families involved. This would identify concepts that could then be related and categorised within the suggested 'fractions' of the lifeworld. Rather than formulating universal theories from these, they would exist as detailed accounts of three examples of the relationship between autism and human experience. However, what they might be able to offer, on a more universal level, to others is an understanding of how complex and individual the experience of autism can be, with the suggestion that those supporting families of children with ASDs might need to respond with an equally complex and varied range of approaches.

In truth, there seemed many similarities between Lifeworld and grounded theory as methodologies (Goulding, 1999) and it is likely that this study is, in fact, a combination of the two approaches. While the findings are presented according to the principles of Lifeworld, as descriptive rather than interpretive (Goulding, 1999; Ashworth, 2003a), the contextual analysis within the discussion chapter is more in keeping with the tradition of grounded theory. I elected to work mainly within the tradition of Lifeworld in order to meet the challenge of working within the philosophical tradition, because of its validation of the participants' perceptions of the experience and because it enabled me to pre-select the participants, rather than waiting for these to 'emerge' through the data (Goulding, 1999). However, both Lifeworld and grounded theory concurred with my ontological position.

Ontological position

Mason (2002) argues that researchers need to identify their ontological position, even before deciding upon a topic to investigate. Understanding how one views the nature of the essence of the social world will fundamentally affect the way that investigations are conducted, including dictating the choice of methodology (Guba & Lincoln, 1998; Mason, 2002). Wilson (2002: 10) also claims that, 'To state one's methodological position is to describe one's view of the nature of reality' and that for the phenomenologist, 'the world...is one of intersubjectively constructed meanings' (p.10). Bryman (2001) identifies two ontological positions: objectivism (realism) and constructionism (constructivism). Objectivism asserts that the social world can be understood as existing independently from those that inhabit it; it is something definite and identifiable.

Constructivists would argue, however, that 'all knowledge is socially produced' (James and Warner, 2005: 120), that the social world is in a constant state of flux and only exists in the interpretation of those that inhabit it (Bryman, 2001). In keeping with the philosophical stance of phenomenology (Wilson, 2002) constructionists assume that what is real is a construction in the minds of individuals (Guba and Lincoln, 1994). Madan Sarup (1996) recognises that an individual's position can be mercurial:

we do not have a homogeneous identity but instead we have several contradictory selves. Moreover, I believe that two important features of the human subject are perpetual mobility and incompleteness' (p.xvi).

Identifying and acknowledging your position, as researcher, is traditionally seen as essential research practice (Guba & Lincoln, 1994). However, for the true phenomenologist researcher this ought to be unnecessary. Bracketing of previous experiences and assumptions means that the researcher sets aside any concept of reality or construction. Instead she/he accepts that the ideographic is the matter to be revealed within the research (Ashworth and Cheung Chung, forthcoming, 2006). However, through conducting this research, I have come to realise that I am a constructivist. I believe a definite, definable social world to be an illusion, that we all create our own 'reality' through our relationship with others and our experiences of the worlds we inhabit (Denzin & Lincoln, 1994; Wilson, 2002). What appears to be a clearly identifiable 'real life' can be challenged at any moment by external events and we then have to formulate a new world in response to these. Our worlds and the 'us' who inhabit them are ever changing, a fluid interaction masked as a solid entity.

I was constantly aware of my own changing thoughts and ideas throughout this study. The investigation seemed to offer, continuously, a myriad of potential new directions. I often felt a tension between maintaining my focus on what I thought I should be exploring and the fresh challenges that presented themselves. One, in particular, which took me largely by surprise, was managing my own emotional response to a focus on parenting. For a while I thought my study might move more towards transcendental phenomenology, as I became 'in danger of' utilising the experiences of the participants in order to better understand my own 'reality'.

Staying focused

Moustakas (1994) identifies transcendental phenomenology as the process that connects the external with the internal. Exploring the experiences of others and the way others perceive the world facilitates us in our reflections on our own experiences and perceptions (Moustakas, 1994). This leads us to a greater understanding of our own, hard to reach, deep feelings and thoughts on how we understand the world and our lived experience. Reflexivity can serve a positive role in research as it can give the account of the research greater transparency, making explicit the role of the researcher in constructing knowledge (Finlay, 2002; Holliday, 2002; Speer, 2002; Cresswell, 2003). However the process of developing greater personal insight should not be the primary goal of the researcher unless this is the main intent of the research from the outset (Johnston, 1995; Finlay, 2002). Rather this process should inform the researcher's interpretation of the evidence (Flick, 2002; Mason, 2002). It should facilitate the researcher in understanding their own relationship with what is

being investigated and with identifying and understanding the influences that may affect their interpretation of the evidence (Finlay, 2002; Cresswell, 2003).

Kvale (1996) describes interviewers as travellers, collating tales within unknown lands. The process of interviewing the parents in this study resulted, for me, in continual personal discovery. On each occasion I felt I either identified a different aspect of the parents' experience or came to understand it at a deeper level. Moustakas (1994) identifies the interview process as one of revealing the, 'partial views of a whole entity' (p.70), carefully uncovering layers of information. Different aspects of the experience were identified through the interviews as we were able to reflect on different 'fractions' of the experience. At other times I felt that researching the experience was like collating all the individual pieces of a jigsaw and then fitting them together to reveal the picture of the whole. However, it is one of those jigsaws where the pieces can be put together in different combinations to form different pictures, reflecting the fluidity of the participants' positions, creating an alternative whole but one that is no less valid than the first. How the picture would look would depend upon a participant's sense of the experience at the time of telling.

As my study has unfolded not only have I learned a great deal of what it meant for these parents to receive a diagnosis of autism for their child but I have also gained new insight into what it means to be a parent and part of a family unit. A child with an impairment who is disabled by society lives within a disabled family. The impact of the diagnosis becomes part of the lived experience of each member. The nature of the entity of the family unit is emphasised within the disabled family. The depth of commitment of parent to child is sharply identified by the willingness of the parent to come into conflict with authority to obtain the services they feel their child requires, take on the role of teacher as

well as parent, educate themselves about their child's impairment, change their own activities, goals and ambitions to accommodate the needs of their child and become interpreters and advocates for their child in a world that does not appear to understand.

I was very moved on numerous occasions as these parents described their experiences. The family unit of parents and children appeared to me as an intense and clearly definable body. Other highly influential members come within the term 'family', such as aunts, uncles and grandparents. These appeared to be one step removed, outside of this smaller unit of parents and children. Parents and children form a 'core unit', to which other parts might be attached, but it is this central structure that is the strongest and most unified part.

The parents I interviewed were closely united in their concern for their children and in the priority this had in their lives. They may not always have been in agreement with each other or at the same place at the same time with regard to their acceptance of the diagnosis and its implications but they always appeared joined in the battle to protect their core unit from the impact of these events. It was not difficult for me to maintain the boundaries of my role, as I perceived them, which was maintaining a degree of 'objectivity', as I often felt the onlooker, the observer recording the life of a separate and contained unit. I found myself, therefore, reflecting unexpectedly on my own position and what a lack of a son or daughter in my life might mean to me.

At one time I thought these questions around being a parent and what it meant to me, personally, would become a major part of this study; I wanted to stop and explore fully this issue that I found to be dominating my thoughts. This proved a

passing phase, however. I felt uncomfortable, as though I was using the sharing of these parents' experiences just to understand better my own feelings and motivations. I did not feel that it was for this that the parents had offered up their time and been willing to expose themselves to the emotional upset of reflecting on their experiences.

My interest remained focused, therefore, on wanting to understand the experiences of the parents and what impact this diagnosis of autism has had on their lives, rather than on my own position in relation to being a parent. I kept my reaction to this issue of parenting alive in mind, however, in order to try to evaluate any impact it might have on my interpretation of the data. I wanted to use these insights from exploring my own personal reaction to what I was witnessing to, 'form the basis of a more generalized understanding and interpretations' (Finlay, 2002: 214). The process was circular: upon listening to and observing what being a parent meant to the participants, I reflected on my personal position on what it might mean to be a parent and then incorporated insights from these reflections into questions for later interviews, to seek clarification on the position of the participants:

Nick: *What's coming for me through this research ... because I'm getting all sorts of things that ... you know, when you set off on something and you think you're going to expect ...I do. I get very moved by it because I think it's ... it's like ... you think, "Well, what a beautiful aspect of life really that one human being can be so committed and have so much feeling for another human being," and kind of what a positive that is really, you know. I suppose it's just struck me time and time again really.*

Rachel (to Bob): *But, you know, being a dad for you is the most prime role of your life, isn't it?*

Bob: *Yeah, absolutely. I love it. I don't know if it's ... you know, if it would have been any different in any kind of way (if Todd had not had autism) and I suppose he's valued even more ... you know, more helpless ... or he needs more help than other children.*

In this way, while I do not claim to have adopted the 'Schutzian' position of social researcher as 'disinterested observer' (Wilson, 2002: 3), I did maintain the focus of the research on the telling of the participants' stories (Goulding, 1999; Wilson, 2002; Ashworth, 2003a) rather than my own.

Analysing the data

Nineteen interviews (approximately one hour each) were conducted, tape-recorded and transcribed. This gave rise to over two hundred and fifty thousand words. Goulding (1999) describes the process of analysing data, within the phenomenological tradition, as a process of 'scrutinising the text for narrative structures or meaning "units" which describe the central aspects of the experience' (p.7). Therefore, I took the first interview with Marie and John Jenkins and identified what I considered to be the 'expressions of experience'. These were the concepts contained within the transcript. I then went through the remaining transcripts for the Jenkins and added any new concepts which arose until eventually there were seventy-four identified. I reduced this number of headings as some were sufficiently related that it was possible to place these within a broader category: e.g. relationship with brother, siblings surpassing in development and balancing needs of siblings could all come under the heading of, 'sibling relationships'. This led to twenty-nine categories. I then went through each expression of each interview and assigned to them a number,

corresponding to the category or categories to which they related. I had originally intended to restrict these to the six fractions of the lifeworld, as identified by Ashworth (2003a) but I felt, initially, constrained by these. I did not trust that all of the concepts identified could be represented within just six fractions.

However, I now accept that they do; all the aspects of the experience, identified by the parents, can be related to these fractions. Indeed as the interviews progressed with the Williams and Brown families, I found myself taking a fraction as a focus for the interview. We would, therefore, spend one interview focusing around issues of 'Project', exploring how the diagnosis had affected what the parents now did with their time and whether it had changed their priorities with regard to the activities in which they engaged. For another interview we would focus more on 'Temporality', looking at how the parents viewed the future and also how they related their current experiences to those of their past. In effect the twenty-nine categories became subheadings of the fractions.

Within this chapter I have, therefore, identified the methodological principles that have guided this study. I recorded how my initial research proposal was, as I now classify it, for an individual model interventionist action research agenda, aimed at identifying 'problems' within the family and, as 'expert', 'imposing' change. When this was met with resistance from the first family I explored other methodologies that would 'fit' better with my own developing ontological and epistemological positions and which would support rather than disempower the parents taking part. I argue that Lifeworld met these requirements as the philosophical principles that 'underpin' it embrace a constructionist perspective and empower participants through emphasising the validity of their experience.

Grounded theory also shares many of these principles, by making the phenomenon the source of the data but with some essential differences, such as the formulation of theory, using the literature as a form of data and selection of future participants emerging from the data. In effect, this study is the result of some merging of the two methodologies. While the findings have been presented in the form of Lifeworld as 'descriptive' rather than 'interpretative', or at least as far as possible (Mason, 2002), themes are elucidated from the data and the literature, which in effect also became part of the data. However, throughout, in keeping with phenomenological principles, I have attempted to 'bracket' my own experience and expectations, described the experiences of the participants before engaging with the literature, focused on conscious experience (Ashworth and Cheung Chung, forthcoming, 2006) and selected participants only on the criterion that they have lived the experience (Wilson, 2002).

Part two of this dissertation will now focus upon the presentation of the data and discussion around the implications of the findings for parents and professionals.

Introduction

Chapters four to eight present the accounts by the parents of their experience. Waltz (2005: 11) identifies that 'the issue of voice' in any narrative is crucial. She observes that professionals traditionally have minimised the parental story within the history of autism. Lifeworld values only the voice of the experiencer (Goulding, 1999; Ashworth, 2003). Within phenomenology, the aim of the researcher is to present a descriptive, rather than an analytical account (Kvale, 1996). The experiences will, therefore, be presented, here, in the Lifeworld form of enabling the participants to 'tell their own story in their own terms' (Wilson, 2002: 2), identifying the 'how' of the experience (Moustakas, 1994). Intuitive speculation as to the 'why', the reasons for what brought about the nature of these experiences (Moustakas, 1994) will be discussed within chapter nine, entitled, 'Summary, Implications and Outcomes'.

The presentation of the findings of this study, does, however, depart from a central tenet of Lifeworld by offering them in a collective form, rather than as individual accounts; this is more in the tradition of grounded theory than Lifeworld (Goulding, 1999; Ashworth, 2003a). However, in keeping with the principles of Lifeworld (Ashworth and Cheung Chung, forthcoming, 2006) the parents' experiences, recorded here, were presented, in this way, before reference was made to the accounts within the literature and are only claimed to represent the experiences of those parents who participated in the study. I selected a 'collective' method of presentation partly to reflect the common features of the experience that came across clearly to me in the different interviews but also to represent the complexity and fluidity of the participants' positions in relation to their experiences. James and Warner (2005) argue that

'different understandings will make sense for different people at different times in different situations' (p.122) or as Hammersley (2003: 754) terms it, 'There are always many different ways of interpreting any scene'. Foster et al. (2000) claim that participants are always committed to more than one value and that they prioritise these differently according to the particular circumstances. Individual differences are therefore evidenced in this study but as 'shades of the experience' rather than as clearly definable accounts. The participants experienced parenting as a complex activity, sometimes adopting multiple positions, in relation to the experience, at any one time. Presentation of the data as a kaleidoscope of experience is therefore intended to convey this shifting landscape of feeling.

The fractions of Lifeworld are not discrete categories but are interrelated and interdependent (Ashworth, 2003a) and so some expressions of experience appear within more than one section, reflecting both the complexity and multiform nature of experience. For this reason, rather than using the fractions of Lifeworld as the titles, under which the experiences are collated, I have elected here to use the headings that appear to capture, most effectively, the connection between these experiences as conceptualised by the participants. The fractions of Lifeworld are interwoven, rather than made explicit, within each section.

Within each chapter I identify what I have 'interpreted' to be, in the sense of this being my understanding of what was being experienced, the essence of particular experiences (Ashworth and Cheung Chung, forthcoming, 2006). These are then supported by brief excerpts of quotation, from the transcripts, to make transparent how these 'interpretations' have been arrived at.

The issue of how much to say about the background of the parents is problematic. These families are still engaging with the professionals referred to within the study and I wish to protect their right to anonymity (Cohen and Manion, 1980). It is very difficult within a small community to prevent participants from being identified but I have taken what steps I can to do so. I have changed all names, tried to remove any identifiable speech mannerisms and kept personal details to a minimum. To do so though, can threaten to take away the personality of those involved and risks dehumanising them, reducing people to a brief collection of facts. May it be noted here that all the families participating within this study consisted of vibrant, rich, loving personalities, which, I believe, is reflected strongly in their voiced experience within this data.

All parents were of a similar age, economic and professional background although there was some variety in cultural background. All the children with a diagnosis of autism were boys. Sam Jenkins was three years of age, attended pre-school and has a younger sibling, Billy. Ben Williams was four years old, attended a mainstream infant school and had an older sibling, Teresa. Todd Brown was six years old, an only child and had been given a diagnosis of autism, three and a half years previously.

Chapter Four focuses on the 'general' experience of parenting, identifying what becoming parents has meant to the participants, how they were experiencing their relationships with their children, the ways in which the diagnosis had affected parents' life-plans and daily activity, the impact of others outside of the parent-child unit and on whether parenting a disabled child was experienced differently to parenting a child who is not disabled.

Chapter Five is concerned with temporality and, in particular, on how the parents 'experienced' the future and the impact this had on the present.

Chapter Six describes the parents' perceptions of their roles in, and understanding of, the development of their children.

Chapter Seven then records how the diagnostic process impacted upon relationships both within and outside of the parent-child unit.

Chapter Eight centres on the parents' experiences of professionals and the diagnostic process itself.

Reading the data

The role of the researcher within Lifeworld is to present a descriptive account of the phenomenon as experienced by the participant (Kvale, 1996; Dahlberg et al., 2001; Ashworth, 2003a). A willingness by the researcher to remain open to the data, to suspend expectations and to listen only to what is expressed within it, is an essential requirement of the methodology (Dahlberg et al., 2001). The same expectation must be made of the reader, who is asked to evaluate whether the data has been presented in such a way that she/he feels able to access the essence of that experience, as described by the researcher (Kvale, 1996). The researcher presents what he/she understands to be the meaning of that experience for the participants. Only that which can be deduced from the data is presented; any previous experiences known to the researcher are only used later to suggest possible factors underlying the nature of the experience (Kvale, 1996; Dahlberg et al., 2001).

In keeping to these principles I have presented the data in the following chapters as statements of understood meaning. I have made every effort to record only what I understood to be the elements of experience as expressed by the participants. Each of these expressions of experience is supported with a brief excerpt from the transcription, to make clear to the reader how this fraction of the experience was expressed within the interview. This should enable the reader to evaluate the 'validity' of my interpretation (Kvale, 1996).

To those unfamiliar with reading descriptive data, accounts presented in this way can appear as a rush of units of experience. Therefore, to make these more accessible to the reader, I have grouped experiences under collective titles where I perceive these as being related. While attempting to maintain the 'flow' of the text, some repetition of experience is inevitable within a Lifeworld presentation. This serves to illustrate that one experience may have multiple impacts on the lifeworld (Ashworth, 2003a). Despair over the future, for example, is clearly an aspect of temporality that will be experienced physically as an emotion (embodiment), may affect relationships with others (sociality), alter perceptions of what is important in life (project) and lead to feelings of lessening personal control over the situation (selfhood). This one experience, therefore, may be recorded within each of the different fractions (Ashworth, 2003a). Further support with accessing the data is also provided by the inclusion of summary statements at the conclusion of the longer sections of the data presentation. These have the effect of creating pauses within the text, thereby giving the reader an opportunity to reflect both on the experiences expressed by the participants and on my interpretation of these.

Developing skills

Signs of developmental progress in their children aroused positive emotional responses within the parents:

'We're delighted...'; '...it's the most wonderful thing...'; '...he's still developing. That's still the joy...'

The nature of the development, although sometimes recognised as different to other children, was not considered to be less significant:

'...clearly he's not the same as everybody else, but he's still developing'

The parents learnt to adjust to their children's styles of development:

'...but we have learnt to ...take stock and realise that most things are phases'

and experienced their children's development of skills, at times, as something wondrous, almost mystical:

'Thing's like that it's amazing'; '...incredibly really...'; '...is something extraordinary'

The parents in this study, therefore, valued their children's acquisition of new skills. These produced feelings of delight, joy and wonder. Although these parents identified their children as sometimes following different developmental paths, they still considered these to be of equal value to the more expected pathways.

Developing independence

Being able to understand what their children desired was particularly valued by the parents:

'...it's the most wonderful thing to know what he wants for Christmas...'

Developing independence, in their children, was also highly regarded:

'But he's so independent...'; '...running his own bath, getting in and out, honestly he's really good'.

Parental input into the teaching of skills and progress made by the children were seen as linked:

'...so I spent ages and if you ask him now...'

Skills and abilities in their children, which surpassed those of the parents, were admired:

'...yes, so he heard it but I didn't'.

These parents perceived their children as developing the skills required to enable them to become independent beings. This was valued by the parents and encouraged through the teaching of specific skills.

Enjoying relationships

The degree of developmental progress made by their children affected the emotional well being of the parents:

'It was completely new language for him and I think that was the time we felt fine...'

The extent to which they were able to enjoy their children was perceived, by the parents, as related to their children's levels of emotional responsiveness:

'...there is a lot more to enjoy about him'; '...you don't get the same responsiveness or the same level of feedback and joy thinking about it...'

Even at the most difficult times enjoyment in the parent-child relationship could be found:

'He still did bring joy, he was very tiring....'

Some of the children's behaviour was perceived as humorous:

'Yeh, that was really good, yeh, it was funny...'; 'He's got a sense of humour and he brings joy by what he does'

When their children demonstrated ability in activities around interests shared by the parents, this was received positively:

'He likes his snooker...'; '...he was really good with his golf club'

and parent-child relationships were seen, generally, as a source of profound pleasure:

'...and you say, 'Oh you're lovely' and that is just something that...you know, that is amazing really'

Enjoying their children was viewed, by the parents, as something that they needed to focus on to avoid domination by the negative aspects of parenting a disabled child:

'We didn't want to detract by focusing on the negative...'

The main source of stress in the relationship between parent and child was not seen as resulting from the child's impairment but from the professionals involved:

'...but the biggest stress was...being told terrible things...and the worse thing was school.'

The parents, in this study, experienced, therefore, a lot of pleasure through their relationships with their children. At times they felt challenged by behaviours associated with autism, such as lack of sleep, but these experiences were always balanced by more positive interactions. Emotional connections were seen as important; the more parents could establish a connection with their children the more they perceived that they got out of the relationship. Parent-child relationships were not seen as a source of significant stress. Rather, stress came from the diagnostic process itself and coping with the spoiled identities of themselves and their children.

Two-way relationships

Value was placed on communication being a reciprocal process between parent and child:

'...it's a two-way feedback'; 'We feel everything's two way.'

This was actively promoted by the parents:

'We're trying to encourage some dialogue.'

The children's responses to requests were evaluated for evidence of understanding and responsiveness:

'We are able to tell him to do things a little bit now like we can tell him to put something in the bin...'

Lack of an accessible communication system between parent and child was thought of as problematic but could be overcome:

'I thought we might have a bit of a problem explaining that one but he just seems to look and see' (referring to a complex concept within a game which needed explaining).

Informal chats between the parents and their children were a source of pleasure:

'...having lovely little chats...'

and being able to use language to take part in family events, such as Christmas, was appreciated and prized:

'So knowing this Christmas it is what he actually wants and understands...that's nice...'

Being able to develop systems of communication between parent and child was important for these parents. These did not have to be conventional methods so long as they led to some sort of mutual understanding and connection. The ability of their children to communicate needs and desires was valued for itself but also because it was seen as evidence of 'normality', a negation of the diagnosis.

Parents as teachers

The parents taught new skills to their children. This was perceived as having an impact on their children's learning:

'So I spent ages (teaching a new skill) he'll (husband) tell you...'; '...so I write 2 and 3 then after that I think he learnt, now he knows from 1-20, even though he missed some numbers like 13, 18...'

Although what was taught might have been different because their children had 'impairments', the parents, in this study, saw it as the role of every parent to teach their children:

'...it's more focused on certain areas (rather than) teaching him to play football on Sunday afternoons'

Doubts were sometimes expressed about how to teach their children certain skills:

'I don't know how to teach him',

but creative ways were found around problems:

'I don't know how to teach him. I then play with the toys and (go) two cars add two cars...'

The parents saw themselves as more aware of what they were teaching their children than parents of non-disabled children:

'...It's a bit more intense...'

At times the children were able to teach the parents new skills; this was something that the parents admired:

'I mean he teaches me songs...'

The parents saw teaching as a natural aspect of the parenting role. They identified skills that they thought their children needed to develop and were creative in devising methods for teaching these. Although the parents saw this as the role of all parents they did feel it was more essential, and needed to be more structured, in the case of disabled children. The parents perceived themselves as learners too, able to be taught new things by their children; learning and teaching was experienced as a shared process.

Team work

The development of communication skills, in their children, was perceived as having a significant impact on both the general well being of their children and the quality of the relationship between parent and child:

'Because he can tell you...'; '...there's a lot more to enjoy...'

Moments were valued when parents and children were involved in joint projects, working together:

'...he looks after Billy (sibling), he helps me out...'

The relationship between parent and child was seen as something that could be valued on its own terms rather than comparing it with previous experiences of parenting or those of other parents:

'...but we didn't know what other people were getting...because we had not had another child'

Trying to get their children's attention sometimes felt like a competition with distracting environments:

'...Get him out of the house...out of the trap...away from the environment that sucks him away'.

Their children were perceived, by the parents, as having a positive effect on their peer group:

'...their lives are being positively enriched with having Todd around'

but the parents felt that only they could appreciate all the positive aspects of their children and that these would not always be recognised by others out of the home:

'They won't see him as the star that he is'.

The parents perceived their children as having a positive impact on them and also people outside of the home. Although they felt that no-one else could see the abilities and value of their children as much as they, as parents, could, they perceived other people as also gaining from coming into contact with their children. The parents valued their relationships with their children, focusing on what they got out of these relationships rather than on what might be missing. Engagement sometimes had to be worked at, drawing children away from 'overly focused' attention on objects, for example, but the parents successfully evolved strategies for negotiating such challenges.

The nature of parenting

Being a parent was considered an important role but it was unclear to these parents if this was even more so when children had impairments:

'...I don't know... if it would have been any different in any kind of way (if he did not have autism)...'

The children's problems became those of the parents:

'If one of us has got a problem then everybody's got a problem...'

The children's impairments were viewed as creating some barriers to closeness and creating problems such as lack of sleep for the family:

'Even when I was with him he was on his own.'; 'I don't know how to explain to him.'; 'If he's not sleeping, none of us are going to sleep'.

Work could also be a barrier to the parent-child relationship:

'I don't like being away and missing out either'

but it could be a relief, too, from the intensity of the relationship:

'I ... actually I'm thinking I I don't want to sit at home and just think about (the children). (My friends say) "go for a part-time job, so you won't think much about (son)," that type of thing'.

The act of children appearing to favour one parent for particular activities was sometimes experienced as problematic:

"(child says) No (want) mummy", and that is becoming a problem now...'

The participants in this study saw parenting as an important role. They perceived themselves as protectors of their children; if they felt their children were under attack, then the parents also engaged with the fight. The nature of the impairment of autism did seem like a barrier to intimacy at times and the parents sometimes felt uncertain as to how to engage with their children because of the effects of these impairments. However, these were accepted as natural challenges within the parent-child relationships and solutions to problems were negotiated within the family. The nature of the relationship between the parents and their children was, at times, highly intense. For some of the parents work was a welcome distraction from this, while for others it was perceived as an annoying interruption to family life.

The highs and lows of parenting

A spectrum of strong emotions was experienced, by these parents, towards the parenting experience. The children's behaviour could engender 'negative emotional feelings', such as stress in the parents:

'...normally we would all be stressed...'

or 'positive' feelings:

'He was brilliant'; '...it was just so relaxed and we did not have to worry about him and misbehaving...'; 'He's just gorgeous'.

Times when the parents were very concerned over their children's behaviour were described as *'hell'*. The emotional impact of the diagnosis was devastating:

'She (wife) was devastated...I was devastated inside'.

It was as though the diagnosis nullified the currently established relationship between parent and child:

'I felt someone had taken my son away...'

This was perceived, however, as being a temporary experience as the original relationship was later reasserted:

'...I'm just glad I've got him back...I'm perfectly happy...'; 'We are on top of Ben's problems'.

Any reduction in the amount of worry corresponded with an increasing level of happiness being felt by the parents:

'...we're just happy...we've not got any worries'.

Identifying signs of new skills in their children also enabled the parents to feel more relaxed:

'I think this was the time we felt fine'.

Within couples, parents' reactions to the diagnosis varied:

'Ann is always positive...but I'm looking at a critical point of view all the time'.

When professionals contradicted the diagnosis of autism, or if they no longer referred to the term, parents experienced happiness:

'...she's (wife) extremely happy'.

These incidences were described as *'good news'* and *'really exciting'* and put parents, *'on top of the world'.*

Improvements in their children's skill levels were also seen as corresponding with an increase in positive emotional feelings within the parents:

'...it's certainly become a lot easier...he seems to have made a big leap'.

Improvement in communication skills was seen as a real help here:

'Nowadays we can talk to him...so it's getting easier'.

As their children's communication skills improved, so the parents experienced more enjoyment in their relationship with them:

'...there is a lot more to enjoy about him...'

Parenting a disabled child led, in one family, to a reduction in finances:

'...this is actually now having a direct effect on our finances...'

and the parents then felt forced into portraying their child in the most negative light in order to claim their 'entitlement' to financial support. This was perceived as a betrayal, like: *'...selling him down the river'.*

Although being a parent was seen to have many positive aspects to it there was also a downside, arising from loss of freedom, personal time and spontaneity:

'In losing your freedom... (You can't) decide, "Oh, I'm going to spend the afternoon in the pub now because it's a sunny afternoon."; 'Relaxing, watching a film, reading a book. It's all bye bye.'; 'Everything that was once pleasurable is no longer available'.

Being responsible for another person was sometimes *'hard work'*:

'You have to be sensible and responsible at times, as well, which is a bit of hard work'.

Parenting children with impairments was experienced as very isolating and the enormity of the experience was difficult, at times, for the parents to put into words:

'I'm short of a metaphor'.

Emotionally taking on your child's own suffering was described as, *'the biggest emotional thing'.*

Although such feelings were generally managed, this could be harder to do at night:

'Sometimes I do (revisit the experience of the diagnosis) at night...'

The parenting experience gave rise to a range of extreme emotions from great joy to despair. Their children's behaviour and the adjustment to new responsibilities, on becoming parents, sometimes led to feelings of stress or restriction. However, it was largely engagement with professionals that engendered feelings such as hopelessness and despair. Pleasure in their relationships with their children was perceived, by the parents, as enabling them to overcome the more negative emotions although they could be revisited by these when their defences were low. Having a disabled child was seen as having practical, as well as emotional, impacts upon the family. A reduction in finances was one example, and the process of seeking monetary support from the state was experienced as bringing on feelings of shame through parents

being compelled to emphasise the negative impacts of impairment, rather than their children's skills and abilities.

The impact of others

Evidence that their children were acquiring skills independently from specific teaching from the parents promoted feelings of relief:

'...that was the time we felt fine...'

The diagnostic process itself was experienced as having a negative emotional effect on the parents:

'...we probably feel tomorrow is going to bring us down again...'

The impact on the parents of assessments of their children's skills and abilities by professionals involved with the diagnosis was identified as '*demoralising*'. The period of diagnosis was described as '*hard times*'. Trying to work out what was best for their children sometimes caused worry and concern:

'I don't know if I've done the right thing (bringing in the professionals)'

Experiences that happened for their children, outside of the home, had an emotional impact on the parents:

'...if they (school) did that (announce at assembly that a child had autism) I would be horrified'

When the children were with people outside the home this could also be a source of anxiety as the parents were concerned about what their children might do and how this might be perceived by others:

'(I think) My God, what is he doing?'

General information about autism was sometimes upsetting if it was seen as fitting with their children's patterns of development, thereby supporting the diagnosis:

'...in case it upset me' (avoiding watching a video about people with autism)

but reassuring if it did not:

'...it didn't because...I couldn't see anything of Sam in them...'

Modifying their parenting style because the parents felt that this was what professionals expected of them, led, at times, to feelings of guilt:

'I think I've probably pushed him too hard now...'

Emotional highs could be tenuous; positive feelings were sometimes deflated by viewpoints from family, friends and professionals that conflicted with those of the parents. Professional involvement was generally discerned of as having a negative effect on parenting skills, encouraging parents to go against their natural instincts, which was later experienced as regret:

'...part of me feels that we didn't have to have that (a stricter regime)...'

The parents suffered uncertainty and doubt over their decisions to involve professionals, unsure whether this was in the children's best interests or not:

'...am I benefiting him or creating a problem for him?'

The parents felt obligated to give priority to their children's needs over their own:

'...is that me being selfish and thinking of my benefit rather than Sam's?'

and believed in the concept of a correct course of action:

'...the right thing'.

The experience of being told by a professional that your child has autism was described as *'heartbreaking'*. It was as though the child had been physically taken from the parents by the professionals:

'I felt she (professional) had stolen him'.

As the term autism ceased to be referred to, this felt, to the parents, as though their children had finally been returned to them. Conflict with professionals generated feelings of guilt in the parents but these were balanced by feelings of not caring what others thought of them:

'I always felt a bit guilty about it at times...'; '...but we don't really care...'

After the negative feelings associated with the diagnosis and the battle against this, receiving assessments, from professionals, which appeared to be more in keeping with the parents' evaluation of the situation gave rise to odd and unsettling emotions:

'To be honest I thought it was quite a strange feeling, didn't you?'

It was also unsettling when the parents' perceptions of their children's skill levels were challenged by observing their children engaging, more successfully than anticipated, with others:

'It was a bit of a shock that...'

Involvement with professionals felt like a battle and was physically wearing:

'...it's the constant battle with the system...That does wear you down'.

It was the combination of problems arising from their children's impairment and the battle with the system that drained parents of energy:

'When you're already suffering from your sleep deprivation...you haven't got a lot of energy left'.

Relationships with professionals were viewed as more stressful than the act of parenting:

'...that's more of a stress in managing than parenting...'

The children's schools were also viewed as sources of stress for the parents. These stresses prevented the parents, at times, from enjoying their children:

'I feel that I should be focusing on (all the positive aspects of my child) more (but I'm not)... because I'm just being hauled into all this'.

Feelings such as stress and despair were seen, by the parents, as originating from engagement with professionals rather than from having a disabled child. The diagnostic process was described by all the parents as having devastating emotional effects. Tensions between parents and professionals and needing to battle on behalf of their children were experienced as denying parents the ability to enjoy their children. These also caused the parents to feel guilt at challenging others, rather than just complying with those who were 'helping'. Professionals suggested interventionist strategies that went against parents' ideals and values. As these carried the weight of 'expertise', parents engaged with these

believing they would help their children to become 'more normal'; they perceived it as necessary to put the interests of their children before their own. The parents also became unsure of what to feel about their children without professional direction; how professionals perceived children as doing dictated the feelings of the parents.

Managing relationships

Coping strategies for managing the emotional impact of the diagnostic process were various. For Marie, a night out once a week with friends was a precious time that needed to be protected, while John was taking medication to help with depression. For Rachel and Bob, opening a bottle of wine in the evening made everything seem much better:

'(Alcohol) it's a comfort thing'.

Avoiding involvement with all professionals, to prevent further negative experiences, was considered but rejected because to put the interests of the parent above the child was perceived as '*selfish*'.

However, the parents did avoid contact with those professionals whose words or actions upset them:

'...since then (when professional had made negative remarks about the child's skills)...I was not going to ask them (how my child has been)'.

The love between parent and child was seen as a source of emotional strength:

'I also draw my support from your love for Todd as well as my own'.

To the parents, the children's happiness and well-being mattered more than academic achievement:

'...if your child's unhappy it's much more worrying than if they can be in the top class...'

Seeing things from the child's perspective

The parents interpreted their children's behaviour within the shared context; they perceived themselves as able to understand what might be motivating their children to act in a particular way:

'...he wasn't being naughty...he just didn't like...'; 'giggling...it's another way of releasing anxiety'; 'He had a kind of frustration'.

They saw their children's perspectives as distinct from their own and formed by different influences:

'I probably wouldn't have said it that way myself but I'm not three and still learning languages...'; 'The last thing you want when you're autistic.'; 'Then the only thing he can do is to throw his arms about because he can't argue with you'.

Behaviour was interpreted by the parents as though their children were actually expressing their thoughts:

'We know how he works, don't we'; 'Sam's sorry for everything, aren't you? Just in case some of it was your fault'; '(By doing that he is saying) Come on. I don't want...'; 'He was beaming with joy (as though), "saying, they're the same"'

Some behaviour surprised parents, such as when skills, previously unseen by the parents, were demonstrated by their children:

'And he just did it and I thought, well how is he going to know what the thing is which looks like it's floating in the sky...It was a bit of a shock...' (on a trip to the optician, Sam was asked a question that his parents did not think he could respond to).

The interpretation of their children's levels of skills as always an indicator of autism was perceived as unfair by the parents:

'...I don't really think that's fair, it's like everything that Sam does you have to think , is it because he's not good at something or is it because he's got some autism characteristics...'

Professionals were viewed as attributing learning characteristics to children just because these were expected from 'autistic children':

'...we've never seen the evidence...that Todd's shown to support this'.

The parents perceived that a case should have been established before 'different' strategies were adopted:

'Prove that this will be useful to him before you put it in'.

They acted as interpreters for their children in negotiations with others:

'...we were both about to butt in and say he won't understand that...'

and decisions were made by the parents after considering the viewpoint of their children:

'...wouldn't be fair to send Todd to school without any support'.

Although what their children were feeling and thinking was not always clear to parents:

'...he is feeling. I don't know...'; 'I don't know what he was thinking'

they felt that they could 'read' their children's emotional responses:

'We don't know what he is thinking, but he enjoyed it'.

The children's peers were also noted as being able to provide insight into the behaviour of the children with autism:

'... (a peer remarked) it's them girls...he wants to get away from them'.

The parents adapted their responses based on their knowledge of their child:

'If I say, "Can you just pick up that thing", he does pick it up'.

People treating their children as 'impaired' were seen by parents as affecting the level of their children's self esteem:

'...that is going to impact on his own sense of self-development'.

The children were perceived by parents as aware of their role within a group:

'...he's...very conscious of it...'

although not necessarily when the children were younger:

'...he doesn't have that awareness'.

The parents perceived professionals as unwilling to listen to their explanations for their children's behaviour. They felt that they were dismissed on these

occasions for *'being in denial'* or as an *'emotional mother'*. This *'hampering'* of their advocacy powers was experienced as disempowering. The parents felt silenced from speaking up for their children by a fear of upsetting carefully negotiated compromises with staff in schools:

'...it's really difficult for me to say something about it...'

Parent-school communication aids, such as home-school diaries, were seen as encouraging close attention to their children's development and promoting reflection on their children's abilities. There was uncertainty though over whether these encouraged reflection to a greater degree than would have happened anyway:

'...you do feel the need to think through what he's done anyway'

Parents took on emotional experiences for their children:

'You've got all that grieving to do for him'

and the parents saw a need to protect themselves from certain painful memories:

'...put that away in the ...don't go there box'

Their children were perceived as experiencing difficulties that other children do not:

'...the difficulties that he's going through, that other children aren't...'

but the parents also identified and valued their children's positive characteristics that supported them through these challenges:

'He's got so much courage...'

The diagnostic assessment process was viewed as leaving both children and parents 'exhausted':

'...it's very exhausting for Ben as well as both of us'.

Development of communication skills was seen as highly significant to the children's level of happiness and well-being:

'...1 1/2 years (ago) he wanted to say something but we didn't understand...'

The children were perceived as having limits as to how much they could absorb:

'...only for one hour. After that he is bored'

but professionals did not appear always to realise that.

The parents saw themselves, therefore, as having a level of understanding about their child that was not available to professionals. However, they also felt that this knowledge was not recognised by professionals. The parents acted as advocates for their children, evaluating how their children might be experiencing situations and communicating these to other parties. The parents perceived themselves as appreciating their children as individuals whereas professionals were thought to view them only as embodiments of a syndrome, applying generic interventions recommended within professional guidance literature, rather than taking account of the way children engaged with the world. Compelled to speak up for their children, the parents felt pushed into conflict with professionals but they feared negative repercussions for them and their children as a result of questioning professional decisions.

Hopes and aspirations

Hopes for their children

The parents were aware of 'normal' developmental pathways and it was important to them that their children followed these patterns of learning:

'...we just want to make sure he's learning what he's supposed to be learning'

They treated their children as 'normal':

'...he's being treated as a normal child by ourselves'

and were hopeful that any current problems with development might be resolved in the future. They did not see the current 'problems' as barriers to significant success in the future:

'She (family member's child) had special needs...but she's top in her class now'.

Intervening with development at an early age was seen as enabling their children to avoid future difficulties:

'...prevent anything that might show itself later...'

Professional involvement was perceived as facilitating this intervention and, therefore, as something which would benefit the children:

'...because he'll get help'

Being accepted as an individual rather than the 'the child with autism' was important because it did not rule out the possibility of their children just being 'normal' later:

'I don't want him referred to as the child with autism...'

Labels were also seen as limiting, in respect of how other people might perceive their children and as hurdles to realising potential. It was other people's attitudes and prejudices, rather than impairment, which were seen as barriers to achievement:

'Any label will limit what you do and how people look at you'.

Living an enjoyable life was something that parents hoped would happen for their children and the development of certain personality attributes were thought to be necessary in order to enable this, a sense of humour, for example:

'I think a sense of humour must be an awful thing to grow up without'.

The parents also hoped that their children would grow up to be sensible, responsible and helpful and these attributes were already recognised and valued in their children:

'Couldn't wish for a better...'; 'He's a very sweet, polite little boy...'; '...he's very responsible, he looks after (his brother), he helps me out'.

Happiness was wished for children more than academic achievement:

'If your child is unhappy it's much more worrying...'

but educational achievement was still seen as a measure of success:

'She has done scholastic performance wise fantastic'.

The parents' goals, for their children, did not always appear to be shared by professionals. Learning to write was seen as a desirable skill by Marie while the nursery staff valued play more highly for children of his age:

'I just wanted him to get writing...'

Hoping their children would have high status careers was not seen as important, by these parents, and trying to achieve their own unfulfilled dreams, through their children, was regarded as *'selfish'*:

'I don't believe you should dream through your children'; 'We didn't want him to be a doctor or anything like this...'

The parents did have hopes for their children, though, and they anticipated that their children would also have their own ambitions for themselves:

'...what we want to achieve, what he wants to achieve'

Success was perceived as achievable in many ways and being autistic was not seen as necessarily a barrier to success:

'I know there are autistic people who are great achievers'

The opportunity to be employed was held to be important and the parents hoped that their children would find work:

'...do some kind of profession'

The children's impairments were perceived as making them vulnerable to other people:

'He can't speak...are they trying to take advantage'

Therefore, the parents saw themselves as needing, while still living, to protect their children from potentially negative future outcomes e.g. from becoming one of *'those guys in the subway'*. Concern over their children's future was felt to dictate all aspects of the family's future planning:

'...affects every single thing I ever think about...'

However parents worked to achieve a balance between being optimistic about their children's future and being realistic, although this felt sometimes like, *'quite a difficult balance'* to realise.

Growing up autistic was seen as having some potentially positive characteristics:

'...quite difficult problems are solved by autistic people'

and the parents perceived their children as being able to make them proud in the future:

'He will make... us really proud of him'.

However, becoming 'normal' was seen as the ultimate goal:

'He's just like any other normal person now'; '...is going to make a wonderful recovery'; 'I hope he will...become a normal child'.

Hopes for themselves

Parents also had hopes and aspirations for themselves. Past dreams changed as the parents found themselves more limited by the demands placed on them as parents of disabled children:

'My personal life plan was put a little bit on the back burners...'

Rachel felt prevented from going back to work through a perceived need to stay at home for longer with Todd. This reduced the family finances and plans for the present and the future changed accordingly:

'...this is actually now having a direct effect on our finances'.

Work was not viewed as being just about earning money though; the parents also saw it as a potential refuge from their identity as parents of disabled children. It was seen as a potential means of escaping from a child dominating a parent's thoughts throughout the day:

'I think about Ben during the day... I (will) go to the job centre...I just want to get off my...thinking about Ben'.

There was tension here as this desire to work conflicted with the felt obligation, as a parent of a disabled child, to engage more with school:

'(father to mother)...ask the special needs teacher...probably go and spend some time with her'.

Becoming parents of disabled children was seen as a life changing experience but one that did not necessarily change personal characteristics; the parents believed that they retained the essence of who they were:

'We've probably become a bit more quirky than we were, but we were a bit odd...'

It could, however, enrich certain aspects of the parents' personalities:

'It's made me so much more compassionate to things like that (homeless)...'

and dealing with service providers was also seen as necessitating the changing of personal characteristics:

'...now all that side of yourself you have to curb...'

Having an impairment was not, in itself, seen as a barrier to success for their children. Greater hurdles were perceived within the attitudes of others, arising in response to learning that children had labels. Early intervention was welcomed as a means of normalisation, a way of removing or minimising impairment; this remained the ultimate goal for most of the parents. Children were recognised as having admirable qualities that would enable them to make valid contributions as adults. Certain attributes, such as being happy and having a sense of humour, were valued above academic success, although the latter was an indicator of 'normality'. The future was something to be feared and, although the parents hoped their children would have positive futures, there were concerns over their vulnerability. The parents felt that they would always need to be the 'lookouts' for their children.

Having a disabled child did impact upon parents' personal plans and ambitions. This was seen, to some extent, as a normal adjustment on becoming parents. However, as parents of disabled children, these parents felt under pressure to be available to engage with professionals, making work problematic. Becoming parents of children with impairments was not seen as something that changed the essence of who the parents were but it did modify their outlooks on life, how they presented themselves to others and led to them engaging with different life projects.

Away from home

Outside agencies were perceived as compelling the parents to address, constantly, the issue of their children's impairments when the parents would, at times, have preferred to focus on other aspects of their lives:

'I just like to have other things to think about ...besides autism and disability...'

Other life activities were seen as important but these had to compete with giving attention to their children:

'We have been doing the garden (so not doing academic work with their child).'

Negotiating with agencies took up time and energy and limited opportunities for experiences outside of autism. The parents saw this as attacking their self-esteem but they tried to maintain a positive sense of themselves by focusing on their own achievements:

'I still try to sort of muster up what is a success in my life and cling to that really'.

As parents of disabled children, the parents felt that they experienced prejudice from others:

'It's the first time really in my life that I've ever had to suffer from prejudice and discrimination...'

They felt less worthy because they perceived others as regarding them as unable to perform the same functions as other parents. Rachel, for example, saw mothers as being 'measured' by how many children they could produce; the more children they had, the more successful they were deemed to be as women. Having a child with an impairment had led to Rachel's abandonment of

plans to have more children. She felt that, in the eyes of others, this decision thereby reduced her worth as a woman:

'I would like to have 3 children, but it's out of the question'.

Changing her previous plans to have more children was explained as partly out of fear of having another child with autism, seen as something to avoid, but also because a child with autism would be a less effective sibling than those children without autism:

'He's (child with autism) hardly going to be a great big brother, is he?'

Alterations to proposed life paths did bring compensations, however. Having only one child was seen, by Rachel and Bob, as enabling them to take a lot of holidays as a family, for example:

'We live quite a nice life really...because we've just got the one'.

Researching autism was both friend and foe; a source of understanding but also a warning of potential problems:

*'It (reading)'s really interesting for me now'; 'I don't want to read any book';
'...those (negative) kind of things will be there in the literature'.*

The negative images in literature were sometimes counterbalanced by parents' knowledge of their own children:

'I've never seen him having any problem with change of routine'.

Literature was not the only agent for affecting how the parents viewed their children. Others, outside the home, were also experienced as influencing

thinking. This was sometimes a 'comfort' but, on other occasions, became an unwelcome barrier to acceptance of reality:

'I won't encourage that' (David talking about a friend who was giving his wife 'false hope' that her son did not have any impairments).

In terms of supporting the development of their children the environment of a mainstream school was perceived as providing the best 'models' for their children and was the parents' desired option:

'He is going to benefit more by interacting with 30 kids'

However, the parents felt they would consider their children attending specialist environments if these were perceived as the best environments for them:

'I would send him there'.

Buying autistic specific educational resources and vitamins, reputed to reverse some effects of autism, was thought of as a positive action:

'Fish oils...stimulate something in the brain'.

These 'interventions' were discovered through reading, the media and discussions with other parents.

The perspectives and attitudes of the parents were affected by others: family, friends, strangers and professionals. Having a disabled child led to feelings of being stigmatised, devalued and positioned as 'other'. The parents did employ strategies to counter the impact of these 'negative' influences. For example, sources of 'negative' images were avoided, such as accounts of autism within the literature. If these were encountered then the parents balanced these

images by emphasising their children's positive features and abilities. When they became aware of their children following unusual developmental paths, the parents' life plans and priorities did change as they felt compelled to expend time and energy on dealing with professionals and to manage the practicalities of having children with impairments.

Different with siblings

Parenting a child with an impairment was experienced as being quite different from parenting children without. The parents felt they had to do a lot more for their child with an impairment:

'She (sibling without autism) learned everything herself...I think I have to teach him (child without autism).'

The parents had different expectations for siblings, adapting ambitions for their children to take account of the impairment:

'I don't want her (sibling) to forget (mother tongue)...but I won't talk to him (child with autism) in (mother tongue) at all.'

Past dreams and future plans

Having a disabled child was seen as limiting options for the families' futures about where they might live and work. The logistics of moving appeared to the parents to be more complex than for those families with children without impairments:

'It's not going to be simple to start over again...'

It was hoped that this might be more of a possibility when the children became older but having a disabled child was seen as only one of many factors which also inhibited such life changes:

'...as you grow old it's kind of getting more and more difficult because of all the ties...relationships and work'.

When David's employment necessitated a move of home this was seen as possible with a disabled child but it needed to be planned carefully to avoid any disruption in Ben's schooling. One factor for consideration was the identification of what resources, in other locations, might be available for a child with an impairment. However, changing schools was something that was considered problematic for non-disabled children too:

'The (current) teacher knows him (disabled child) very well...'; 'She's (non-disabled child) fed up moving and changing the school'.

Having a disabled child was not believed to prevent the fulfilment of parents' dreams:

'My personal dream life is more or less what I'm doing now...'

Plans and interests did change, however and new experiences, such as exploring alternative medicine and religions, were engaged with as a means of coping with the stress brought about through parenting a disabled child:

'So I've been to the herbalist...'; 'Bob's had a flirt with Buddhism'.

Previous ideas and assumptions were re-evaluated through having a disabled child. Happiness, for example, was now seen as the result of luck and as

something that could be taken away at any time; nothing was taken for granted any longer:

'....don't expect it to last...'

Having a disabled child was an event that changed how the parents viewed the world. Some aspects of parents' life plans could be progressed but revisions were also required to take account of these altered perspectives. The parents saw this, in part, as an inevitable element of becoming parents but having a child with an impairment seemed to make this more complex; the parents felt that they could be less flexible about where and how they lived, for example. Parenting a disabled child also led, however, to engaging with positive new experiences that may not have been considered otherwise.

Changing ways

The early years of parenting were experienced as being *'well out of control'*. Worry became a major feature in the life of the parents. Although this was recognised as a universal experience for all parents, it was felt to be more *'intense'* for parents of disabled children, turning non-worrying personalities into worriers:

'I was not a natural worrier before'.

The parents saw themselves as having all the usual worry of being parents but that this was greatly exacerbated because their children were disabled. Being able to dream for your children was seen as a compensation for all the negative aspects of parenting but this was not thought to be a benefit that was available to parents of disabled children:

'I've got the condition of motherhood exacerbated by times 10'.

Being parents of a child with an impairment led some of the parents to alter their own patterns of behaviour:

'We don't share the same bed anymore'.

These adjustments were made because:

'it's easier that way'.

Finding time for themselves and their own interests was made more difficult, in some cases, by a reduction in opportunities to leave their children with others. It was seen as positive for their children to experience new things out of the home:

'It's better than him staying at home...'

but after school activities were difficult to access. When these could be found the parents felt obliged to stay, rather than leaving their children as other parents would:

'I think you ought to stay'.

Having disabled children required the parents to alter their life activities to attend medical and educational appointments with their children. These were experienced as stressful and were perceived as being set up more for the ease of professionals than parents:

'...that was just very stressful'.

Opportunities for social interaction were reduced if the children found these hard to tolerate; if the children were not relaxed then these were *'not quite good fun'* for the parents either.

Parenting was seen as a partnership with each partner bringing different skills, interests and attributes to the relationship:

'I'm the one to (research autism)...but Bob does loads and loads of stuff with Todd...'

Becoming a parent of a child with autism was described, by Rachel, as *'...my nub of sadness'* and something which had *'ruined'* life. Even so, it was still not perceived as fundamentally altering the essence of the family:

'I don't think it (our family life) would be that much different at all (if our child were not disabled).'

There was a tension between wanting to provide for the child's future and parents' own personality characteristics:

'... just too lazy'

The parents' ambitions for themselves changed as a result of having children with impairments. This led to positive new directions being taken, which might not have been otherwise:

'I might turn to be...a kind of researcher'

Positive relationships were formed, in some instances, with new people connected with the field of autism:

'You wouldn't have met those people if all this hadn't have happened'; 'I'm quite happy to sit together with an autistic child's parents and talk to them and listen to them'.

Becoming parents initiated changes in the participants' personality and activities. Concerns over their children's development created anxiety within the parents that was then exacerbated by the diagnostic process. The parents adopted complex positions in relation to having a child with autism. For example, Rachel, although she celebrated the joy that Todd had brought to her and her husband's lives, still referred to him as her 'nub of sadness...'. The parents changed their own patterns of behaviour to accommodate their children. Although the children's behaviour presented challenges, the parents formulated strategies for meeting these. They saw themselves as working in partnership with a common focus. The diagnostic process led to changes in spatiality, in terms of the places that the parents visited. Medical appointments needed to be attended, which led to a significant increase in stress and discomfort for all the family. Having an impairment was perceived as restricting children's opportunities for independent experiences outside of the home. The parents felt that they did not have the same opportunities to leave their children in the care of others as did the parents of children without impairments.

To summarise, this chapter focused on how the participants experienced the act of parenting. It has established that although parenting a disabled child was perceived by these parents to share many of the characteristics attributed to the 'general' practice of parenting, the act of parenting was thought to be a more intense experience for parents of disabled children. Activities, engaged with prior to becoming parents, changed to accommodate taking on the

responsibilities associated with raising children and also to take account of the needs of the children themselves. Life plans were revised accordingly and new opportunities embraced. Parenting gave rise to complex relationships; children were both a source of intense joy and worry. Although some behaviour, associated with autism, did present the parents with challenges, the most significant sources of stress were not in fact associated with the practice of parenting. Rather they arose from engagement with professionals, the diagnostic process and being stigmatised by others.

The next chapter will focus on temporality and in particular the impact the diagnostic process had on the participants' perceptions of the potential future for their families.

Predicting development

The parents felt unable to predict what their children with autism might be like when they became older:

'...that's the one thing that confuses me.. I don't know what to expect Sam to be like at that age.'; '...with autism I know in some levels they won't develop any more, isn't it?'

The literature was seen as identifying a number of developmental difficulties associated with autism and the parents were unable to select which of these were likely to apply to their children:

'We're just worried that we've read many of these children have learning difficulties and there might be learning difficulties we're not aware of yet.'; '...they said he got this thing (autism) and we don't know when it is going to come, when he is going to change his behaviour, I don't know ...'

Predicting future development sometimes relied upon looking back to the past:

'As I was telling you, probably he's a late bloomer... there's a huge, strong family string of late bloomers, you know, in our family. They're all engineers...'

A diagnosis of impairment suddenly made the future seem more 'unknown'. The developmental pattern of children with autism was something that the parents felt that they could not predict. They looked to the literature for guidance but found this made the future seem a confusing and frightening prospect.

Emotional responses to the future

When the parents focused on their children's strengths, rather than the label of autism, this was felt to promote a more positive outlook:

'We all had a positive outlook that one day he is going to get better; that is driving us in spite of that word autism being mentioned...he will be more kind of normal you know. That is his behaviour from the very beginning'.

When they perceived the diagnosis of autism as no longer applicable to their children the future seemed free from anxiety:

'...we've not got any worries about it, have we?'; 'I feel I've got him back so no worries about his future; I'm perfectly happy'

but good times were now seen as something that could not be trusted:

'...It can't stay like that of course. It's just too good at the moment'.

The future seemed to be a very bleak prospect for their children:

'That's how far away I think and I do ... you know, in the dark moments I see these guys in the subway, you know, scrounging change and I think, "God, that could be Todd."...I think of every sad case in terms of, that could be Todd...'

Having a child with autism was perceived as something that completely changed perspectives on the future:

'... it does change your whole outlook of the future... I used to be able to be very positive and look to the future with positive promise. You can't do that anymore and ... that's enormous, you know'.

The future was seen as something that could be viewed positively or negatively, depending on how a parent chose to view it. Being realistic appeared, to the parents, to mean embracing a negative perspective. Trying to counter this with optimism was seen as a difficult juggling act:

'...you have to try and look on the bright side and be optimistic and...but at the same time be realistic and that's quite a difficult balance'.

Looking into the future was seen as unhealthy and best avoided. The parents saw themselves as being able to redirect their thinking away from predicting the future:

'...it's no good for anybody really in terms of the old mental health...nobody really knows really what's going to happen in the future. It's not healthy to project too far in the future too much...'

For some of the parents the future was something that could not be changed so it might as well be approached with optimism:

'I'm not ... I'm not a great worrier...The future's going to be whatever it's going to be and we just have to deal it at the time how we can ...I always look at the positive side of it and ...'; '...whatever will come will come and you can't plan for this, so there's no point in changing it...'

Not worrying about the future was, however, perceived as something others might criticise parents for doing:

'Maybe people say I'm shutting that off in a way by doing things, but yeah, that's kind of what I am about...'

but, in spite of this, living in the present was seen as more of a priority:

'...there's so many things to deal with in the first place'.

Thinking about the future was something the parents felt they could try to limit:

'I'm not thinking about the future but ... I think... he's going to pick up within one or two years ...'.

The parents hoped that one day their children might become 'normal':

'We've a very positive outlook about Ben and almost I would say 100%, if not totally 100% that Ben will make a complete, normal kind of recovery ...'.

Comments by professionals about a child's current skill level could either make the parents anxious about the future:

'When I heard today what she was talking to me about. I said, "I don't know what is going to happen to Ben"'

or optimistic:

'His class teacher said ... she said, "I'm not promising this, but I think Ben is going to be normal within one year..."'

The future, for these parents, was embodied in the form of emotional responses of fear and anxiety. The parents developed strategies for managing their anxiety, such as focusing on the present and on their children's strengths for example. To what extent parents could do this, however, was, they felt, dependent on their own personalities. The act of others recognising their children as, or showing the potential to become, 'normal' was seen by the

parents as the event most likely to make the future seem more positive. The life of the parent of a disabled child was perceived to be a bleak prospect, where the 'child' remained dependent throughout life.

Having a child who showed developmental differences also caused the parents to go back into the past as well as considering the future. 'Normality' was again the driver here, as the parents searched for signs in the past that might explain the difference as a family trait, rather than as 'deviant development'.

The future affecting projects

Thinking about the future and planning for what might happen to their children had a significant affect on living in the present:

'...I think it affects every single thing I ever think about...I'm constantly thinking about leaving stuff behind for Todd...'

There appeared, to these parents, to be more of a need to plan for the future because their children were disabled. Planning for after the parents' deaths was seen as morbid but necessary:

'It is morbid, isn't it, but ... we can't assume that he's going to have the same level of independence that it's fair for most parents to assume.'

The parents saw their children with autism as growing up to be dependent adults. They felt obligated to continue to provide for them into adulthood, even creating potential employment opportunities:

'He's going to be a dependent ...Yeah, sheltered employment... (father's company) could be a sheltered employment place for people with Asperger's Syndrome.'

Thinking about the future dominated daily life:

'I think about everything. Every day I think about it in some way'

but thinking did not always lead to action; other personality characteristics could interfere with planning for the future:

'We're not driven by that...Although I am obsessed with the whole autism thing it doesn't drive us, just too lazy'.

The parents saw themselves as denied the opportunity to dream through their children, to fantasise about what career paths their children might take. This was perceived as a loss, as being able to dream through your children was seen as compensation for all the negative attributes of parenting:

'...other people can dream through their children, can't they and that's a mental boost...We haven't got that luxury ...'; 'Yeah, that's...one of the compensations for all the dross you put up with in parenthood...'

There was, however, some confusion over the concept of dreaming through your children. Although this was viewed as natural, it was condemned as 'selfish' and something that should not be done anyway:

'...it's a very selfish thing to do...'; 'You know, if you want to compete, do it yourself and don't do it through your children, but I would say that, wouldn't I?'

The parents did not have specific expectations, for their children, for the future:

'...no expectation as far as grand plans. We didn't want him to be a doctor or anything like this'

but they hoped their children would be able to achieve whatever ambitions they might have for themselves:

'...I've got a gut feeling, you know, he's going to make a tremendous improvement and... he's going to achieve what he wants to achieve when he's growing older'.

A career was not viewed as the only means through which their children could become successful but employment was seen as an available option:

'...(he could be) successful in other ways. He's got aptitude on computers and things ...'; '...when he becomes big (he might still be) interested in the computer...'

The parents saw their children as 'gifts' but anticipated that their pleasure in their children would not continue as they became older. The parents expected their children, at some point, to become burdens on them:

'...because they're not yours, are they? They're sort of gifts for you to enjoy for a certain period of time and you do your best and let them move on. But with Todd... he's just going to be around for a lot, lot longer with us...'

The parents predicted that they would need to care for their children well into adulthood:

'I still foresee ... I still have a premonition of the granny flat really, you know...'; 'He's going to be living with us well into his ... well into his 20s ... I kind of think that's where we're going to be'.

They saw this as something parents of disabled children would always have to do:

'We kind of know that he's going to be the odd kid living with his mum and dad until, you know, he's 30 or whatever ... or 40...that's gone on for ages, hasn't it?'

What would happen to their child after their death was seen as problematic:

'I think (we will look after him) right to our death. ...Todd's not a problem until we die'

Early intervention was seen as a means of preventing problems from arising later:

'...we just want to make sure he's learning what he's supposed to be learning...at the minute we just want to prevent anything that might show itself later on, from being a problem'

Professional support was felt to be necessary to achieve this but remaining one-step-ahead of professionals was considered to be vital:

'I constantly have to be one step ahead ... and trying to pre-empt what's going to happen next...'

The future generally appeared as uncertain and waiting for it required patience:

'Because her daughter has got the same problem, so she says, "No, it's not a very fast process. It's a very slow process. You have to be very patient'

For these parents the perception was that at some point in the future they would cease to enjoy the parenting experience. It was felt that eventually disabled children would become burdens on their parents. Disabled adults were associated, largely, with dependency in spite of the parents being able to see that their children had skills and abilities that ought to enable them to become independent. Preparing for dependence was something that was considered, by some of the parents, early on. It then dictated the parents' own projects as they focused on preparing for their children's futures rather than their own present interests.

To summarise, this chapter has shown that for these parents the future for disabled children and their parents was perceived as something fearful. Even though the parents currently enjoyed their relationships with their children they all saw this being replaced, in the future, by a burden of care. In spite of their children clearly having the skills and abilities to enable independence, being dependent was largely seen as the only possible outcome of disability. The parents felt it was up to them, therefore, to make provision for their children into adulthood. Although the future did appear bleak, parents found ways of managing this stress by focusing on the pleasures of the current parenting experience and concentrating on the present, rather than dwelling on the future.

The next chapter will identify how the parents had become experts on their children and describe how they perceived the responses of professionals to this knowledge and understanding.

Noticing everything

The parents observed and evaluated every aspect of their children's development from interaction with others to self-help and independence skills such as toileting:

'We're kind of assessing his stages of improvement quite closely'.

Observation and reflection on the significance of behaviour began as soon as the parents became aware of possible developmental difference, even before a formal diagnosis:

'...all by himself, sitting there, lining up these bottles'.

Those behaviours that indicated difference were regarded as particularly significant:

'I would definitely put a Steven Spielberg 'errrrrr' (sounds like dramatic 'Jaws' type music) on it'.

Autism may not have been considered, by the parents, but some rationale for the behaviour was made:

'We put it down purely to speech and language'.

Once autism had been suggested by professionals, the parents challenged the diagnosis by putting forward alternative explanations for why the children might act in ways associated with the syndrome:

'I think it's partly shyness to be honest'; 'We know more about my background'.

The parents evaluated behaviour in the context of the situations experienced by the children, rather than through the decontextualised testing that professionals appeared to favour:

'He'd been watching Dora the Explorer, she did it with her eyes, he was copying the cartoon'.

The parents considered themselves as responsible for some of their children's different development:

'Sometimes I felt in the past that we might have been guilty of slipping into things...'; '...and you think that's probably my fault that he's copying that...'

Being aware of their children's skills and challenges was seen, by the parents, as important and it was not enough to be just aware; parents expected to be doing something about these. Accepting their children as developmentally different did not seem, to these parents, to be an option. They felt obligated to try to change their children in spite of enjoying them as they were:

'It's very easy to be quite comfortable with Todd and be happy with his behaviour'.

Once given a diagnosis the parents experienced being on the alert for signs of autism as a source of worry:

'There are some things you said like a lot of children with Asperger's have a very robotic or stilted sounding. I was a bit worried about that...'

Concern over development created a sense of urgency for the parents to work on skill development:

'I really want to work on him, getting him drawing more, getting him to write his name, and I know he's only three for writing his name but I am just trying to develop it'.

Working with their children, because they had impairments, was something the parents considered that they would do naturally, without any pressure from outside agencies:

'we'd be doing it anyway'.

This was felt to be necessary for a child with an impairment but not for a child without:

'So when somebody is... bringing up, you know, kind of normally, you know, you don't tend to kind of focus on what they do...'

Upon noting signs of developmental difference, the parents became even keener observers of their children. They felt more of a need to do this than other parents because their children had impairments. This sense of urgency was reinforced by the parents' sense of what professionals expected from them.

Parents as partners

Interaction with agencies was seen as increasing the level of parental scrutiny on their children:

'You are scrutinising constantly'; 'You have to go through so many extra things (with a child with impairments)...'

School staff were also perceived as observing the children more closely:

'The class teachers used to say his mouse skills are quite extraordinary'.

Writing the home-school diary was felt to encourage closer observation and reflection:

'I write a daily report'.

The parents questioned their own interpretation of behaviour and looked for support from others to help interpret it:

'I don't think he sounds stilted, do you?'.

Professionals were not perceived as always having the same agenda as parents:

'She (nursery staff) says, "well, you know, if he wants to do it, he'll do it but, you know, we but we do learning through play so we don't push it"'

but school was viewed as a source of learning:

'Those kind of things he learns only from school'; 'We haven't taught him and so he has got it from school'; '...after he is going to school he is picking up some ideas'.

Professional input into their children's development was monitored closely by the parents and evaluated:

'They don't enforce anything...he is very happy at nursery, whereas at pre-school he has to draw with his... more often and do more things and therefore they push it a little bit more and he does it there so...'

Identification of potential problem areas, by professionals, was seen, by the parents, as responsible for changes in their own behaviour towards their children:

'...we forced it, being told he wouldn't get things like that...'

The parents saw professionals as a source of expertise that could help them to interpret and understand aspects of their children's behaviour. At the same time they did not feel that the professionals always shared the same agenda in terms of expectations or projects for their children. In spite of this, the parents felt that they tended to alter their own behaviour in order to meet the 'felt' expectations of professionals.

Evidencing normality

The parents monitored their children's behaviour closely and aspects of behaviour that might contradict a diagnosis of autism were noted:

'...he is really sharp in some of his computer skills...'; 'I don't think there is a lack of eye contact'.

Behaviour that might suggest autism was explained away, by the parents, as normal for the child's age or arising from the particular circumstances of the situation e.g. learning a new skill or a personality characteristic:

'We were writing it off as an aspect of his personality or a family trait'; '...we know more about my background'.

Characteristics of autism, described by professionals, in terms such as a tendency to 'overfocus' on an activity, were reframed, by the parents, using more positive language:

'I think he has an ability to focus'.

Differences in language and communication skills were perceived as the most difficult to 'explain away':

'We put it down purely to the speech and language again...'; '...if it weren't for his speech, it was his speech that made me actually do something pro-active about it...'

Interactions between their children and people outside of the home were important to the parents as they saw these as more objective; the allowances they might make naturally as parents were not available to strangers. These meetings were carefully observed and evaluated:

'...the optician took over...'; 'He's been invited to all the parties'

Parental attitudes towards behaviour that could be indicative of autism were ambiguous; sometimes it was accepted as a possibility but at other times it was explained away:

'I could see when he was younger that he had signs that could be but I think you could point to any child and say, 'my child doesn't want to join in doing that'; 'All kids have been through a stage...'

The parents found their children's behaviour confusing; some aspects appeared to suggest autism:

'He never listens...'

while others did not:

'I don't think there is a lack of eye contact...'

At times the focus on their children's development could be relaxed as parents became caught up with 'normal' daily life:

(In response to being asked if she was still so focused on teaching Ben, Ann replied, *No. No. (Not) now because we have been doing the garden'*.

The parents perceived themselves as constantly being alert to the indicators of autism within their children's behaviour. After the diagnosis behaviour was now always considered within this context and analysed for signs of the syndrome. The parents resisted, however, seeing everything in these terms. At times they interpreted what their children did as evidence of their skills and abilities or family traits rather than as indicators of 'deviant' development. The parents felt confused about their children's development, unsure as to what could be attributed to autism and what might just be typical behaviour of a child.

Highlighting skills and abilities

New skills and abilities that the children achieved were observed, noted and valued, by the parents, across all areas of development: social, language, behaviour, academic, play and independence:

'...very flexible and he is very attentive...'; 'He went bellyboarding'; '...he is really good in numbers, match shaping, sorting...'; '...emotionally, he is amazing'.

They encouraged their children to demonstrate new skills to others:

'Show Nick your...'; 'What colour are...?'

The parents perceived their children as having a sense of pride over these new achievements:

'...he does want to show his skills, definitely'.

The acquisition of new skills was viewed positively:

'That's nice, isn't it?'; 'There's a lot more to enjoy...'; 'Having a lovely game...'; 'Having lovely little chats'; ' ...which is extraordinary...'; '...he is amazing sometimes...'; 'I mean a huge difference ...very pleasing ...'.

The development of skills was also perceived as leading to a reduction in behavioural 'problems':

'...a lot of the problems which we've always thought were caused by frustration have gone'; 'If he wants something it is sort of no problem now'.

The mastering of new skills often required a lot of input from the parents before their children achieved them:

'We're trying to encourage...'; 'We forced it....'; 'So I spent ages...'

The development of new skills, by their children, was celebrated by the parents and this brought about positive emotions within them. The parents saw

themselves as putting a lot of effort into the teaching of these skills but felt that their children also learnt from other sources outside of the home.

Does my child behave like other children?

The parents viewed their children as individuals:

'It maybe a bit different then but at the moment it's all we know, how Sam is'

The issue of comparing the development of their children with other children was seen as a confusing one. Although comparisons were made:

'He looks just the same as they all do'

these were also sometimes denied:

'I don't know about any other 3 year olds'

Comparisons were seen as enabling the identification of skills to work on. This was perceived as important to facilitate their children with 'keeping up' with their peers:

'Now he goes to the toilet like the other children so that's not a problem now'

The possibility of their children appearing 'different' in later years was seen as a particular cause for concern:

'My only thing I keep imagining is at 10 years old how he's going to stick out from the crowd'

Children with a diagnosis of autism were perceived, by the parents, as unfairly treated: they were denied credit for strengths in their development. Rather than being celebrated these became signposts towards 'deviant development':

'If they (children without autism) did that we would think of it as a strength but because Sam does it, some people think of it as is that a sign of autism'.

The parents compared their children with others of a similar age in order to evaluate the level of developmental difference. At the same time they also resisted this tendency, wanting to accept their children for who they were, celebrating their talents and contributions as individuals. Comparisons were seen as necessary, however, in order to highlight skills that needed to be worked on. Supporting children's development in the early stages was perceived, by the parents, as a means of preventing differences in development from emerging later.

Is my child behaving like a child with autism?

The parents became alert to the behavioural indicators of autism:

'I mean she never said the child, you know, has autism but I thought the few things that I'd picked up while he was there...'

Recognition was made that behaviour that their children demonstrated when younger had similarities to the behaviour of other children with autism but this was perceived as belonging in the past and not relevant to the present:

'...not now, maybe when he was younger'.

A distinction was made between acting like a child with autism and actually having autism. It was believed that a child may act like a child with autism, when younger, but, when older, he might stop acting in this way:

'If a child has autism he is not going to grow out of it, whereas he has grown out of all the things that were possible signs.'

Comparisons were made between what others (professionals and writers) identify about the problems that children with autism might encounter and what the parents saw in their own children:

'...like they say children with autism can't read people, can't tell that you're angry, can't tell that you're upset. He loves his expressions, he loves doing his angry face.'

Observing, hearing of, or reading about, behaviour in older children with autism caused concern and uncertainty, in the parents, as to whether any of these behaviours might apply to their own children:

'And he (boy on the television who had autism) was very much that style of speaking (robotic) and all of that and I worried if he (son) might have that...'

Although there was confusion over how useful comparisons were:

'...they are saying each child is different. We can't compare...'

the parents constantly made them:

'...I'm always trying to gauge where Todd is in terms of being...'; 'I just want to know if other children also are behaving ...like Ben.'

The parents could see essential differences between their own children and other children with autism:

'I can see a difference between Sam at 3 and Philip at 7'.

Contact with parent support groups was seen as giving access to other children with autism to facilitate comparison:

'...I just wanted to get a feel of...the other kids'

and this could reduce anxiety if their children seemed quite different:

'(about own child)...that kind of improvement I can't imagine in...a child with autism...'

Comments from others that argued against autism as a diagnosis were received positively:

'She (mother's sister) says, "Oh look at Sam..." She can't see, you know, the same problems that these other children have got'.

The parents experienced it as uplifting when autism was not referred to, when professionals were speaking about their children, when their children were just grouped with all 'children':

"Well that's 4 year olds for you, isn't it?" And that was so lovely for me to hear that, when she said that...'

Other children with autism and their parents impacted on the lifeworlds of the participants through family and social contact, work, school, literature and television. The parents, in this study, observed other children with autism and

compared their behaviour with that of their own children. They interpreted this behaviour in different ways. Differences in behaviour could be used to argue against the validity of the diagnosis, for example. Alternatively the parents felt that their children, even if they did prove to have autism, might not necessarily develop in the same way as other children with the syndrome. However, similarities in behaviour, in older children, were sometimes taken as a 'warning' of what behaviours the parents might see, in their children, in the future. Knowledge about the nature of autism was acquired through the literature, the media and talking to other people. In particular the parents became aware of the defining behavioural characteristics of autism and potential 'outcomes'.

Learning about autism

'Ability' was seen as something contrary to autism:

'...because he was so capable and able we just couldn't accept...'

The parents 'self diagnosed' their children using resources such as the Internet:

'...I went to the website...'

Reading about autism was viewed both as a support:

'I have read...quite difficult problems are solved by autistic people...'

and a source of anxiety:

'...I don't want to hear all of these things...'; '...autistic children...sometimes can regress'

Reading was a source of information about the developmental characteristics of autism:

'I mean which going to the books I can't appreciate the autistic child can make that kind of improvement'.

Knowledge about autism affected the way parents interpreted their children's behaviour:

'...we think because he has got this thing, that is why he is doing...this'.

Comparisons between the accounts of autism and their own children were felt to be confusing:

'...some of the descriptions doesn't fit with Ben, some of them fit with Ben...'

When the diagnosis of autism seemed less likely to be correct, the parents perceived the need to read about autism as less important:

'...whenever I get the time because I'm busy with (work)...'

Comparisons were made less:

'I used to but nowadays no...'

Being unable to see the behaviours of children with autism in their own children gave rise to feelings of happiness:

'...I couldn't attribute (the behaviours of the child with autism) to Ben and I was happy...'

The parents were confused by the information available on autism. They found it difficult to predict which aspects of behaviour described in the literature, or observed in other children with autism, might apply to their own children. In spite of this lack of clarity the parents were still influenced by suggestions within the literature and changed their behaviour towards their children in response to these.

Parents as experts on their children

The parents felt that they could attribute meaning and motivation to their children's behaviour. They acted as interpreters for their children:

'...he thinks you'll respond if he says...'

Professionals did not appear, to the parents, to do this. They were identified as interpreting the children's behaviour in a different, and often invalid, way to the parents. This was experienced, by the parents, as *'demoralising'*.

The parents recognised what their children had difficulty with:

'He's got problems with his language...'

and also predicted behavioural outcomes:

'He'll get over it in a minute.'

However, they could not always interpret their children's behaviour and accepted this as:

'...just one of those things that we just don't know with him.'

The parents recognised their children's limitations and identified the strategies that the children used to overcome these:

'...then the only thing he can do is....'

The parents also empathised with how their children's difficulties might impact on the children themselves and would sometimes result in behaviour that others might term as naughty:

'...he wasn't being a naughty boy, he....'

They perceived their children as sometimes behaving in one way while feeling another:

'...he manages to really hold himself together really well...'; '...it seems that he's laughing at you'; '...and he's not, he's scared'.

The parents observed their children's behaviour closely in order to be able to interpret their needs:

'(observing Sam's movements)...do you want pooh, pooh?'

They perceived themselves as understanding their children better than other people:

'Well we know Sam better than anybody else...'

but were still influenced by the interpretation of their behaviour by professionals:

'I think it's affected how we've dealt with things'.

They experienced this effect as a pressure to 'push' their children to work on skills that the parents might not have focused on otherwise:

'Because we were pushing things so hard on the premise that he'd got autism...'

This had caused them to act in ways that did not always feel natural to their parenting style:

'I've been very tough on him'.

Some of the parents perceived their original beliefs in the 'normality' of their children as having later been accepted by professionals. This then led to a lessening of professional control. This, in its own way, was also experienced, however, by the parents, as unsettling:

'Now you kind of think well that's really what we thought all along, that now because of what you've told us, we're thinking, we thought at first are you backing off too much'.

Within the couples, the parents identified each other as having different experiences of and knowledge about their children:

'Well, you know better than me probably'.

They identified their knowledge as coming from an emotional basis, a sort of a bond with their children that created a sense of certainty:

'...I felt it and always knew it'.

This enabled them to feel confident with predicting future development:

'We always said when his language was there he would be fine'.

The parents experienced uncertainty when evaluating the effect of their input into their children's learning:

'I don't know if he knows it because I've done that...'

When their children behaved unexpectedly with strangers and demonstrated unforeseen skills, beyond parents' expectations, this was described as a positive and proud experience:

'And he just did it'

Professionals were seen as being *'rigid'* in their interpretation of behaviour, applying text book theory rather than listening to the parents or the children:

'...it's a very rigid way of going about things without taking account...'

The parents saw themselves as sources of expert knowledge on their children that could be used to support professionals:

'We had to really work hard with the nursery...'

However, this information was not thought of as valued by all professionals:

'...you're parents, you don't know anything'

The parents observed behaviour in their children that challenged generally accepted theories on autism:

'...contrary to the stereotype where you're not supposed to...'; '...been a bit of a struggle for me with buying into this...'

but to question authority in this way sometimes felt like *'being bad'*.

The parents believed they could frequently interpret successfully what their children were feeling, often, but not always:

'...it gave him deep joy...'; 'It's a difficult one that (sometimes working out what he feels).'

Professionals were perceived as making judgments based only on a 'snapshot' of the children's abilities. They were not viewed as understanding the contexts in which the children were operating:

'...that isn't evident in a test situation'; '...we know more about my background, his background'.

Really knowing the child was felt to be critically important:

'...get to know Todd and how he works'.

The parents did not feel 'expert' all of the time:

'I don't understand, nobody understands...'

What to teach and how this would be experienced by their children was confusing:

'We don't know what to teach him, how to teach him'.

Educators were not perceived as needing to know a lot about autism in order to be effective; particular personal qualities were valued as more important:

'...that's just plain, obvious, caring logic...there in lots of people'.

The children's behaviour was observed and analysed by the parents in every context:

'And like today he's been to MacDonald's'.

Although at times confused by their children's behaviour, the parents perceived themselves as knowing their children better than anyone else. They felt they understood their children's frames of reference and could interpret, from this, their children's motivations and intentions. The parents did not feel this knowledge was either recognised or utilised by professionals. The parents valued more others wanting to know the child than professionals having expertise on autism. The parents saw their own expertise as arising out of their emotional bonds with their children but felt that professionals saw this as a weakness rather than a strength.

This chapter has recorded how the parents identified that they had become experts on their children through constant observation and analysis of their behaviour. Although they frequently used this knowledge to act as interpreters for their children, the parents felt that this expertise was not generally acknowledged by professionals. The label of autism created confusion within the parents and lessened their confidence in their expertise in relation to their children. Intellectually they began to see the literature and professional opinion as more expert but emotionally they still challenged ideas found within these. Suggestions made by professionals or found within the literature that did not harmonise with the parents' understanding of their children were, sooner or later, rejected in favour of the parents' interpretation of their children's behaviour.

The next chapter will now describe how the diagnosis of autism impacted upon relationships within the families and also with friends, colleagues and wider society.

Brotherly love

Positive interactions, such as playing together or demonstrating affection, between siblings were valued and encouraged by the parents:

'Ah, look at him, that's nice.'

Sharing was taught:

'Billy is having a go...'

and siblings were reminded to think about each other:

'What was Billy (at the fancy dress party)?'

Negative interactions, such as physical aggression, were punished and parents intervened to rectify the situation and to teach strategies for reparation:

'Sam, naughty, say sorry to Billy.'

Harmony between siblings was valued but the parents also identified the pressures that their children sometimes put on each other:

'Billy is always wanting what he's got.'

Siblings, even if they were the younger child, were identified as a resource for encouraging the development of the child with autism:

'I feel especially with Billy as well he's gonna get constant interaction...'; 'He will watch, he will watch'; '...she has put her own effort quite a lot...talking to him...trying to teach him...'; '...I feel so happy because when they're playing with each other he will learn something from Teresa.'

Skills learned at home through sibling play, such as sharing, were seen as being transferred to school:

'...he'll also do the same things to his friends also at the school...'

but siblings were also seen as potentially hindering the development of new skills by doing too much for their brothers:

'...so she was doing many things for him so that was our concern'.

Even though their younger child without autism might surpass, in some areas of development, the skills of the older child, the parents maintained the expectation of the role of the older child:

'(to younger child)...by your big brother at times, don't you...'; 'He's very kind to Billy and he knows what to do to look after him'.

Having a younger child without autism caused John and Marie to re-evaluate the early development of their child with autism:

'...now we have seen the difference in Billy's development than Sam's ...we...notice what Billy does that Sam, even at his age still does not do'.

For Rachel and Bob, who only had the one child, the diagnosis was perceived as a reason for not having further children:

'I kind of thought that I would like to have three children, but it's out of the question'.

The thought of being pregnant again generated feelings of fear:

'...I woke up nearly crying. I had palpitations and everything'.

They predicted that having a child with autism as an older brother would be a negative experience for a sibling:

'Todd's hardly going to be a great big brother, is he?'

and having more children would make life:

'...even more ruined than it is'.

There were, however, benefits perceived from being part of a small family:

'...we can go out and do more things...'

Where there were siblings the child with autism was felt to have a 'sibling relationship'. This was evidenced by the parents through stories of the children defending each other when in trouble:

"Mummy, say sorry to Teresa"...' (child with autism rebuking his mother on behalf of his sister).

Upset caused to the parents by the diagnostic process, was viewed as also affecting siblings:

'She was worried in the sense because we were worried...'

Teresa perceived her brother as, *'...acting like a normal child'*. She observed and analysed her sibling's behaviour:

'...he learnt it really fast from the other children'.

Siblings were a source of comfort to parents:

'She didn't show it much...she was comforting me rather than I...'

In the two families where there were more than one child, relationships between the siblings were highly valued by the parents. The children were seen as gaining from each other. In the family, however, where the child with autism was the only child, having a sibling with autism was seen as a potentially negative experience.

Is this inherited?

The question of whether autism was an inherited condition was experienced, by the parents, as a confusing one. The parents recognised behavioural characteristics in their children that were also part of themselves and felt uncertainty over whether or not they too had autism. Their own behaviour was re-evaluated and analysed against the criteria of autism and so was the behaviour of other family members:

'...so that either makes me and me Dad slightly autistic...'

Parents revisited their own past experiences and those of other family members, re-evaluating them for evidence of behaviour that could be characteristic of autism or for examples of inherited behaviour that might mimic behaviours associated with autism:

'...there was a delay with my speech'; '...my sister's daughter...she had kind of similar problems'; 'One of my uncles started talking late...'; 'Probably I might have had a bit of autistic features when I was a child'.

The parents questioned whether their children's behavioural characteristics were just aspects of their personality or identifiers of autism. Their children were

perceived as unique individuals with their own aspects of personality that the parents could not always recognise in themselves:

'While, when I was a child I'd have been a bit wary of playing with other kids he was straight in...'

The parents did not see themselves as having 'caused' the autism:

'...we don't think anything what we have done, or we haven't done, has caused this you know...'

but they did feel as though their own behaviour might have sometimes affected development:

'...we did things for him... (we thought) he can't speak so let's help him by doing it for him'.

Once their child was diagnosed as having autism the parents re-evaluated their own development and also that of other family members. The parents began to look for indicators that might explain where the autism had come from. This led, at times, to a greater understanding of why some family members behaved as they did and in turn was seen, by the parents, as also providing insight into their own children. While the parents felt that they would genetically have greatly influenced their children they also considered them to be individuals with their own unique personality and genetic 'makeup'.

Working together

The role of parenting was experienced as a joint project: *'We both were'*. Both partners experienced the positives and negative aspects of parenting. Individual identities were sometimes merged through shared thinking:

'We were on the verge of; 'I think we've always felt...'; 'I can't say we have actually consciously thought that...'

At the same time parents maintained their individuality within the relationship. They identified each other as having different knowledge:

'I think, that's fair to say, isn't it?'

and as having different roles within the relationship:

'I'm a kind of buffer role'.

Different approaches were regarded as complimenting each other:

'I kind of say, "Well maybe," and then she calms down a bit...'

Within couples, the parents perceived themselves as experts on each other:

'John will know I am ...stubborn aren't I?'

They sought confirmation of their own perceptions of their children from each other:

'...there is a lot more to enjoy about him, isn't there?'

and reinforced each other with behavioural strategies:

(Marie): *'No pushing'*. (John): *'That's naughty'* .

Also with the recall of information:

(Marie): *'All they'll do now is introduce him to the...'*; (John): *'Child Psychologists'*.

The parents also provided reassurance for each other:

'but look at what he's tackled up to now'.

They saw themselves as united against professionals:

(Rachel): *'...we really had to, really, really, stand our ground'*; (Bob): *'Stand our ground, yeh.'*

They were 'partnerships' and perceived themselves as the only ones who really understood the experience of parenting their children:

'There's only one person (husband) I want to talk to about Todd'.

Love for their children was felt to be a crucial element of the parents' partnerships:

'...there's only me and Bob that love him like we do...'

The family relationship was experienced as very 'powerful'. The parents drew support from each other:

'...his love for Todd is actually a constant pillar as well for me'.

Even being at work, for one father, felt like missing out:

'I don't like being away and missing out...'

The children's behaviour was identified as having some negative impacts on the parents' relationships:

'I just go in his (child's) bed. It's easier that way'.

Within the partnership parents sometimes had different approaches to the diagnosis of autism:

'She's extremely positive...the only ...doubting Thomas is only me'; 'He wanted to know more about autism. I don't want to...'

This was then experienced as *'difficult'*:

'It was a difficult period'.

Sharing a child with autism was seen as a unique experience which only the parents could understand. Although they saw themselves as bringing different abilities to the experience the parents perceived the act of parenting, largely, as a unifying event that positioned them and their children against the rest of the world. The diagnostic process also led, however, to division between the parents as they came to an understanding of it in different ways.

Living a normal family life

Family life was experienced by the parents as 'normal' and they perceived the behaviour of their children's behaviour as generally 'normal':

'...just kids really isn't it?'

The parents accepted and valued their children for who they were:

'We don't really, it's just Sam really, to be honest...'

Within the family the children were given responsibilities:

'Sam, can you watch Billy for me?'

Family relationships were valued and encouraged. Looking after members of the family was a prized activity:

'He's very responsible, he looks after Billy...'

The parents experienced adaptations to meet the particular needs of their children as just normal, typical of family life:

'...cos' that's just normal practice, isn't it, as a family?'; '...they're just normal strategies'

The parents viewed themselves as simply carrying out expected parental activity:

'I don't think we've done anything that other parents wouldn't have thought of...'

Professional opinion that supported the notion of 'normality' was welcomed:

'(Professional said) "That's 4 year olds isn't it" (rather than, 'that is typical of a child with autism') And that was so lovely for me to hear that...'

Adapting family life to accommodate their children's behaviour happened almost imperceptibly:

'We probably didn't realise we were adapting but we were...'

Stress came not from managing family life but from outside the family:

'The biggest stress was when the world came tumbling down on us and we were being told terrible things...'

The parents perceived themselves as *'presenting'* their family, as a family with a disabled child, to the outside world:

'...now we present ourselves as this family because it's not a secret...'

Fewer opportunities were felt to exist for their children to experience being independent from the family. The parents perceived that they needed to keep their children close to them:

'We would have been leaving him with other children...'; 'We're the security that he really needs really so we tend to do everything really in a threesome'; 'Not everybody is all very compassionate and caring about disabled people'

This isolation was exacerbated by the children missing out on, what the parents saw as, some aspects of 'normal' childhood experience:

'He's not getting the same level of things happening after school...'

The physical environment of the home was sometimes seen as encouraging autistic behaviour:

'It's his hive of habits...'

The parents felt under pressure to conform to normal social rules even when these did not feel appropriate:

'...other parents...expect at least some...formal redress...'

Although the parents worried about their children they saw this as part of normal family life:

'Most parents worry about their children'.

Teacher feedback was perceived as being given more frequently for children with impairments and this could be stressful:

'I never asked the class teacher how he is...I don't want to hear what she is going to say...'

However, some special attention, for the children, was regarded positively:

'...quite positive because it's special attention off a specialist'.

Autism interventions in the home were perceived as contrary to 'ordinary life':

'You're having your ordinary life...you don't want to be regimented with an ordered system...'

but autism was not felt to be a barrier to engaging with family activities:

'We can just take ourselves off anywhere'.

Within the home environment the parents saw family life as generally 'normal'. Only when the family had to engage with the outside world did they feel 'different'. Difference was not something that the parents felt was usually accepted by others and so, at times, they felt compelled to act in ways that did not feel appropriate for their situation, in order to accommodate the attitudes of others.

Family, colleagues and friends

Family

The parents identified that family members were also affected by the diagnostic process:

'...because she used to worry about him as much as I do half the time'

Comments from family members, who seemed to support the diagnosis of autism, were unwelcome and gave rise to resentment:

'I don't want to hear that from you...' (referring to what Marie thought when her sister appeared to be agreeing with the professional viewpoint).

Similarly, comments that seemed to discount parental concerns, without due consideration, were also felt to be unsupportive:

'...whether she was trying to console...'

Family members, who took a 'realistic' viewpoint and recognised the impairment, if not the label, were seen as more helpful:

'...she was quite supportive to both of us...'

The parents preferred not to tell some of the family about the diagnosis of autism:

'...why should we tell all our dear and near ones...'

and tried to 'hide' the label of autism where possible:

'...(the speech problem)...that's something we can't hide...'

This was done through concern that knowing about the diagnosis might affect how family and friends perceived their children:

'They think it's a big thing... "Oh he's the child with autism. He's not going to like me..."

Telling others that their children had a diagnosis of a speech and language communication problem, rather than autism, was viewed as preferable:

'...she is not very keen on mentioning about autism...'

Absence from a large family support network was seen by Ann and David as affecting Ben's development, as it reduced the opportunity for learning from positive models:

'(when with the family there is)...no lack of prompting or boosting at any point...'

Family members who saw the children infrequently were useful, though, in that they could note significant changes in the children's development, which the parents might not have seen over time:

'...but she definitely said...he has improved a lot'

The diagnosis of autism impacted on relationships within the family. Tensions sometimes arose if family members adopted a position different from that of the parents towards the diagnosis. Fearing that knowledge of the diagnosis might affect how some family members perceived their children, the parents kept the information from some of them. If information was shared among the family then

other labels, such as speech and language difficulties, which were perceived as carrying less of a stigma, were sometimes preferred to the term autism.

Colleagues

David found sharing the diagnosis with others at work was helpful:

'...I just ...wanted to tell others...'

as he found his colleagues to be a source of comfort and support:

'...the way I tried (to) ...get over it was to share my feelings with my colleagues...'

Those colleagues who shared their own experiences, or had knowledge of autism, were seen as 'supportive' and colleagues with an interest in autism were sometimes a source of practical advice:

"Don't do anything for him..."

Friends

The parents had compared the development of their own baby with the babies of their friends:

'...we had loads of people at the same time having babies...'

but they found this became 'upsetting' and 'worrying':

'...that upset both of us...'; '...that contrast...made us very worried'.

Comparing children's development was perceived as having a competitive quality to it, from which these parents felt the need to remove themselves:

'...ooh, backing off from all that...'; '...so that group of friends we guess we have kind of moved away from...'

Telling established friends that their children had autism was problematic as:

'...their perception of you as a family is going to be altered...'

It was easier to make new friends where the diagnosis was known from the start; this felt more honest:

'...they know the score with Todd'

Once others knew that they had a disabled child it removed the parents from the competitive field:

'(we became) Non-threatening, therefore likeable'

The making of friendships was impeded by the establishment of different school arrangements for children with impairments:

'...but we weren't part of that (being at the school gate at the end of the day)...'

but the school still became a source of new friendships:

'...we went en masse ...with 5 families from Todd's class'

The experience of parenting a child with an impairment led to Rachel feeling generally 'let down' by people:

'You generally feel let down by human beings'

although this was seen as compounding rather than changing her view of humanity:

'...we were both quite cynical before...'

Rachel felt that she learnt not to, *'expect anything from anybody...'*

The parents perceived their children as *'enriching'* the experiences of other children:

'She (peer)'s got a fascination with Todd', '...he (peer)'s been enriched...with life skills'.

People who demonstrated empathy with their children were more likely to become friends while the parents *'pulled away'* from those who were not *'going to be good for him'*.

How the other children related to their children also played a significant role in the parents' selection of their own friendships, although exceptions were sometimes made:

'...I guess I really like Debbie and I don't think Claire, her daughter, is great for Todd'.

The parents felt that other children were sometimes guided away from their children, by their parents, but they saw this as an understandable reaction:

'...you wouldn't want your child associating (with a child with autism)...'

This made relationships confusing as the parents were sometimes uncertain whether *'friends'* had issues with them or their children:

'Maybe it was something we'd done wrong and we were blaming it on Todd...'

They felt that other people expected the parents of children with autism to be miserable:

'...they get a bit narked if you, with this autistic kid, aren't less happy than them...'

and that they would *'rub your problems in your face'* in order to try and make parents of disabled children feel as bad as they thought the parents ought to be feeling.

The parents saw how they presented themselves to others as important and as what dictated whether others would want to have a relationship with them. Being known as the parents of children with autism seemed to carry its own agenda and the parents preferred to present themselves as individuals first:

'So I don't like to be presented as a mother with an autistic kid. I like to be presented as myself.'

Controlling information about themselves became important, therefore:

'...somebody went, "Oh yeah, Rachel's got an autistic kid," and I wasn't happy about that...'

Social contact did play an important role in parents' lives:

'I find socialising very de-stressing...'

but the behaviour of their children was considered to inhibit social opportunities for the parents:

'...he wasn't settling in really so it wasn't relaxing...'

The reactions of other people to their children's 'odd' behaviour also restricted social access:

'...that has hampered us a little bit because we're now getting the head turning...'; '...I'm not confident about taking him to people's houses...'

The parents appreciated why other people might react in the way that they did:

'...I can see things from both sides all the time'

and they sometimes felt under pressure, from other parents, to deal with their children in a certain way, even if they felt this to be inappropriate:

'...they expect at least some...formal redress...'

The parents identified that they removed themselves from relationships with others as well as being excluded from them:

'I think a lot of it was a self choice thing'.

Some 'friends' were perceived as not wanting to establish friendships with parents of disabled children:

'...whether those friendships would have been struck up...probably not...being them'.

Restrictions on the parents' opportunities to go back to work made their activities different from their friends and sometimes created a divide:

'...another thing that started to make me different from...is that they all went back to work'.

Receiving the diagnosis impacted significantly on the parents' friendships. Even before the diagnosis, awareness of differences in their children's development had led to some parents re-evaluating old friendships and withdrawing from these, at least to some extent. New friendships, made with people who were aware of the diagnosis, felt easier to the parents as they could then be sure that autism would not become a barrier to these relationships. Acceptance of their children became the major factor in parents selecting new friendships. Practical issues, such as not returning to work, also affected relationships as the parents' interests and projects began to differ from those of previous friends. Social contact was valued, and seen as essential to well being, but this became more problematic for those parents where social engagement was a challenge for their children.

School relations

For the parents, highlighting their own 'strengths' and positive characteristics was seen as a necessary strategy when negotiating with staff at school:

'...I try to demonstrate to them what I can bring to the relationship...'

in order to counteract the perceived view of the parent of the disabled child as:

'...the whinging, complaining, bitter parent of this statemented kid'.

The parents perceived themselves as being judged negatively by the behaviour of other 'awkward' parents of disabled children:

'... they're going to lump us all together...'

The parent support groups were thought of as useful as a place to talk openly with others who understood the experience but they also felt, *'...quite heavy and depressing...'*. However, networking with other parents was valued and desired:

'I want to network with her...'

The parents also felt able to empathise with others in the same situation:

'...I knew that's where she (another mother of a newly diagnosed child) was at'

and there was a desire to help other parents of disabled children:

'I mean if I could help anyone...'

These parents were curious about other children with special needs:

'...I just wanted to see what she is doing...'

and formed relationships with other parents to discuss this, although contact with parents of children with autism was felt, sometimes, to raise unnecessary concerns:

'...sometimes I think when is he going to get that behaviour (challenging behaviour observed in another child with autism)...'

Relationships with school staff had to be carefully negotiated. Parents felt they needed to keep school staff 'on side' and, therefore, presented themselves in ways that they thought would appeal to the staff. Positioning themselves with other parents of children with special needs then became problematic. Although this sometimes enabled parents to feel more powerful it could also make them

feel vulnerable to rejection from members of the staff, guilty by association. The parents often did not see themselves as being able to fit comfortably with either 'parents' or 'parents of children with special needs'. This then led to a sense of isolation within the school setting.

Children's friendships

The parents perceived their children as making friendships with other children:

'...he is making his friends at school'.

These were valued, by the parents, as important learning opportunities:

'... he's learning more words from his friends...'

Developing friendships for their children out of school was also seen as important but experienced as problematic. There were not always children close by, for example:

'...this row of houses...there is no young kids'

and other children with impairments sometimes experienced difficulty coming to visit at home:

'(A mother said) My Harry (child with autism) will be difficult to come over to your place (to meet with son with autism) because he doesn't like moving his usual thing..'

It can be seen, therefore, in this chapter, that the diagnosis of autism had a significant impact on the parents' relationships with others. While this led to a re-evaluation and occasionally rejection of some friendships, with others it enabled the deepening of existing bonds. New friendships were also formed. Control of information was an important strategy for these parents as a means of enabling them to manage their relationships with others. Life within the family often seemed 'normal', to the parents, and it was only when negotiating the outside world that they sometimes felt positioned as 'other'.

The next chapter will describe the parents' experiences of professionals throughout the period of diagnosis.

Professionals creating problems

Professional involvement with family life was seen by the parents as the start of their problems, before that daily life was 'normal':

'...we just got on day to day and we don't really have any problems'; 'Nothing worried us until having this Team told us that he might be having autism...'

Professionals were felt to create problems rather than offer solutions:

'...they give you more problems than answers...'

and they appeared to focus on the negative aspects of children's behaviour, the 'can't do':

'...lack of this, wrong with him that...'

This felt like a 'wiping out' of all the positives that the parents had recognised within their children. If the parents tried to balance this negative focus by highlighting positive characteristics then this was interpreted by professionals as either the parents being in denial:

'...yet, I've not got my eyes shut.'; '...it's a cheap shot to just say 'in denial' whenever you've got a parent that's maybe thinking for themselves'

or by labelling the parents as 'confused' because they were 'so emotionally attached' to their children.

Labelling

The professional focus was perceived as being on the 'autistic', rather than on the whole child:

'...that was the first and only thing to say about him'.

The parents perceived professionals' expectations for their children as arising from the label rather than their capabilities:

'... (I said) "No he doesn't need that, that's not how he works" and they (professionals) said, "but that's how they (people with autism) are"'.

While the professionals only seemed interested in labelling the child, the parents saw this act as:

'...the most damaging thing that you could ever do'; 'It could...potentially ruin somebody's life...'

Labelling was felt to be something that would have a negative effect on people's perceptions of the children:

'You're going to alter everybody's perceptions of him...'; 'She (class teacher) said everything was fine...the second week (after a suggestion of autism had been made) ...I could really see the difference in her, in the way she talked...(I thought) "Oh no, she is never going to see Ben as a normal child any more"'.

A little knowledge, about autism, for professionals, was seen as a dangerous thing:

'...she (class teacher) is going to stamp Ben as autistic and in her words autism means, "Oh they're just wandering around in their own world"'.

The emotional impact of how professionals described their children was devastating:

'I was devastated the way she (professional) talked to me'

and, as a result, parents formed masks to hide their feelings when dealing with professionals:

'I didn't make my face go gloomy or...depressed at that time'.

Professionals were seen as more effective if they were not *'intent on the label'* and some were able to offer support without this need:

" they (professionals) said, what you want, you know is fine".

Professionals were seen as disagreeing amongst themselves whether the label applied:

'...there are two groups of people, one saying he has autism and the other denying it...'

Labelling the children was seen, by the parents, as the primary concern of the professionals. Labelling was perceived by the parents, however, as a damaging and dangerous activity as it stigmatised their children. For these parents, understanding how their own children were experiencing learning was far more significant than 'expertise' in the syndrome.

The diagnostic process

The parents saw the diagnostic process as an opportunity to find out more about their particular child:

'...we were kind of expecting something a bit more refined...'

but they felt that professionals positioned children with autism as 'they', manifestations of a syndrome, rather than as individuals. The parents found this a frustrating and alienating experience:

'It was very frustrating and made it very much us versus them'

Conflict was seen as starting, between parents and professionals, immediately with the diagnosis:

'...so instantly then we were into conflict...'

The parents felt that the professionals had wishes for the children that were contrary to those of the parents:

'...I wanted....they were not for that at all.'

The process of being given the diagnosis was found by the parents to be more stressful than managing their children's behaviour:

'...the biggest stress was when the world came tumbling down on us'; '...we were being told terrible things really...'

Making appointments to see professionals was:

'...just very stressful'

and inconvenient, for parents:

'...it was always at a time convenient to them...'

The parents perceived themselves to be clients accessing a service but this seemed to be more set up for those providing rather than receiving it:

'It was so unclient focused, it was untrue'.

One particular stress, which was identified, was being made to wait with a child with autism whose behaviour could be challenging in this environment:

'...we were all expected to wait around for ages...he was a handful...'; '...they were late...all the time'; '...your blood was boiling from all that tense waiting...just keeping him entertained and sane...'

The end product, the diagnosis, was a let down:

'...just, whack, 'autism' and that's it'

just a label and no clear picture of skills and abilities:

'...we didn't get the picture of Todd'.

This was not what the parents were seeking. They wanted:

'...a meaningful knowledge of him...that provides solutions that are actually tailored to his problems'.

This lack of understanding about individuals seemed, to the parents, to impact upon teaching approaches for children with autism generally:

'(those designing teaching approaches are) just not getting into those people's (people with autism) heads at all'.

Professionals did not take account of parents' individuality either:

'(When giving a diagnosis)...you need to know the framework, the mental attitude of the parent you are going to talk to...'

Diagnosis was perceived as having some benefits; it was seen as enabling children to access resources, for example:

'...we are quite aware now...have focused on Ben quite a lot'; 'And, he is (as a result) getting his special needs...'

Those with the most knowledge of autism, the most experienced professionals, were seen as keeping this to themselves rather than sharing it with those who actually supported the children:

'...what's required... (is that) people with the knowledge and the expertise ...actually run some sessions themselves...'

The parents had anticipated that the diagnostic process would inform them about their specific children. They hoped that this would enable a greater insight into how their children were developing. Instead they found that professionals were more involved in the actual process of diagnosis than learning about individuals. This was felt to create a tension and placed both parties, parents and professionals, in opposition.

Power

It seemed as though professionals wanted to isolate and control the children:

'...lock him up and put him in our hands, and not being part of the real world...'

However, not all professionals were perceived in this way; some were experienced positively:

'...we had built up a relationship with the people at nursery and they were really being quite helpful...'; '...we like that sort of attention from the intellectuals.'

Some professionals were perceived as having certain skills in the education of children with autism:

'They're very good at what they do and how they encourage children...'

but this was not felt to extend to parents:

'...but their people care skills with parents...taking on board our opinions on it are very much not taken into account'.

There was confusion over whether, overall, professionals were a help or a hindrance and whether or not it was right to seek their help in the first instance. Although this was seen as having been the start of the family's problems it also brought in help that had been useful to the children:

'...am I benefiting him or creating a problem for him...'; '...and then I think I did because he'll get help'.

Professionals were also felt to create confusion with their words that were open to interpretation:

'...I don't really know what they're saying...'; 'I...am not really sure...what she really meant by that...'; 'I don't know what she is expecting...'

However, the parents did not always accept professional decisions without question:

'...part of me feels that we didn't have to have that...'; '...we thought at first, are you backing off too much?'

although they were unsure to what extent they would be 'allowed' to question:

'If we keep on asking them about Ben, I don't know whether they are going to like it...'

The parents set, therefore, what they thought were acceptable parameters:

'I'm planning to ask once in two weeks...in two weeks I'll ask how is he coping in class'

Dealings with professionals were experienced as a form of bartering; agreeing to unwanted labels in order to secure resources, for example:

'...then we agreed the trade off should be to get him statemented...'

This experience was like *'heavy emotional blackmail'*. The parents felt obliged to agree for the sake of their children:

'...wouldn't be fair to send Todd to school without any support...'; 'It was either, "do it our way or you're not getting anything"'

Entry into school was even more of a negative experience because:

'...it's all gloom and doom...'

The parents avoided contact with teachers as they did not want to hear bad news:

'...if I ask her, I get all the complaints about Ben and I don't want to hear it'

Professionals were perceived as having their own agenda, separate from the welfare of the child and the family:

'...she saw Todd as a potential addition to her empire club...'; '...they are getting all their money for Ben, but...I don't think Ben is getting ...one to one...'; 'There's a lot of people...being very protective about their jobs...'

and, they even appeared to act outside 'the law' to pursue this:

'...it was against the law you know. '

Their children were excluded from regular activities in which the parents felt they ought to have been entitled to take part, such as lunchtimes and they were also categorised as part of the 'special needs group' rather than recognised as individuals:

'...the Down's Syndrome boy went home for lunch so Todd had to...Otherwise (school staff claimed) it wouldn't be fair...'

Professionals set the agenda. They were felt, by the parents, to create an illusion of success by focusing on the 'can't dos' for the children at the start of an intervention, only recognising the 'can dos' at the end. The professionals were seen as:

'...manipulating the perception...fitting into this self-fulfilling prophecy thing'; '...she (class teacher) said, " See, Ben has written his name", when (in fact) he had started writing about 3 or 4 weeks ago...'

Some professionals had more power than others and seemed able to exert control over their colleagues:

'They're all creeping to her, so...there's a little power pocket going on there...they basically think what she tells them to really.'

The parents felt *'controlled'* by an *'entourage of sinister forces'*. They saw themselves as vulnerable because their actions might rebound on their child:

'I'm Y (year) 2. I've got another 4 years to go and they could very well conspire to kick him out'; 'I am just keeping quiet for the best interests of Ben...'

and were afraid what the power of others might mean for their children in the future:

'...it's only 50 years ahead when Nazis marched on the doorstep'; 'I'm scared of them having a hold over my son...'

The parents felt under pressure, from professionals, to adopt different parenting styles. This led them to treating siblings differently, which seemed inequitable:

'...he gets away with murder but with...'

The parents' perceptions of their children could be influenced significantly by remarks from other people:

'...the class teacher says he can be aggressive...that ...is a bit difficult to take in but maybe true, he maybe doing that'

Engagement with professionals was experienced as disempowering by these parents. Professionals were viewed as having all the power and the parents felt the need to act extremely carefully in order to avoid being disadvantaged by them. At times the parents felt that they had to act against their own instincts, as parents, in order to avoid professionals taking against them and also to secure

resources for their children. Professionals were seen as the gatekeepers of these. The parents perceived professionals as willing to use essential resources as a means of securing parental capitulation.

At war

The parents felt that their children were treated by professionals like pawns in a war, with parents and professionals on opposing sides:

'...they made a war over funding'; '...the actual campaign is really dodgy...you're playing into the hands of the people who are your enemies...'; 'I was always battling...'

Battles continued over long periods of time:

'...this went on for about a year...'

and within this war professionals became entrenched:

'...they wouldn't be flexible in any way...'

Some professionals appeared to influence other professionals to bring them onto their side:

'...she had obviously done a whole hatchet job on us...'; '...she never misses an opportunity to drum up a bit of anti-parent fervour'.

Finding professional allies was problematic for the parents, owing to the complexity of the system:

'...I'm trying to investigate the organisational structure...it's quite difficult because they haven't even got a tree'.

Labelling was employed as a weapon to marginalise parents and make them voiceless:

'...on the statement I got labelled as an extremely sensitive mother...'; 'You're just an emotional mother or whatever'

and professional language was used to mask acts of aggression:

'They wouldn't let him in...It was termed, 'phased integration''.

School staff were perceived as punishing parents who had been given negative reputations by other professionals:

'We went in with this billing (so it was like) we're not going to make it easy for you, you're going to suffer...'

so parents resorted to guerrilla type activities; they learned to play one professional off another:

'...I knew I was being naughty...They all fell out big time'.

The parents felt they were sometimes perceived, by others, as the *'bitter saddo'*, which led to their views and opinions being discounted. The parents then felt disempowered by this experience:

'...your advocacy powers are extremely hampered...if they don't want to listen...'

Arguing their point seemed hopeless:

'...I just feel like you're talking until you're blue in the face'; 'She was very stubborn'.

The parents felt their words had no authority because they were:

'...completely discredited in the fact that...you're just a parent, in denial....you are really disempowered...'

It was as though no one consulted them over what might be best for their children:

'How on earth can they expect to have any kind of preparation for teaching him without speaking to us first?'

Denied a voice, the parents felt dependent upon professional allies to speak for them:

'I really hugged that lady (psychologist) after her summary. I said, "You are really speaking for me"'

At times the parents abandoned motivation and encouragement as tactics for securing co-operation, from professionals, in favour of the 'stick' as only this seemed to make a difference:

*'...you so much try and be very positive about all the help you get...';
'...ultimately...a bit of stick is required'; 'I'm going to get the Code of Practice out and whack it down at them big and hard.'*

It was felt that the only thing that would make school staff stop and listen was:

'...the fear of what might happen to them if they don't...'

Professionals could retaliate, however, as they were perceived as having:

'...many ways of making your life very difficult, as difficult as possible...'

Stories from the battlefield created a fear of future consequences:

'Well, they (school staff) did manage it (to get rid of another disabled child from the school) with Tanya'

The effects of this war were felt personally and deeply; they impacted on everyday life:

'People (school staff) won't look me in the face when I'm in the playground...'

Some professionals seemed to have a:

'...pathological contempt for parents...especially ones who have opinions and think for themselves'

In this war no prisoners were taken:

'...she's (professional) just spiteful really...She's got this spiteful side to her'

This brought on to the parents:

'...a whole load of unnecessary stress...'

This was felt as a greater burden than the act of parenting a child with autism:

'...all that politics stuff, that's more of a stress in managing than parenting...parenting's a doddle by comparison...'; 'It's always stuff to do with the school and what's happening there with him...that attacks me'

The parents perceived professionals as also feeling the effects of the war:

'They get more and more defensive...they take it quite personally'

This created emotional confusion in parents. They experienced feelings of guilt over their behaviour but at the same time they felt as though they had no control over how they acted:

'I couldn't stop myself.'

Gains seemed hard won but easily lost:

'...it's really difficult for me to say something about it because I'm only just at the stage where I've got them to let me go into help when I know for a fact they were desperate to get parent helpers in and they just wouldn't let me in at all.'

Professionals were perceived as sometimes fighting amongst themselves and the parents were frightened of becoming casualties if they became caught in the middle:

'I didn't want to be involved in any kind of controversy between them...'

The parents adopted the language of professionals:

'So we've been using that for sort of turntaking'; 'Not just chasing games but inter-acting games'; '...stopping using language minimalisation'

and sometimes challenged the 'professional mystique' of jargon:

'...one of the Speech Therapists was trying to say he has got echolalia...I know exactly what echolalia means...'

For the parents, it felt as though they were engaged in a brutal and exhausting war with the professionals. As professionals seemed to have all of the power through their ability to control resources, the parents saw themselves as compelled to undermine rather than to directly confront them. It was difficult to

find allies among the professionals as these were seen as colluding together to protect their position.

We must be wrong

Parents found their perceptions of their children challenged and changed by professional intervention. They experienced confusion as statements from professionals caused them to question their own beliefs about their children's abilities and styles of learning:

'...I was quite pleased with how he's doing. Now I'm thinking is he doing well or is he just giving the impression of doing well...'

Even feeling positive about how their child was developing became a cause for concern as though being positive was inherently a bad thing, a refusal to accept the 'negative' reality:

'...one of my concerns is that I feel positive and I sometimes think am I just ...not accepting that there will be problems...'

The parents began to view their children's behaviour through the professional 'lens', reinterpreting what was previously seen as 'normal' behaviour as indicators of autism:

'...instead of just thinking that it's a 3 year old...we ultimately think that Rita (autism professional) would say, "well, that's one of the signs (of autism) or something like that..." ; '...even if he does the same thing as normal children...we think because he has got this thing (autism), that is why he is

doing this' ; '...I am sure that it won't affect him...but then we don't know...he's autistic...autistic children, they don't want to change... things....'.

They became concerned about future development, perceiving professionals as predicting the onset of more significant difficulties than those currently being encountered:

'...because that's what they kept telling us (that he would become like other children with autism)'.

The professional outlook seemed, to the parents, to be unnecessarily gloomy:

'...I (parent) don't feel they are as bad as you (professional) think they are...'

However, professionals could also reassure:

'...she (professional) said some kids do improve with this particular autism...'

Professionals were seen as persistent and difficult to resist:

'...they kept telling us...'; '...they kept saying...so then I started thinking...'

As a result, the parents changed their behaviour, even though this meant going against their own instincts; later, parents perceived this as having disadvantaged their children:

'...I assumed they were saying he might not be understanding it, so I was repeating it over and over and over, of course, the poor lad's hearing this 100 times over, understanding it the first time, hearing it 100 times.'; '...so then I started thinking well maybe I'm just fighting it because I'm scared of the word (autism), maybe I ought to give a little bit and accept what they're (professionals) telling me is right ...so I started to go along with it...'

Influenced by professional input, parenting styles became more directive and intensive:

'So it's been drilled into him...'; 'I have been very tough on him...'; '...we changed when we accepted their expert...'

Even so, the parents felt that they maintained their fundamental beliefs in their children's abilities:

'And I've never changed my way of thinking, I never have done and I did try...'

The parents did, at times, question their own perceptions when professionals cited 'evidence' from interactions not observed by the parents:

'She (professional) says that the signs would be more evident outside the home...'; '...the class teacher did mention that ...when he is irritated he can be aggressive which I think may be true (but)...that kind of thing we haven't noticed at home...'

If something was said by a professional then the parents felt it must be true:

'...I don't know, he must be doing that (being aggressive in class), we don't know'

Professional opinions were seen as difficult to counter without running the risk of repercussions:

'...if we even question anything, that's it. You've had it'

When professionals accepted the parental perspective this then felt, to the parents, like 'both sides' were working together:

'...they've come round to the way I've been thinking and what I've been saying'

Seeking help for their children sometimes felt like, 'selling *him down the river*' as parents saw themselves as forced to emphasise all that their children could not do:

'...when we went for Disabled Living Allowance...that's when you think I can't believe I'm writing this about him'.

Professional opinion was experienced, by the parents, as a powerful force that was difficult to resist. The professional agenda was perceived by the parents as being unnecessarily focused on impairment rather than ability. However, the parents found, at least initially, the strength of the professional discourse too strong to resist. Emotionally, though, the parents retained their belief in their children's abilities and felt able to reassert their original position as soon as they perceived any weakening of the professional position.

Professionals have their uses

Professionals were seen as being practical and efficient and highly skilled, in some areas of their practice:

'...they are very practical...all the I's are dotted and the T's crossed they are very good...' ; *'She's very skilled. She's got loads of skills. She's got charisma...'* ; *'I have a lot of respect for them...they're doing their job'.*

Recognition by them of the children's progress was highly valued by the parents:

'...(she, professional) actually was very good last time she came. She said she could see great improvement in him...'

Positive comments from professionals were welcomed and accepted as valid:

'...she was a lot more positive...'; 'We can see that they are seeing him (our son) now, they are seeing him'

and engendered a positive emotional effect:

'I was on top of the world'

Greater value was placed on professional opinion when the parents could see their own children reflected in the observations:

'...we knew they now see him as opposed to just talking about a subject in general...'

Professionals were seen as able to access resources and provide educational support for the children:

'...somebody to be sat with him to encourage him to...'; 'He is getting special needs (support). He is making tremendous progress'

In some cases this appeared to make all the painful interaction with professionals worthwhile:

'...he's on the right track and he's getting special needs care which would not have happened if we kept quiet...'

There was some empathy with professional constraints:

'Mind you, he's so young it's difficult to predict how things are going to work out...so they (professionals) don't make any comment on it...'

and it was viewed as positive that professional monitoring would be in place when their children were in school:

'...if there are any problems there's somebody who knows about him...'

Professional opinion could be reassuring:

' (Professional) says she's perfectly confident he'll just go into school and have a good time...'; '...she didn't say " Oh well you see that's part of the autism", she just said, " Well that's four year olds for you, isn't it?" and that was lovely for me to hear that ...'

Lessening of professional intervention was experienced as a positive sign for the future:

'...she just phones me up, "Right I'll see you maybe next year"...'

Professionals were seen as individuals with some being thought of as more helpful than others:

'...they were really being quite helpful...there was some genuine compassion in that place. ' ; '...they're not all the same. They're all individuals...'

because they appeared to keep an open mind and were 'responsive' to parental input:

'...she's a freethinker...she's great...'; '...lovely lad...he's got a reasonably open mind'.

Positive relationships with professionals led to a softening of position and a lessening of conflict:

'...then liking them...I do slip down from my high horse'.

Professionals did not have to get it right always but the parents had to perceive them as trying to do so:

'...they were so responsive and so...trying desperately to do the right thing'.

The Local Education Authority was seen as an ally in disputes with other educational professionals:

'...the LEA were very good...laying down the law...'

but this was perceived as having limited effect:

'But whether that in the long run has done us any good, I don't know'.

Professionals could facilitate interaction between the parents and others parents of children with autism:

'...every month they (parents group 'organised' by professionals) are going to get together some place...I thought it was a wonderful idea'.

Some professionals were, therefore, experienced more positively by the parents. Positive experiences tended to arise when parents felt listened to and when professionals seemed more interested in the children than finding the correct label.

Professionals are cold and emotionless

Professionals were perceived as tough and without compassion:

'They don't try to pretty anything up...'; 'Rita's (professional) not scared of using it (the word autism)...'; '...they don't give you any sort of comfort do they'; '...they went in quite hard...'

The parents felt uncared for and disregarded in their interactions with professionals:

'...but their people care skills with parents...taking on board our opinions on it are very much not taken into account...'

The motives of professionals often seemed cruel and manipulative:

'...give you another couple of months to stew on it...'; '...some kind of shock technique or something...'; 'They try to knock you down so they can build you up again'

The desire to help parents seemed to be absent:

'She's (professional) just of a frame of mind where she doesn't want to be helping people like us'

Some professionals were seen as having personality characteristics that made them unsuitable for their work:

'She's got this spiteful side to her'; '...she's a control freak'; '...she does it on purpose. She finds out what bugs you and then she goes and does it'; 'She was a bit abrupt...'; '...she was very stubborn...'

At times they seemed more animal than human:

'...they'd form packs against you...'; 'They're ruthless bitches frankly'

although some were seen to have some positive qualities:

'...they're so gentle...she's a nice doctor...she asked both the times, "What do you think now?"...'

Professionals also seemed distant and remote from the children:

'...he (child) didn't know her (professional) and it was kind of no trying to interact with him'

Overall the impression of professionals was a very negative one. The parents perceived them as uncaring and intent on pursuing their own agenda at the expense of children's welfare. The professionals did not appear, to the parents, to have any desire to understand or support the parental position.

This chapter has focused on the parent's experiences of professionals. It has established that the parents felt disempowered and disregarded in their relationships with the professionals involved in the diagnostic process and the education of their children. The professional agenda was felt to be distinct from, and in opposition to, that of the parents. The parents felt compelled to appear to engage with the professional agenda to avoid negative repercussions for their children. Rather than confronting the professionals openly the parents, in this study, carried out various forms of subversive resistance. Only when parents felt that they were truly listened to did they feel able to work alongside professionals.

The final chapter will summarise both parts of the dissertation and conclude this work by suggesting how professional practice might be modified to enable partnership, between parents and professionals, rather than conflict.

Chapter Nine: Summary, Implications and Outcomes

In part one of this dissertation I identified the focus of this study as an explication of how the process of diagnosing autism impacts upon the lifeworlds of three sets of parents. I then placed the research within a context of new challenges to service providers, as diagnostic boundaries broaden and more children are diagnosed with the syndrome. Within the review of the literature, related to the experiences of parents of children with autism, I illustrated how the autism specific literature has traditionally presented a negative view of the parenting experience. This was then contrasted with the more positive accounts of parenting a disabled child arising from generic disability research. Two principal models for understanding disability were also defined and compared. These were the individual and social models of disability, which I then considered in relation to the agendas of disability research. Lifeworld was identified as the methodology selected for this study and the phenomenological principles underpinning it were elucidated. I highlighted the emancipatory nature of the methodology and described how Lifeworld was adapted to meet the needs of this particular investigation.

In part two of the dissertation I have, so far, presented 'how' the participants in this study experienced the process of their children being diagnosed with ASDs. I illustrated this through a descriptive 'phenomenological' account that recorded the experiences as collated and 'interpreted' by me as researcher.

In this final chapter I will now consider the 'why'; speculating, based on my knowledge of these parents' experiences, contact with other parents through my previous professional practice and the literature reviewed in chapter two, on the reasons why the parents might have experienced the process in this way. I will summarise what I have discovered about the experiences of parents involved

with the diagnostic process and distinguish the findings of this study from those discussed within the literature review. A critique of the research methods will be offered with suggestions for how I might approach and inform future studies. Relevant foci for further investigation will also be identified. I will end the chapter by suggesting guidelines, based on the evidence of this study, for how professional practice might be improved in order to provide an enabling and empowering service for parents and children.

Summary: Surviving diagnosis

The following sections summarise my 'interpretation' of the participants' experiences of the diagnostic process and of how this process impacted upon their lifeworlds. The parents, in this study, experienced the diagnostic process of autism as a circular journey with four key stages. Prior to the diagnosis, they began as, *Parents*, enjoying their relationship with their children, although they had some concerns over aspects of their children's development. These concerns led to, *Professional Intervention*, originally sought, by the parents, to support their children with specific developmental issues. However, this resulted in the parents feeling as though their children had been 'stolen' from them. Disempowered, deskilled and perceiving themselves as viewed as different from the parents of non-disabled children they became, in turn, *Disabled Parents*. Eventually, '*Parental Resurgence*' occurred; the parents experienced a return of confidence in their ability to parent their children, learning to 'see' their own child again by focusing on the child rather than the syndrome. They then saw themselves again as 'simply' '*Parents*'. However, at the '*Parental Resurgence*' stage of the journey the parents sometimes returned to the '*Disabled Parents*' stage, for temporary periods, rather than moving forward to

'Parents', as levels of confidence and belief in a positive future could vary at any time (see figure one below). Each of these stages will now be considered in more detail.

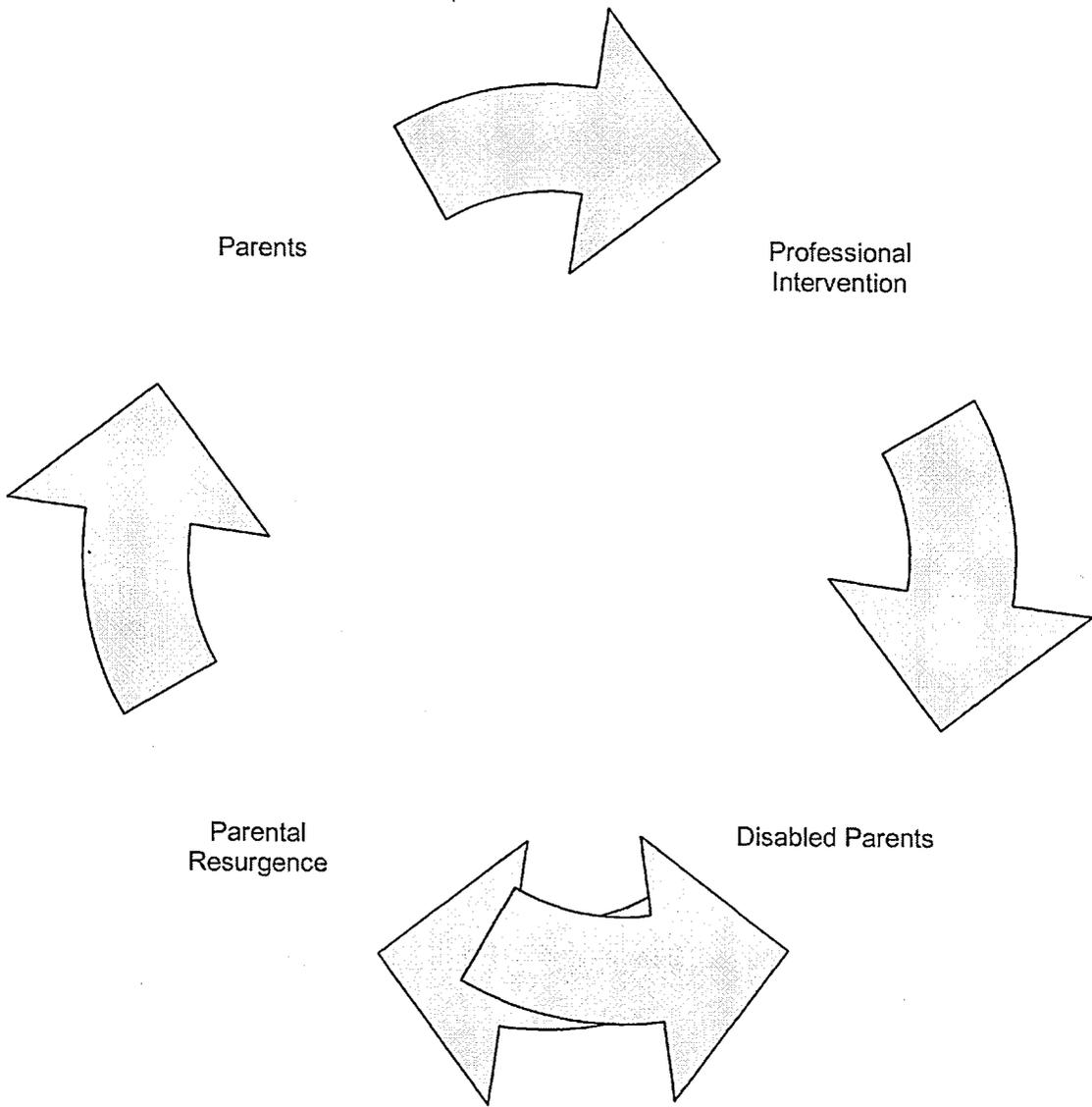


Figure One: A Circular Journey

Parents

The parents talked about the experience of how they began by loving their children, feeling bonded, perceiving themselves as experts on their sons and in charge of what happened to their family. Pleasure was taken in achievements; humour found in idiosyncratic behaviour. They speculated on positive possibilities for their children's futures. Some concerns, for example 'slow development' of language skills or a tendency for their children to isolate themselves, arose in relation to their children's development. These issues were raised by the parents, other family members or directly by professionals. Comparisons were made with other children of the same age, sometimes enabling the parents to allay concerns but, more frequently, fuelling anxiety. Professionals were consulted for practical ideas to help the children boost these skills, speech and language usually being the first request.

Professional intervention

One professional brought in another, sometimes without any prior consultation with the parents; concerns were shared between professionals and plans formulated without the parents being present. Continued professional intervention made the parents uneasy that something was significantly wrong with their children's development. Eventually one or all of these professionals, as this appeared, to the parents, to have been decided by them collectively, without consultation with parents, mentioned the word autism. The parents argued against this, offering evidence for why their children's behaviour was like other children or just a bit delayed in some areas. The parents looked to their own development to find evidence that their children were 'just like me' or they saw behaviours as inherited from other family members who had 'turned out

alright'. They put forward accounts by childcare professionals in day care or nursery who had commented on the children's achievements. Professionals countered these arguments by emphasising, to the parents, the nature of the children's difficulties. They used expressions like, 'I am very worried about him, 'he is very isolated' and 'he is very autistic' to encourage parents to 'accept' the diagnosis. These negative portrayals of the children were not recognised by the parents and they countered these interpretations by identifying their skills and abilities. Although the parents recognised their children did have difficulties in the areas identified by professionals, they could not accept this was the whole picture; they needed to balance this focus on the 'can't do' with a reminder of the 'can do'. Professionals appeared then to interpret this behaviour as parents being 'in denial' and made their arguments for the children's difficulties stronger, perhaps to encourage parents to accept the 'problem'. They brought in other professionals, such as autism specialist speech and language therapists and autism specialist support teachers for support with highlighting deficits.

Disabled parents

The parents then felt faced with a conspiracy, a force too powerful to fight through argument and persuasion. Feeling under attack, they retreated and regrouped by tightening family bonds to form a protective defence around their children, ready to protect against professional and societal negativity. Others outside the immediate family unit were treated with suspicion; parents distanced themselves from family and friends who appeared to support the professional position. Current friendships were re-evaluated as interactions were analysed to identify who had negative feelings towards disabled people or might feel pity towards the family. Keeping the diagnosis secret from some friends and family

helped the family to feel 'normal' and was seen as necessary to protect the children from prejudice and discrimination. Linking with other families of disabled children made 'playing it normal' more difficult and harder to protect the secret. Continued relationships with old friends were sometimes emotionally painful. If friends had children of the same age, this emphasised, for the parents, the difference in development between the children and acted as a reminder of what their children 'should' be doing but were not. The parents became highly focused on every aspect of their children's development. Each behaviour was evaluated as 'for or against' the diagnosis. Behaviours that were previously amusing and attributed to being a typical toddler were now alarming and evidence of 'abnormality'. The children's skills and talents, rather than being celebrated, became feared as evidence of 'autistic talent'. On learning of the label, the parents observed the attitudes of people around the children changing; they perceived other people as becoming unsure of how to interact with these children with autism. It seemed as though people were unable to see past the label to the children.

The parents entered into a battle for their children. The sons that they loved and celebrated were being taken away; professionals tried to replace them with 'autistic children' but parents were unsure of how to act with these new children because they were not 'experts'. However, they felt unable to withdraw from contact with professionals altogether in case this denied their children any help or support which they might need. Instead they adopted guerrilla warfare tactics; treating all professionals with suspicion. They used those professionals identified as allies to undermine those who were viewed as the enemy and sometimes forged alliances with others, also under attack, to create a stronger collective force.

Energies previously put into career or other activities necessarily became diverted to the fight; personal life goals changed as the parents put the needs of their children before their own. The literature on autism was both an enemy and a friend. As a friend, it provided the parents with a theoretical explanation for their children's development and also enabled them to argue with others using the language of professionals. As an enemy, it offered a bleak and depressing picture of the future, taking away hope. The parents became mystified by an individual model presentation of autism as something that required complex and specialist therapies and educational approaches. It appeared as though only professionals, with many years of specialist training, could understand and interact with children with autism and the parents felt deskilled and inadequate. They could not position their children within the spectrum and so were unable to recognise which children in the literature were like their own and which were following very different developmental paths. Even if their children had never shown any sign of such behaviour developing, the parents fearfully anticipated the onset of 'negative' behaviours predicted in the literature, such as, extreme withdrawal and aggression. Resistance to professionals began to weaken as the parents started to feel like amateurs in a technical field.

Parental resurgence

Over time belief in their power to parent returned. This resulted from factors, such as natural enjoyment of being with their children, positive signs of development occurring within the children, recognition of their children's talents and abilities by others, maintaining a distance from those professionals considered to be 'negative' and a reduction in use of the label by professionals. The parents once again felt able to celebrate all that they loved about their

children and to feel 'expert' about them. For some, this corresponded with professionals seeming to accept the viewpoint of the parents. The parents then became unclear what professionals actually did think about their children in relation to autism but preferred to leave this unspecified. Attitudes towards some professionals mellowed and parents began to acknowledge the professional perspective. With other professionals the parents distanced themselves and avoided contact wherever possible. The parents focused on the present, avoiding predicting too far into the future. Time with their children was highly valued. The diagnostic process was seen as one that 'robbed' the parents of the joy of parenting; living in the 'here and now' was seen as a way of restoring this.

Relationship with prior research

The findings of this study argue against the vision of a 'gloomy prospect' of parenting claimed within autism focused literature (e.g. Jordan and Powell, 1995; Wing, 1996; Howlin, 1998). For the participants in this study, whilst acknowledging that parenting was a complex and life changing experience (Lupton and Schmied, 2002) their experiences support the literature which argues that parents generally enjoy their relationships with their children with autism (e.g. Case, 2000; Schall, 2000). Bob encapsulates this by saying:

You know, five minutes after he's (son) been a pain in the arse you've forgotten about it and you say, "Oh, you're lovely," and that is something that...you know, that is amazing really.

There were some pressures arising from behaviours associated with autism and which have been traditionally reported within the literature (Siegel, 1996; Randall and Parker, 1999; Tunali and Power, 2002). Todd experienced

disturbed nights, for example, which then affected the sleep patterns of his parents while communication issues between Sam and his parents led him, at times, into 'temper tantrums'. However, the parents tended to find their own creative ways to manage these behaviours; methods which suited their philosophy of parenting and which they saw as a natural adjustment, a normal part of negotiation within a family. Parenting only became a 'gloomy prospect' when professionals became involved and a diagnostic label was assigned, supporting the claims of Avdi et al. (2000) and Gillman et al. (2000), that diagnosis can produce negative effects. The findings here also inform these two previous studies by identifying particular tensions that the diagnostic procedure generates within individuals and between couples, as parents employ different and sometimes divergent strategies to manage the diagnosis. For example, in each couple one parent elected to find out about autism through the literature while the other found this to be either stressful or unnecessary, preferring to let the child's development take its own course. This then became an isolating factor and a potential cause of conflict as one parent wanted to share what he/she had read while the other was unwilling to hear or discuss the information.

Gray (2003) found differences in how mothers and fathers coped with parenting a child with high functioning autism. He attributed these to the continued adoption of traditional roles with women as primary carers and men 'escaping' to work. Although two of the mothers in this study were based at home and one was working part-time, the impact of the diagnosis, for these participants, did not appear to have any lesser effect on the fathers than mothers. All the participants seemed highly affected and the positions adopted presented as more complex than being gender defined. For example, Bob saw work as an

annoyance, depriving him of time with his son while Ann perceived it as a potentially positive distraction from worrying so intensely about her child. In all the couples both mothers and fathers were highly engaged with professionals throughout the diagnostic period.

In terms of strategies for 'coping' emotionally with the diagnosis, Gray (2002) found that women tend to share more with friends while fathers either 'bottled up' emotions or took a philosophical approach of 'wait and see'. Within the three fathers in this study, there was a range of responses evidenced. John was on medication to help with depression, David found that talking with colleagues, who had some knowledge of the area, was helpful and Bob adopted the philosophical position of accepting that the future could not be changed. Although the numbers involved in my study were small the findings here suggest that the identification of generalised gender differences is an oversimplification of the complex and variable positions, adopted by parents, towards the parenting experience.

The participants reported experiencing stigma, as identified by Goffman (1963), Dowling and Dolan (2001) and Green (2003). This was perceived as emanating from those outside of the home and, as Gray (2002) asserts, particularly within the school environment. This supports Armstrong's (2003) claim that some professionals continue to position parents of disabled children as 'other' and, therefore, as 'problematic'. Gray's (2002) finding that parents did not distinguish between 'felt' and 'enacted' stigma is also evidenced within this data as is Green's (2003) claim that parents manage this stigmatised position by trying to control information. It was important for the participants to be able to choose to whom they revealed that their child might have an impairment (Gray, 2002).

Identifying with other parents of disabled children left parents and children vulnerable to exposure (Green, 2003) but could also be a source of emotional support, shared campaigning, information and a means of developing new and positive friendships (Gray, 2002; Tunali and Power, 2002).

Unaware of its potential significance at the time of the interviews, I did not ask the participants specifically about their attitudes towards disability. However, there are strong indicators of the adoption, by these parents, of an individual model perspective, with a negative perception of disability predominating (Murray, 2000; Kearney and Griffin, 2001). Parents were clearly emotionally devastated by the identification of their child having an impairment; this was seen as a negative and less desirable than the norm. Rachel and Bob had lived with the diagnosis for longer and had come to 'accept' it but the other participants believed and hoped that their children either, through intensive support, would change and become 'normal' or that the diagnosis of autism would be disproved. This is not to say that they wished their children to change significantly but rather that others would no longer see them as developmentally 'deviant'.

Even though their children were currently a source of joy all participants expressed concerns over future development and anticipated an older disabled child as a source of stress rather than continued pleasure. The future was something to fear; seen through the individual model lens, disability would inevitably lead to tragic consequences. Bob had elected to focus on the 'here and now', 'the present and becoming' (Fisher and Goodley, 2005), finding this less stressful than predicting the unknown. All the participants identified this as a necessary strategy to maintain a sense of well being, although professionals

were perceived as using a fear of the future to 'encourage' parents to engage with intensive strategies of early intervention. The parents reported that the professionals used terms such as, 'We are very worried about him...'; 'He is very isolated...' and 'He is very autistic', all of which positioned the child as problematic. As Avdi et al. (2000) state, fun was taken out of the parent-child relationship as parents began to scrutinise their children for signs of 'developmental abnormality', leaving them unable to celebrate talents and abilities, fearing these to be further signs of 'developmental abnormality'.

Professional as 'expert' continues to be the dominant discourse (Foucault, 1980; Kearney and Griffin, 2001). Marie illustrates this through her reflection that she felt persuaded to act against her natural parenting instincts:

I have been very tough on him...We changed when we accepted their expert advice

something, which Marie later came to regret. In 1963 Goffman claimed that those who are stigmatised develop strategies for 'fighting back'. This concept of active agents, challenging oppressive discourses was not discussed by Foucault (Sarup, 1996). The evidence of this study identifies clearly a number of strategies parents used to counter disabling influences. These included controlling information, avoiding certain professionals, joining forces with other parents in the same position, pretending to agree with professionals but then subverting interventions, locating professionals who might be sympathetic to the parental viewpoint, becoming experts in the literature and learning 'professional language' in order to advocate for their child on an equal footing.

Brown (1998, cited Case, 2000) noted that the parents in his study all shared a dissatisfying and conflictive experience of most of the professionals they

encountered. This was also experienced by the parents in this current study. Professionals were seen as powerful controllers of processes and resources. They appeared, to the parents, to collude together to move forward agendas, the contents of which were kept from them. Professionals were perceived as making no acknowledgment of parental expertise and as dismissing parental objections as the 'delusions' of parents 'in denial'. The participants had not been enabled, by professionals, to explore their feelings towards the diagnosis (Russell, F., 2003). Rather, the professional focus was on changing the child. The parents in this study were looking for professionals to intervene in a way that built on a child's strengths and aspirations (Russell, F., 2003). Instead they felt drawn into conflict, challenging the professional emphasis on deficit with examples of their children's capabilities.

The professional position

The accounts of the parents in this study identify a discrepancy between how professional services are intended and how they are experienced. If we are to assume that professionals are seeking to give families the best support possible, then the question is raised as to why their actions are not being perceived in a more positive way. It is important to acknowledge the significance of the fact that professionals operate within a political context. In the last ten years there have been significant attempts made by the government to protect the rights and entitlements of disabled people and their families (Russell, P., 2003). This has been done through enactment of new legislation such as the Disability Discrimination Act 1995; 2005, the Carers and Disabled Children Act 2000 and the Special Educational Needs and Disability Act 2001 and a set of programmes for change including Valuing People (DH, 2001),

Together From the Start (DfES and DH, 2003), Every Child Matters (DfES, 2003) and the National Service Framework for Children (DfES & DH, 2004b). Generally, the government's programme of change is claimed to be a shift in policy from the individual model towards the social model of disability (Russell, P., 2003) with a focus on removing social barriers to inclusion. The three key initiatives; Valuing People: a new strategy for learning disability for the 21st Century: Towards Person-Centred Approaches (DH, 2001); Every Child Matters (DfES, 2003) and The National Service Framework for Children, Young People and Maternity Services (DfES & DH, 2004b) are setting out for professionals new standards for identifying and meeting the needs of disabled people and their families. The emphasis within these is on listening to disabled children and parents, flexible delivery of services to meet individualised need, enabling equality of access to community facilities, including after school clubs, and providing parents with information and advice and early assessment to identify need. However, in spite of these positive developments there remains a:

compelling body of evidence from research and inspection reports that many disabled children and their families continue to face multiple discrimination, low expectations and many physical and social barriers to full participation in society (Russell, P., 2003: 216).

The findings of this current study indicate that although the legislation adopts the language of the social model, professionals continue to apply individual model based interventionist strategies, aimed at changing the child and the family, rather than identifying and dismantling external barriers to achievement. The evidence presented here identifies that the parents in this study did not feel listened to. They perceived that their views were dismissed as unreliable on the grounds of their emotional involvement with the child. Nor did these parents

experience services as being provided flexibly, in response to their aspirations and values. Professionals remained 'expert' and therefore powerful (Foucault, 1980), applying general interventionist, autism specific, approaches, regardless of children's individual characteristics.

Current governmental policy, as identified above, has ended up as a hybrid of the two main conflicting models of disability. Although charging professionals to remove external barriers to inclusion, the importance of early identification of 'need' and the introduction of interventionist strategies continue to be emphasised (DH, 2001; DfES, 2003; DfES & DH, 2004). There is very little support for enabling professionals to move away from familiar practices, centred on child and family focused interventions, to engage with disabling barriers. The findings of this study identify that further research is now needed in this area. It will need to consider how professionals are responding to these new challenges of identifying and dismantling barriers to inclusion in order to help develop guidelines on how they might make the social model a practical reality. The ideals underpinning the social model are well-established (Swain et al., 2003) but researchers have yet to make explicit how these should be translated into the practice of supporting families. The findings here suggest that Woolfson (2004) is right to argue that parents need support to reframe their thinking towards a more 'social model' view on disability. This would enable the parents to anticipate a more positive future. However, again there is no detail on how professionals should first change their own thinking and, once done, the practical steps that they should take to support parents with this reframing.

Spectrums

The findings of this dissertation contradict the previous presentations of the experience of parenting a child with autism as inevitably negative and potentially overwhelming (Jordan and Powell, 1995; Siegel, 1996; Randall and Parker, 1999). The argument that researchers may have traditionally focused on the negative aspects of the experience might explain some of this discrepancy but this is unlikely to be the complete explanation and more research is needed to clarify this issue. Charman and Baird (2002), as reported in the introduction to this study, argue that services are now making earlier and broader diagnosis of ASDs. It may be that the children within this study would not previously have been 'categorised' as on the autism spectrum; there may have been some concerns over development but these may not have been seen as pervasive and fundamental. New research argues that early diagnosis of ASD for this 'high functioning' group ensures a more positive 'outcome' for individuals and minimises the effects of anxiety and depression (Tantam et al., 2005). I would argue, however, that it is not the label that is of value in itself. What is needed is support for parents with understanding how their child is experiencing the world and the development of strategies for enabling them to realise their ambitions for their family. This study would indicate that, just as there is a spectrum of autism, so too there is likely to be a spectrum of family needs and values. Some parents, mystified by their child's developmental path and, perhaps, losing confidence in their parenting skills, may welcome an early explanation for their child's development and autism specific professional guidance (Randall and Parker, 1999; Tams, 2001). Other parents may have some questions about their child's development but would find it emotionally devastating and undermining to have their child, and their family, 'labelled'. One challenge for

researchers will be in formulating, with parents and professionals, systems for identifying parental positions and creating a range of flexible strategies for negotiating appropriate levels of support.

Any support for this process is currently found, not within the autism specific literature that has traditionally focused on the negative aspects of the parenting experience but within generic disability research. This, I would argue, has traditionally been outside of the frame of reference for most autism-focused professionals. From the findings of this study, I would, therefore, argue that it is time for autism-focused researchers to contextualise their work within the wider disability debates. If not, then autism studies will continue to maintain an individual model agenda, focused on the effects of impairment on the person, rather than identifying the barriers which prevent individuals from leading inclusive and autonomous lives.

Reflecting on the research process

This design of this study emerged from my frustration with the outcomes of an attempt to impose, what I would now argue to be, an individual model, action research intervention that aimed to 'show' parents how to parent their child with autism. When it became clear to me that this approach would be intrusive and unhelpful because the participants were already clearly skilled in the act of parenting, I turned to a methodology which would enable me to understand how the participants were experiencing the situation; a methodology that asked questions rather than tested answers. I found this approach in phenomenology and in Lifeworld, in particular. The insistence on the researcher bracketing previous experience and assumptions enabled me, as far as possible, to stand

back from my previous position as a teacher and to concentrate on recording how the diagnostic process impacted on these parents. The findings of the study challenged my initial expectations that the parenting experience would be revealed to be an essentially tragic one. I have personally been led by the data to discover and engage with the social model of disability, which has caused me to question my previously held convictions, that early intervention and 'educating parents' are always the answers. I now understand parental positions to be complex and variable, requiring sensitive appreciation by professionals. Lifeworlds' insistence on maintaining the voices of the participants as primate, I would argue, is both empowering for participants and enables the reader of the research to evaluate its validity. To support the readers of this study with this process, I have presented the description of the experiences alongside quotations from the transcripts. This was intended to evidence the source of the data and show how I arrived at identifying the essences of the experience, thereby making transparent, as far as possible, the process of analysis.

Lifeworld is an ideal methodology for emancipatory research because it values only the conscious experience of the participant. The 'expert' is the one who is experiencing the phenomenon. As a researcher I was concerned with identifying and following up concepts that I 'sensed' to be important to the participants. In this way the research agenda was constantly revised and adapted; the research agenda was not overtly directed by the participants but they were certainly active in shaping it. Interviewing the parents over a year was really helpful here, enabling me to pursue participant led discussion without worrying about moving too far from my own agenda. In addition the fractions

within Lifeworld are sufficiently broad to provide a general framework for discussion without becoming overly prescriptive.

Feedback

Making sure that the data presented is representative of the participants' experience is an essential element of phenomenological research (Ashworth, 1993, Moustakas, 1994; Kvale, 1996). Interviewing participants over a year provided me with the opportunity to 'feed back' to participants, within the interviewing process, what sense I was making of their experience. This enabled points to be agreed, clarified or revised until my 'interpretation' captured the experience. I am reassured, in my concern over the extent to which I was able to do this in practice, by Rachel, one of the participants. In response to an article that I had written (Hodge, 2006), which drew on my experiences of conducting this research, Rachel wrote:

It feels that you are listening very carefully to us and taken on board our experiences and views. No-one could ever accuse you of being an "arrogant professional", it's obvious that you respect our position by the way you are so willing to make adjustments and take us seriously. I send a well firmed ripple of applause to you along with a hearty nod of approval (personal communication by email, June 2005).

I have yet to identify how participants will respond to their personal experience being presented as part of a collective account. My expectation is that they will be able to recognise clearly their own voice within the text but also have empathy for the other positions recorded there. I will explore this with the participants once they have had an opportunity to read through the full account of the study, presented in its current form.

I would also like to discuss with the participants in what other forms they would like to see the findings presented and to whom. While I would like to devise and co-present these findings with the participants, I anticipate that they might have a range of responses to this. Some might have 'moved on' now from the experience of diagnosis and not wish to revisit it. Others, however, may welcome the opportunity to discuss their experiences in the public arena.

I certainly intend to use Lifeworld in future studies. I would explore different methods for presenting the data, utilising the fractions as headings for example. I would also explore systems for supporting with the analysis of data, such as NUD.IST, ATLAS and CAQDAS (Silverman, 2000). I managed the data manually this time, finding it helpful to immerse myself completely within it; I was concerned, once I had started, that computer programmes might disturb rather than support this process.

Implications for professional practice

An important component of the dissertation for a professional doctorate is that it should offer a contribution to the development of professional practice (Tinkler and Jackson, 2004). Supported by the evidence from this investigation I argue that professional practice needs to be improved in the area of diagnosis if this process is to offer effective support to parents. The findings suggest that professionals would make their support of parents enabling and empowering if they were to adopt the following guidelines.

Guidelines for inclusive support

- See and know the child rather than the diagnosis
- Identify parents' positions towards disability before advising
- Understand that some parents may want and will be helped by a label but others may not; labels empower some parents but disempower others
- Highlight, value and celebrate positive parenting skills and encourage parents to reflect on what makes them successful parents
- Highlight, value and celebrate children's skills and abilities and encourage parents to identify all that they enjoy and admire about their child
- Encourage parents to live in the here and now, enjoying the moment; be realistic about the child's anticipated developmental path but always highlight any potentially positive aspects of the experience
- Offer relevant advice and support to parents without making this conditional upon acceptance of a label
- Attach resources to personal entitlement rather than a label
- Challenge your own position on disability and reframe this, if necessary, supported by an affirmation model of disability (Swain and French, 2000)
- Recognise that although the child with autism may need to learn adaptive skills, so too will society. Services challenge the child as much as the child challenges services

- Enable parental access to literature that promotes a positive view of parenting disabled children
- Support parents with evaluating whether connecting with other parents of disabled children is right for them, at that time and, if so, facilitate engagement with parents who have positive experiences of parenting children with similar abilities and challenges
- Include parents in inter-professional discussion about diagnosis
- Accept that, if parents are challenging what is being offered to them, then an alternative needs to be found which suits them better as a family and fits with their parenting philosophy.

In order for these developments to occur in practice, however, professionals will need to be supported with reflecting on and transforming their own perceptions of disability. Social model researchers need to support this by making explicit practical changes that will enable shifts in thinking. Arendt (1951) suggests that ordinary people commit oppressive acts, not necessarily through maliciousness but rather because of a misguided belief that what they are doing is for the greater good. Armstrong (1999) cites Sibley's (1995) concept of the 'oddness of the ordinary', acknowledging that the majority may have simply come to accept certain practices as 'normal' and 'how it is', without appreciating the potentially exclusionary nature of these. The social model, supported by a clearly articulated and achievable framework for practical change, will empower professionals to reassess their perception of what constitutes 'doing good' in

relation to disability, to surrender the burden of expertise, develop new collaborative practices and to explore accepted practices from different perspectives. A body of literature is starting to emerge which challenges the application of individual model practices to people with ASDs. These works challenge the previous assumptions about the experience of parenting a child with autism (e.g. Green, 2003; Hodge, 2005; Smith and Goodley, 2005; Waltz, 2005). This study will contribute to this discussion both by identifying practical strategies to enable change and demonstrating the value of generic disability research to the development of autism services. The question of how we can improve service provision for people with autism and their families is challenging and complex. However, conducting this research has shown me that if we are to find out what the parents of children with autism want and need, in order to achieve their goals, then we should simply ask them.

In this final chapter I have, therefore, recalled the foci of previous chapters. I then synthesised the meanings and essences of the experience of parenting a child through the diagnostic period (Moustakas, 1994). I revealed that the parents underwent a circular journey and identified four major transition points. I argued that professionals, working within an individual model of disability, negate rather than enable the parenting experience. The motivations of professionals were then considered and placed within the context of the political agenda. I claimed that the government, by employing, within the legislation, conflicting discourses, has trapped professionals within an individual and social model dichotomy.

I also related my findings to previous studies, arguing that the evidence here disputes the autism specific investigations that promote a predominantly negative image of parenting. Rather, the results of this study support and

extend previous findings which have arisen largely out of generic disability studies and which claim that the experience of parenting a disabled child is a more balanced one.

A critique was offered of the research process for this study, with Lifeworld evaluated as a useful methodology for emancipatory research. I identified trialling different methods of presenting the data and utilising computer support packages for analysis, as areas for my own development. Suggestions for areas of future research were also made, emphasising the need for researchers to support professionals with identifying mechanisms for removing barriers to inclusion and entitlement, thereby making the theory of the social model a practical reality. The chapter concluded by suggesting how professional practice might develop in order to move away from an individual model focus on deficit and to embrace a social model agenda. This would mean enabling professionals to support parents with reframing their attitudes to disability, celebrating positive experiences and, collaboratively, identifying and removing barriers to the achievement of aspirations.

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