

**Report to the National Council for Special Education
Special Education Research Initiative**

**Parents of Children with Autistic Spectrum
Disorders (ASD):
A Survey of Information needs.**

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Disclaimer

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EXECUTIVE SUMMARY

The primary aim of this study was to explore the information and education needs of parents of children with Autistic Spectrum Disorder (ASD).

Methodology

Six focus groups with parents of children with ASD, were conducted over a two-month period in 2005. Focus groups lasted for approximately two hours each and took place in the evenings. A total of 27 mothers and 11 fathers participated.

The focus group questions emerged from a literature review of parents' experiences of having a child with ASD and parents' perceptions of their information and education needs. Literature pertaining to focus group interviews (Kruger, 1988; Merton et al. 1990; Morgan, 1997; Vaughn, 1996) was also reviewed. In addition, advice and guidance was obtained from two experienced lecturers/practitioners who each directed and ran several focus group interview projects within their own departments.

The topic guide devised for these focus groups addressed the following questions:

- 1) What were parents' experiences immediately following the diagnosis of their child with an ASD?
- 2) What were parents' past and current information and education needs?
- 3) What were parents' primary sources of information?
- 4) How satisfied were parents in terms of the quantity and quality of information offered to them? Finally,
- 5) What were parents preferred sources of information?

Summary of Findings

The difficulties experienced by participants at the time of diagnosis appeared to be compounded by the way in which the diagnostic process was handled by the professional(s). Moreover, parents of younger children who are likely to have

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struggled to have their child's past and current needs met may anticipate a similar struggle in terms of having their child's future needs met. Many parents stated that it would have been helpful if the diagnosing professional(s) informed them about the positive as well as the negative aspects of the ASD and how it might impact not only on the child's development but on the family's way of life. It is also possible that too much negative information may be inappropriate at this time and that this added further stress and anxiety to an already delicate situation.

During the diagnostic process, parents reported having to deal with several professionals and services at the same time which often led to more stress. Similarly, parents felt that the lack of collaboration among service providers and professionals was somewhat responsible for their having to discover themselves which needs were met by the different services.

Parents' experiences around the time of the diagnosis may predict future family adaptation to the ASD, parental stress, parents' information and learning needs as well as the quality of the parent-professional relationship. In light of this, the diagnostic process appears to have an all-encompassing influence on parents' perceptions, experiences and sense of empowerment in the immediate and long-term future.

Despite the family's GP or the public health nurse being the first point of contact for many families, neither of these clinicians was perceived by parents to be helpful in terms of being able to answer specific questions or provide them with practical information on ASDs.

Parent participants reported having significant information and education needs before, during and after the diagnosis. Indeed, education was a high information priority for parents in this study. Parents also reported wanting practical advice on how to apply what they learned from books or training programmes to everyday living with their child. In terms of the child's future, many parents were concerned about the child's level of independence and their ability to maintain relationships. Parents were also worried about what would

happen to their child if they themselves became ill and could no longer take care of them.

The majority of parent participants stated that meeting other parents of children with ASDs who had or were experiencing similar difficulties was beneficial and that strategies should be put in place to facilitate this.

Most parent participants searched intensely for information following the diagnosis including attending as many lectures and seminars related to ASDs as possible. Others reduced the intensity of their search for information subsequent to the critical period subsiding. This may indicate that while all parents searched intently for information prior to and after the period of the diagnosis, only some remain active information-seekers. Different parents may have wanted and benefited from different amounts of information. Therefore, professionals and service providers need to be aware of the potential variability in parents' information coping styles if they are to effectively meet the information and education needs of parents.

The themes identified in this study will now be used to inform future quantitative investigations of information needs and their correlates.

Conclusion and Relevance for the Sector

This study highlights some failures in the provision of effective information and education services for parents of children with ASDs. The provision of accurate, reliable and relevant information should be based on a multidisciplinary approach where it is shared and made accessible through health, educational and legal organisations. Information may equip parents with the knowledge, skills and confidence to advocate for their child with ASDs. Although it cannot guarantee that families will be allocated appropriate services and support relevant to their child's needs, it may help them to face potential challenges and problems with a greater sense of empowerment.

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Many of the concerns and information needs expressed by parents involved a need for more information about educational provision for their children. Other concerns related to more general provisions. It is imperative that those involved in education should be aware of these concerns and needs. It is intended to disseminate this information through conference presentations and peer reviewed publications.

Chapter One *Introduction*

When a child is diagnosed with a physical disability or a developmental disability, parents are often thrust into a flurry of emotions. Experiences around the time of the diagnosis, particularly in relation to the manner in which the diagnosis is disclosed or managed by professionals, can have a significant and long-term impact on parents' psychological wellbeing. For example, parents' level of satisfaction with disclosure of the diagnosis may be associated with the structure, manner and level of information offered to parents during this time (Baird, McConachie and Scrutton, 2000).

According to Stoner (2005), parents' first reaction following a diagnosis is to look for information and practical advice. This response, be it immediate or gradual, brief or intense, is thought to facilitate adjustment and adaptive coping (Beresford, 1994; Lazarus and Folkman, 1984a, 1984b; Whitaker, 2002). Searching for information may also be an alternative way of handling the diagnosis as opposed to seeking emotional support (Seligman and Darling, 1997). It may help parents to respond more effectively to a range of life-changing events that may invoke stress (Starke and Möller, 2002; Stoner, 2005). It may also give parents a greater sense of empowerment in managing daily routines and activities (Nachshen and Minnes, 2005; Shepard and Rose, 1995) as well as increase family adaptation (Heflinger and Bickman, 1997; Lam 2003).

Several studies report that for parents of children with ASDs, life proves more difficult and frustrating than for parents of children with a long-term illness or developmental disability (Bouma and Schweitzer, 1990; Koegel and Schreibman, 1992; Randall and Parker, 1999). Parents may experience increases in stress, depression, anxiety, financial difficulties or relationship problems as well as decreases in self-competence and self-confidence (Fitzgerald et al. 2000; Symon, 2001). This may be caused or exacerbated by a combination of factors including an overall lack of information. When individuals access unhelpful information, this may frustrate them even further (Nicholas and Marden, 1997).

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The majority of parents will need a range of supports in order to cope with the demands of caring for a child with a developmental disability, including information, support, social support (e.g. expanding a parent's social network), community services (e.g. access to professionals services), respite care and financial support (Bailey, Blasco and Simeonsson, 1992; Bailey, Skinner, Correa, Arcia, Reues-Blanes, Rodriguez, et al. 1999; Carr and O'Reilly 1996; Chadwick et al. 2002; Ellis, Luiselli, Amirault, Byrne, O'Malley-Cannon, Taras, et al. 2002; Treneman, Corkery, Dowdney and Hammond, 1997). The type of support needed may be determined by a range of child, parent and situational variables including the child's behavioural problems, motor impairments, parents' gender, parenting roles, parents' socioeconomic background and parents' attitudes to childrearing (Albanese, San Miguel, and Koegel, 1995; Bailey and Simeonsson, 1988; Gowen et al. 1993; Granlund and Roll-Pettersson, 2001; Pain, 1999; Sparling and Lowman, 1983; Turnbull and Turnbull, 1990). In addition, mothers are known to experience more stress than fathers especially when it comes to managing their child's behavioural problems (Hastings, 2003; Moes, 1995) whereas fathers appear to be more affected by their family's financial situation (Rodrigue, Morgan and Geffken, 1992).

Findings from the studies cited above, as well as those of similar studies, suggest that information needs should be examined from a multilevel perspective where needs are explored in relation to a variety of child, parent and contextual variables. For example, Ellis, Luiselli et al. (2002) examined the needs of families of children and adults with a developmental disability. Forty-seven parents of children attending either a day-school programme (aged between three and 12 years) or a residential-school programme (aged between eight and 22 years) participated in their study. Ellis et al. (2002) found that parents of younger children reported the greatest number of needs including a need for information compared to parents of older children. Parents of younger children reported a greater number of needs because they were more likely to have been newer to the service system and therefore, had fewer experiences of dealing with service providers and professionals compared to parents of older children (Ellis et al. 2002).

It is equally important to explore the ways in which parents would like their information needs met. For example, parents may prefer to attend parent education

programmes at night, during school hours or at the weekend (Dangel and Walker, 1991). They may demonstrate a preference for receiving information from clear and detailed booklets (Mitchell and Sloper, 2002) or a preference for accessing information from the Internet (Cook, Rule and Mariger, 2003). Furthermore, the quantity of information is also significant given that too much information can be as challenging as too little (Goore, Mangione-Smith, Elliot, McDonald and Kravitz, 2001).

1.1 The present study

Despite the significant role that information may play in helping families to cope with their child's diagnosis, no known studies have conducted a comprehensive examination of the information and education needs of parents of children with ASDs. A potential reason for the lack of studies with this group of parents may be that the provision of services including information and education support for families is often based on what professionals believe families need rather than asking parents themselves what their families need (Walker and Riley, 1989). Furthermore, few studies in the area of developmental disability have successfully examined the information needs of fathers. Perhaps the reason for this is that mothers tend to spend more time with their child than fathers, who are usually working. Similarly, on a more practical level, mothers tend to be more available to participate in research than fathers which might explain why there is so little information relevant to paternal needs (Bailey and Powell, 2005).

The primary aims of the present study were to explore parents' information and education needs. It was hoped that the information obtained would inform future quantitative investigations of information needs. As this was a relatively unexplored area of enquiry a qualitative methodology was used. The next chapter outlines the methodological approach in greater detail

Chapter Two *Methodology*

Focus group interviews were used to examine the experiences and information needs of parents of children with ASDs from their perspective. Focus groups are discussions among a purposively selected group of participants and are used to explore participants' views on a specific topic or area of interest (Krueger, 1988). According to Pain (1999), focus group interviews are the ideal method for assessing the information needs of parents not least because they offer parents the opportunity to engage in open discussions with other parents. Another advantage of using focus group interviews is that they facilitate quantitative and qualitative paradigms through planning and structure while at the same time, allowing for interaction between participants (Vaughn, Schumm and Sinagub, 1996). Indeed, group discussion benefits from the dynamic interaction between participants which sets it apart from other qualitative methods (Morgan and Krueger, 1993). Focus groups also afford the opportunity to examine parents' beliefs, feelings and experiences in their own words and at a deeper level (Gibb, 1997). Similarities or differences between participants may be identified during the group discussion rather than such conclusions being drawn only at the analysis phase (Morgan, 1997). Finally, focus groups may be used to generate questionnaire items or to revise pre-generated items (Morgan, 1997).

Krueger (1988) suggested that it may be preferable to make focus groups homogenous in terms of gender, should the discussion be of a sensitive nature. However, all of the focus groups in the present study consisted of both mothers and fathers for two reasons. Firstly, several parents informed the researcher that parents of children with ASDs are asked to participate in many studies throughout the year; this can be frustrating and can lead to research fatigue. Therefore, it was anticipated that the number of parents, especially fathers, who agreed to take part in this study would be quite low. Secondly, it was concluded that having mothers and fathers in the same focus group might not only enrich the discussion for both sets of parents but that it might also open up channels for further understanding of key topics and areas of concern during the analysis phase.

In line with Merton, Fiske and Kendall (1990), three principles were followed in order to conduct successful focus group interviews. Firstly, a wide range of topics was addressed during the interview process to avoid confining the discussion to those topics deemed important by the authors. Secondly, participants were provided with a description of the purposes of the focus groups prior to the actual event and by agreeing to participate, were already motivated to participate and share their experiences with other members of the group. Finally, the conduct and analysis of the research was grounded in an awareness of the participants' personal and social context, since these may have influenced their responses to questions and to the remarks made by other members of the group.

In terms of analysing the data, Morgan (1997) claimed that it is important not only to recognise the influence of the group on each individual but also, the influence of each individual on the group. Processes and interactions that occur within a group may be influenced by the individuals who make it up. Morgan also proposed coding focus group interviews using three approaches: to record (a) all references to a given code, (b) a participant's references to a given code and (c) whether each group made references to a given code. Similarly, there are three ways to determine the importance of a topic: (1) the number of groups that highlight the topic, (2) the number of participants within each group that mention the topic and (3) the overall interest generated among the group members on the topic (Morgan, 1997).

2.1 Sampling and recruitment

Purposive sampling was used to recruit participants. Participants were selected on the basis of predetermined characteristics relevant to the study. The selection criteria were that (a) parents had a child with an ASD; (b) the child was aged between 4 and 14 years and (c) the family resided in counties Dublin, Wicklow or Kildare. Thirty-eight parents participated in the focus groups. Originally it was intended to recruit ten parents for each group interview. However, this proved to be difficult due to the unpredictable nature of parents' schedules which the researcher anticipated. A total of six focus group interviews were conducted over a two-month period in 2005.

Parents were recruited in four ways: firstly, the researcher presented the study to a group of 30 parents attending an evening ABA training programme in a school.

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Secondly, several ASD-specific service providers located in Dublin, Wicklow and Kildare, including several schools, were asked to identify those parents whom they felt might be interested in taking part in the study, and to send them an information sheet, a consent form and a stamped-addressed-envelope. Thirdly, the researcher was aware of an ongoing study being conducted by the Department of Psychiatry in Trinity College Dublin in conjunction with St. James's Hospital with parents (N = 200) of children with ASDs from all over Ireland. This research team agreed to send out 200 flyers inviting parents to participate in the study along with their monthly newsletter. The researcher's contact details were also included on the flyer. Finally, the various ASD-specific organisations and parent groups across Ireland were emailed about this study. The first and third methods proved to be the most effective.

Out of the 38 parents that participated in this study, 27 were mothers aged between 35 and 46 and 11 were fathers aged between 36 and 45 years. All had children aged between 4 and 14 years with classic autism, Asperger's syndrome, Pervasive Developmental Disorders (PDDs), higher functioning autism or PDD-NOS (PDDs not otherwise specified). All children were currently attending either an ASD-specific school, a special class in a mainstream school or a mainstream school. **Table 1** shows dates, gender, number of parents and where each group session took place.

Table 1 *Date, Gender, Location and Number of Parents who participated in Focus Group Interviews*

Focus group date	Gender of parents	Interview site
18/ 09/05	8 mothers, 2 fathers ^a	Dublin
19/09/05	5 mothers, 1 father ^b	Dublin
20/10/05	3 mothers, 1 father ^b	Dublin
21/10/05	2 mothers, 2 father ^b	Dublin
25/10/05	5 mothers, 2 fathers ^a	Kildare
26/10/05	4 mothers, 3 fathers ^a	Kildare

Note. ^aCouples present

^bTwo parents did not attend due to unforeseen circumstances.

2.2 Conducting the Focus Groups

Six focus groups were conducted over a two-month period. Focus groups interviews lasted for approximately two hours each and took place in the evenings on either a Tuesday or a Wednesday night in accordance with parents' preferences. Four focus groups were held in a small and comfortable room in Trinity College Dublin. The final two focus groups took place in a national school in Co. Kildare.

Parents were asked to complete a short demographic questionnaire for the purpose of identifying their age, address (in order to organise the groups in terms of location), contact details, their child's age, the type of ASD and the child's educational setting. They were also asked to sign a consent form indicating that they agreed to the recording of the sessions. Each focus group session was recorded using two audiotapes; the second recording acted as a backup.

Topic Guide

The focus group questions emerged from an extensive literature review of parents' experiences of having a child with a developmental disability (Baker, Blancher, Crnic and Edelbrock, 2002; Bouma and Schweitzer, 1990; Donenberg and Baker, 1993; Floyd and Gallagher, 1997; Hastings and Brown, 2002b; Henderson and

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Vandenberg, 1992; Koegel et al., 1992; Plant and Sanders, 2007; Schopler and Mesibov, 1984; Tobing and Glenwick, 2002; Weiss, 2002) as well as parents' perceptions of their information needs (Ateah, 2003; Bailey and Simeonsson, 1988; Gowen et al. 1993; Granlund and Roll-Pettersson, 2001; McConkey, 2003; Murray, 2000; Scharer, 2002; Westling, 1997).

Each interview proceeded in a similar fashion. The same discussion guide was used with each focus group, ensuring a level of consistency. There was also certain flexibility in that there was room for probing or discussing emerging or unanticipated topics deemed relevant to the focus of this study. The interview schedule consisted of five questions separated under two broad headings: (1) Parents' Experiences immediately after their Child was diagnosed with an ASD and (2) Parents' Current Experiences.

Focus Group Schedule

- 1) What were parents' experiences immediately following the diagnosis of their child with an ASD?
- 2) What were parents' past and current information needs?
- 3) What were parents' primary sources for information?
- 4) How satisfied were parents in terms of the quantity and quality of information offered to them? and finally,
- 5) What were parents preferred sources for information?

Focus Group Procedure

The focus group sessions were conducted by a two-member team: a moderator and an assistant moderator. The moderator's role was to guide each interview using the interview schedule, facilitate the discussion through use of probes for further comments, and summarise key points raised by parents throughout and towards the end of each interview. Parents were frequently requested to comment on how representative the summaries were of what was previously discussed. The role of the assistant moderator was to take field notes during and immediately after each interview, manage the audiotapes and keep track of time. During the five-minute break and after the completion of each interview, the moderators discussed the field

notes, focusing on the main points that were raised by participants and the overall nature of the interview.

2.3 Data Analysis

One focus group interview was fully transcribed by the moderator while the other five focus group interviews were fully transcribed and all six analysed the assistant moderator. Field notes were also used where necessary. Interviews were transcribed in Microsoft Word, saved in Rich Text Format and imported into *Nvivo*, which was used to organise and analyse the qualitative data.

For the purposes of the current study, there were two units of analysis: the group and the individual. Inductive and deductive methods were used to analyse the data in line with content analysis (Berg, 2004). Firstly, a set of codes were drawn up from the previous literature review. Secondly, each transcript underwent section coding in *NVivo* initially using the questions in the discussion guide as the main categories. New codes were developed by reading and rereading each transcript several times with the aims of the study in mind. These new codes were then applied to transcripts, while old codes were revised or redefined until a final set of codes and categories were established. This is in line with Vaughn et al.'s (1996) data analysis procedure, in which the development and revision of categories is an ongoing process. Codes that were deemed important included those that (a) occurred in four or more groups or (b) were discussed by participants for some considerable length of time. Although the aim of this study was not to compare groups, it was anticipated that group differences might occur especially where participants were linked in with different services. For example, references to specific services and voluntary groups were anticipated and made by certain focus groups with children with Asperger's Syndrome.

During the coding process, all focus groups were compared in a cross-focus-group analysis in order to identify common themes. Following this, similar themes were combined into categories. Apart from analysing verbatim transcripts, the credibility of the findings was also established by asking three researchers external to the research project to read through the interviews and independently evaluate the validity of the codes, themes and resulting categories developed during the

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preliminary analysis. In line with Vaughn et al (1996), any discrepancies or disagreements between the data analysts in relation to the categories were negotiated until all parties agreed. In addition, all participants in the focus group interviews were sent a summary report of the findings and requested to comment on the content and the accuracy of the report in depicting their experiences as parents of children with ASDs living in Ireland, as well as their information and education needs.

Chapter Three *Results*

This chapter presents a thematic analysis of the findings of the six focus groups conducted for this research.

3.1 Diagnosis

Initial Suspicions

The majority of parents stated that they suspected that there was something wrong with their child's development before a formal diagnosis was made by a clinician. The child behaved or responded differently from other children and developmental milestones which were reached tended to occur later than normal. However, many parents reported that they found it difficult to pinpoint their child's exact problems which often meant that their initial suspicions were discounted by professionals or family members.

You know the way when you're a mother you just notice something is wrong with your child? You just can't put your finger on it, but you know that there's something wrong. *Focus Group A ((P5))*

So I guess I suppose our immediate feeling was, it was not a huge shock in the sense that it was kind of all, the evidence was building up that he had some sort of, he was on the spectrum. *Focus Group C ((P1))*

Looking back I can say this now but at the time you knew there was something. But my first real thing of saying there is something here was the time his younger sister fell and he was oblivious to the fact that she had fallen and hurt herself. He was in his own little world and I kind of went that's not normal. He was at school then and I went, there is a problem here. *Focus Group B ((P2))*

But like that, I knew there was something and just little clues along the way especially with language. I know she didn't use language or understand language or communicate the way other children did, children who were younger than her. *Focus Group E ((P5))*

Three types of parents were identified. Firstly, there were parents who had suspected that there was something wrong with their child and were relieved by the diagnosis because it confirmed their suspicions. Secondly, there were those who suspected there was something amiss but were still overwhelmed by the diagnosis;

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words such as 'shocked', 'saddened', and 'devastated' were used by these participants in attempting to convey their emotional reaction to the diagnosis. Finally, there were parents who were unaware that there was something wrong with their child until another person, usually a teacher, brought the issue to their attention.

Many parents focused on the child's ability as opposed to their disability. For example, one parent was surprised when the Speech and Language Therapist questioned the child's language skills because she believed that he spoke extremely well, even if it was with an American accent. Others challenged the original diagnosis and sought a second or third opinion before accepting the final outcome. In some cases, it took parents several months and sometimes a year to come to terms with the final diagnosis. There were also incidences where teachers might not have considered the presence of a DD but thought the child to be a trouble maker. For these parents, relief formed part, though not all, of their reaction to the diagnosis:

I think we were actually relieved that there was actually something that could be worked with. *Focus Group B ((P3))*

Well I can say that it was a relief. But it was a relief for me that there was a name for it. But for my husband and for other relatives, it was devastating. And it was a relief that went into a huge bout of shock and a huge freefall for about a year when you grapple with I can honestly say a tear strained A4 page that [name of child psychiatrist] scribbled for me, calling all the numbers, looking for to see what can I get, what can I get and finding out that I could get very little if nothing. And then I kind of settled into what I found worked. But initially a free fall. *Focus Group F ((P1))*

[I] just couldn't handle [the diagnosis] and I was devastated and every time she said something I was like ahh [sic]. *Focus Group A ((P4))*

It's the first thing you realise...we found out, [wife] was kind of cut up to bits, I kind of had suspicions and sort of said to [wife], you know , no, no, no, let's wait to hear, but there was suspicions there telling you. But then when we heard it, it was just a shock. Same type of thing like, kind of hits you like a stone. *Focus Group A ((P7))*

I think certainly from our perspective, I think we knew from the age when [child] was two - two and a half years old that there was something up. *Focus Group C ((P1))*

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They do some things that are not typical [of an ASD] and they're the ones probably you hang on to; [you] hang on to them and say 'that's really normal, that is. *Focus Group A ((P2))*

Now [wife's friend who runs a playschool] reported back to [my wife] and said look I think you should get [child] checked out because he's not communicating the way children should communicate and he doesn't like the feel of certain substances. *Focus Group D ((P4))*

Often, when parents received a diagnosis, they immediately thought about the impact of the disorder on the child's development and the implications of the disorder in terms of the child's future. Although the child might be very young, some parents imagined what the future would hold, for example, whether the child would be capable of maintaining normal relationships with the opposite sex, or whether she or he would be capable of reaching third level education. Despite having these and similar concerns, parents stated that there was nothing in place for the child or the family after the diagnosis to abate their fears.

When we got our diagnosis, my husband said, you know I can laugh about it now but it wasn't funny at the time and this is when autism was first mentioned and we were both in shock and I was obviously physically upset, and I said at the exact same time, will he have friends? Will he ever get married and my husband said will he go to college and get a job? It was so funny. And we laugh at that now. *Focus Group B ((P5))*

Well the diagnosis of [child] really hit me hard, my wife as well but I was quite upset after, I mean physically upset. It really hit hard and it was hard to deal with. By the time [sibling] came along I thought, God we can't be that unlucky as to have a second one but you're sort of hardened to it. And Professor [name], I remember well, we said well you know, now we have a diagnosis what do we do next? What's out there? And she said I'm so sorry to tell you this that there is nothing for you. *Focus Group D ((P3))*

My husband said what's the prognosis? And [the clinician's] answer to us was quite flippant. It was he could end up in [name of intellectual disability institution] or he could be a mathematics professor in Trinity. But that was devastating to my husband that the other was a possibility. *Focus Group F ((P1))*

Prior Knowledge

For parents whose children were diagnosed over nine years ago, many had no prior knowledge of ASDs and could only associate it with the Oscar-winning film Rainman.

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Although the label existed on the grapevine for several years, it was a relatively new area of interest in Ireland and information was either scarce or vague. Very few professionals were trained to recognise the symptoms and even fewer were qualified to diagnose the disorder. The lack of information only added to parents' concerns, particularly in relation to how the child might cope in the future.

Basically, it was on his third birthday, he was three years of age...when I found out. I was told by the [doctor] and a speech and language therapist, a psychologist that my son, after doing all the tests and things that he was ASD. I'd never heard of ASD in my life, I'd no idea it had anything to do with autism or anything and although I did suspect, because he'd given me just one leaflet to take away, and I didn't understand why they had given me this leaflet to talk about ASD and the word autism was kind of thrown in, every now and again. But needless to say you go with an open mind and you hope that when you go, and you're expecting the best rather than the worst, and when she didn't include the word autism, I hadn't got a clue. *Focus Group A ((P4))*

Like we obviously came in and like everybody else we didn't know anything about it. We had no reason to know anything about it. We had heard of autism before but wouldn't have known what it was. *Focus Group F ((P2))*

We went to [name of professional] and he's a neurologist and he did all the tests and he said no, no, no, he hasn't got epilepsy and we were so relieved...but he said I think he has something called Asperger's Syndrome and we said WHAT? [And] at that stage the only thing anybody knew in Ireland about autism was the Rainman you know. The film was about the only thing that we knew about it. I think there was no information to be had anywhere. *Focus Group D ((P2))*

You were saying like on the negative side you're told your child has autism and you've seen Rain Man, and your like 'oh Christ' and your brain can't stop going ten, 20, 30 years down the line, where your child is going to be then, and you think 'oh Christ'. It is heart wrenching. *Focus Group A ((P9))*

Delay in the Diagnosis

Parents described difficulties in having their suspicions validated by family members. This, combined with the struggle to obtain a formal diagnosis, only exacerbated their existing feelings of worry, frustration and social isolation. Indeed, parents were often passed from professional to professional without any mention of the ASD label until they raised the idea themselves. Only one parent reported having a positive experience in terms of obtaining a formal diagnosis. Whether having no label resulted from professionals' lack of knowledge, lack of relevant qualifications to

diagnose, a reluctance to diagnose or the presence of other developmental disabilities such as learning difficulties, parents felt obliged to seek information and services relative to their child's needs themselves. Parents in this study stated that they soon discovered that a child without a label was a child without entitlements. In the end, parents had no other option other than to strive for the diagnosis with some going abroad in order to kick-start the process.

We had been in [name of clinic] for the best part of a year. In and out with no diagnosis forthcoming. *Focus Group B ((P1))*

I don't care what you actually call my son, he needs help, he has a problem and you can put whatever label you want on it. *Focus Group A ((P?))*

During the process of getting the diagnosis, we kept getting first of all [that] minor speech impediment ... was the problem. So that kind of...you lose a couple of months but that kind of gives you comfort for a couple of months. And then you wait for another diagnosis. [Eventually] it became a minor learning difficulty. *Focus Group F ((P2))*

But like that the [public] health nurse I said it to her even two days afterwards I said it to her 'there is something definitely wrong with my son' the same thing 'your imagining it, he's grand, he's born premature, he just needs to catch up you know . And this was ongoing and ongoing until I got so fed up that I just went to my GP. *Focus Group A ((P5))*

I kind of noticed myself at about four that there was something different with [child] and for a long time I was saying it to people and everyone kept saying no it's you. *Focus Group E ((P3))*

We had been asking people for about a year beforehand was it autism and they kept telling us no. *Focus Group F ((P3))*

And when I went to my GP he sent [child] for a physical check up. That was the hearing, the whole lot. He said you'd want to be very wary about giving him a label and at that stage I was going 'label'? What do you mean? I didn't ask him. The label of ASD you know. And then I went looking for the label because you don't get any services without a diagnosis. *Focus Group C ((P2))*

It's like getting a label. People use to say to us early on what do you want a label for? At least if you know what you're up against, what you're fighting, you can then go and fight it. *Focus Group D ((P3))*

Lack of Professional, Informational and Emotional Support

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The majority of parents in the present study reported receiving very little or no support from professional organisations around the time of the diagnosis, and reported a lack of useful information, direction or guidance. One parent spoke of her disappointment upon discovering the absence of support following diagnosis. Instead, parents were left to cope with the diagnosis with little assistance from professionals and service providers working in the area of ASDs. Parents were informed that early intervention was critical and yet, they found that there was a dearth of services available to children with ASDs. Furthermore, if services were available, parents were not told where these services were located or how to access them. Parents perceived a reluctance among professionals to share information with them, even if this was not what was intended; ultimately, parents were left to make their own enquiries.

But basically, like at the time, we couldn't see that the information we got, it was just so negative and so unhelpful. It was only looking back that we suddenly realised you know, this is, this is not right. No parent should be treated like that, be brought in and given a leaflet and told your child is diagnosed, there you go, go and think about it and come back in a week and tell us how you feel. Oh, and if you want to go on the Internet, if you've got a computer, go on the internet, type in the word autism and, you know, hopefully you'll get more information. Which made things even worse because you were getting you know, more information, which you didn't know if it was or wasn't connected with your child, so to me the diagnosis of my son was just absolutely horrific. *Focus Group A ((P4))*

I think one of the other things that I found very negative, that we were told in the hospital was right, ok, we ended up asking them, is he autistic or not? They said yes he is, right. But as they were going through, well what is our next step or whatever, I'm not sure who it was but one of them turned around and said you know, don't get your hopes up, because the services out there at the moment are brutal. [And] I felt like saying you've just told me that my child is autistic and now your telling me there's nothing out there? [Why] don't you kick me again? *Focus Group A ((P8))*

We had to do research and read everything and fight for everything. *Focus Group B ((P6))*

We had a diagnosis but we had nothing else, absolutely nothing else. Nothing. We weren't being referred on to anywhere else. We were just being told our child had this condition and that was it. And they couldn't tell us how it was going to progress. They couldn't tell us how they were going to treat it. Nothing. Absolutely nothing. *Focus Group D ((P2))*

No pathway. No guidance. No specialists. *Focus Group B ((P5))*

We didn't get any sheets. We were lucky if we got a piece of paper. I mean we basically got verbally told by [name of child psychiatrist] yeah he's on the autistic spectrum and then I think a week later we got an official diagnosis written up later. But I suppose [wife] just got on with it then really. I mean ... it was slightly different for us in a sense that we were coming to that conclusion ourselves. So whilst it was sad obviously to have that formally confirmed, it was kind of not maybe the greatest shock in the world either so I suppose we'd been thinking like that. *Focus Group C ((P1))*

You're not given any information. You're given a diagnosis and then you're told goodbye. *Focus Group F ((P3))*

Moreover, parents felt that opportunities to seek help from professionals were restricted to normal working hours (i.e. Monday to Friday, nine to five), despite parenting in general being a twenty-four hour experience. Although a rare occurrence and depending on the service(s) available, there were three parents in this study who did report having access to professional support over the telephone on an ad-hoc basis:

And if there's a problem that occurs that we feel really needs, I can pick up the phone and say look [name of teacher] can I talk to you? This is happening. How are we going to cope with it? What can we do? And I know that she will come back to us and we'll discuss; tease it out. She'll talk to [child] you know, whatever, whatever help she can give. Now sometimes she's not able to. Sometimes there are problems that there are no simple solutions but...it would be great but there aren't. But it's that sort of access that most people don't have. *Focus Group D ((P2))*

[But] even my wife was able to talk to [professional] today for nearly an hour on the phone about issues. So we have someone to go there to. *Focus Group D ((P3))*

However, other parents indicated some surprise at the level of service this parent had received:

And that step that you had, 'come back and tell us how you feel'. We didn't have that. We had 'we'll post you out a report' and it's like that's their job finished, as you say, that's our bit done. *Focus Group A ((P7))*

3.2 Information

Information Searching

By the time parents in this study received and accepted the diagnosis, they were eager to move forward. Although the diagnosis may have been perceived in different ways, the majority of parents found themselves propelled into a process of information-searching and service scouting. However, parents eventually established that there was very little information available and that which was accessed was done so through perseverance.

I'm not saying you don't, but it's one of those things. You still have to pull yourself back to reality and say to yourself now where do I go, and what do I do; because if you continue grieving, your child is going to be the person to lose out. *Focus Group A ((P9))*

We weren't told of the services available, like who we should speak to. We weren't told about [service provider]. When we did hear about [service provider] I presumed it was a service like say for example [residential service for people with special needs], because I have a sister who's mentally retarded ... So from the square one I really didn't have a clue. I was totally blind as to where I was to go. But I persevered and I found out and I had to find out all of the information for myself about the benefits, I had to find out about the home tuition, I had to find out about the schools that were available, all of that I had to actually find out about on my own. I don't know how many letters I had to [write]. *Focus Group A ((P4))*

You couldn't say that there was any great plan to it. It was kind of just you'd find out something new, some piece of information as to where you can go and then you try to make the best use of it. *Focus Group C ((P1))*

And of course we went on the web like crazy and were like nuts. *Focus Group B ((P6))*

I probably didn't do an honest day's work for about three months afterwards. I sat in the office on the Internet and found out. *Focus Group F ((P2))*

Despite a growing need to have access to information, parents found it difficult to find relevant and useful information sources. Many parents felt that the information they collated was as a result of their own strengths and resources. Accessing information was described by several parents across all focus groups as similar to like fighting a battle. In other words, they felt they were continuously pushing or

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struggling for information from professionals and service providers. For example, one parent was handed a leaflet and advised to come back in a week. Another parent described her experiences of sitting on a bus and accidentally overhearing another couple's conversation about their child with an ASD. Others spoke more generally about this issue:

I mean you know when you're given a diagnosis. You're told there's a diagnosis, bye bye...you're given sheets of information. You're not given a direction or path by which you can go. So you have to find your own way, make your own way and like that find bits of information or talk to people who have been there before so that you can make your own choices and go from there. *Focus Group C ((P2))*

There's nothing there, like you don't kind of get your diagnosis and then basically this is what you need to do. You get your diagnosis and then you walk out and you have to find out yourself what to do next. *Focus Group F ((P2))*

The only way that parents got information was by actually pushing for it themselves. *Focus Group A ((P7))*

I have to be quite honest. You were listening to people talking maybe in a setting somewhere else, just to hear what they were doing. *Focus Group B ((P1))*

So it was really a question of trying to find out about different things, about different places. To be honest the wrong person is here in the sense of trying to explain everything that you had to go through because really it was my wife who was stuck with it to a certain extent on a Monday to Friday basis because I was in work and she's the person on the phone trying to find out, trying to get the right help all that sort of stuff. *Focus Group C ((P1))*

You don't get any information. It depends on your ability to seek out that information yourself. *Focus Group F ((P3))*

It was kind of just you'd find out something new, some piece of information as to where you can go and then you try to make the best use of it. *Focus Group C ((P1))*

Parents stated that they were forced to advocate for their child due to the lack of information available, particularly regarding the availability and accessibility of information on services and entitlements; although services were lacking, parents reported they wanted to know what their child's entitlements were. They felt that it

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was their responsibility to seek answers in relation to services and entitlements. They felt they had no alternative other than to search for information, which often left them feeling exhausted.

You make your own. You cut through the jungle and you make your own way.
Focus Group E ((P5))

Nobody knows it. The school don't even know it. The school don't know it. You ring the department, the department don't know it. So you have to make it on your own. It's like you're making each time...That's what you have to do the whole time to find out about anything. You have to find out. And you ask this person. I don't think you're entitled to that. And then you get on to somebody else and they say oh yes but you have to get on to this person. And you're literally just building little walkways for yourself. And if you don't do it for yourself, nobody else will. Nobody. *Focus Group E ((P4))*

[But] you might have to read 30 books to try to get half of what your child is about. You know it's a lot of reading, a lot of expense where again it just comes down to how do these people diagnose? If they diagnose something, they have 30, you know, all those questionnaires. They have a method of coming up with this. But yet there's no book out there to tell you how they came up with this, why they come up with it and this is the future mapped out. You know. You have to read. You could read and read and read and read but you're not getting to where you need to be. *Focus Group E ((P2))*

Dissatisfaction with Available Information

Overall, parents in this study reported being dissatisfied with the quantity and quality of information available to them following the diagnosis. Any information that was available tended to be unhelpful, irrelevant or vague or worse still, too much, too little and too late:

And basically what they did then is they gave me another sheet which kind of gave me a dreadful picture of what my son could have grown up to be like and it was just horrible. Rain Man and everything, that picture...it was just awful, just absolutely horrific, and I think I cried and cried and cried for a whole two days. *Focus Group A ((P4))*

(P6): [The child psychiatrist] wrote down empathy training, social skills training, eight things and went bye. I went out the door and said where am I going to get all this?

(P1): You feel so lost

(P5): Did you get that?

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(P6): He told me to go get a book on...the mind and I bought the book; never read it. I was devastated. I wasn't even dealing with that. *Focus Group B ((P5))* And again the sheet of paper that I was given was very vague you know saying he has traits similar to those with Asperger's Syndrome. *Focus Group E ((P1))*

One parent emphasised the need to pace the information and make it more pertinent to where the child is at in terms of his/her development.

But when you met good professionals or like went on the courses, you got sort of reading lists and it's so complex. You really need to read. Sometimes we read some wacky books you know and I found the English ones are very good. The English society seems to have really brilliant [books]. I think it was something 'Autism: the facts' and it was really depressing because I read it when [child] was really young...I started reading about puberty and like things I shouldn't have read. So I think information for their age, like at primary a set of information and when they hit puberty...pacing it [because] you can't even believe some of the stuff you have to think about for puberty and it's just totally irrelevant because some of the things from primary are gone kind of by the time they're that age. *Focus Group C ((P4))*

Interestingly, those parents who were fortunate enough to access parent education around this time reported being relatively satisfied with the information they received:

All the information was relevant, accurate. All the interchanges that I had with all the health care professionals, I had a written report after it which was very professional. *Focus Group D ((P4))*

Parents tended to collect information in fragments, which increased the likelihood of information gaps. Many parents described themselves as pursuing different information avenues in order to meet their child's needs. Moreover, some parents stated that they adopted the role of information provider when it came to their interactions with a number of professionals.

The information is not accessible. Even the information that is there, it's extremely hidden...it doesn't tell you, ok; ideally it'd even be nice to have a contact list. It'd be nice to say 'well, here's the areas of expertise that are available, here's the schools, here's an Irish map, here's anyone within your locale. *Focus Group A ((P9))*

I would exhaust every avenue and if the avenues didn't exist, I'd ask the question why didn't they exist? Because what I want to do is I want to take

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advantage of anything that I could for the benefit of my child. *Focus Group D ((P4))*

It was just I was gathering a bit here and a bit there and I had kind of known what it was myself so it kind of came together gradually. *Focus Group E ((P5))*

Parents in this study perceived that meeting other parents of children with ASDs, finding useful and accurate information and accessing appropriate services for their child was down to being pushy, knowing the right people, potluck or a combination of all three. Luck was also associated with having the financial means to take legal action against service providers or the Government.

That's the thing, that's the, we felt the [name of hospital] were brilliant. But again its potluck. *Focus Group A ((P1))*

But you don't have that leaving your assessment centre. You only get the other parents, either through potluck, or when they start maybe, some sort of schooling session, or [name of service provider]. *Focus Group A ((P2))*

I was saying we were very, very lucky because we had access to the Internet at the time. Now I know that everybody nowadays has access to the internet but you're talking about 8 years ago. People didn't and we were just lucky that we did. *Focus Group D ((P2))*

I think we've all learned whoever shouts the loudest the longest gets the most. *Focus Group B ((P7))*

You can call it fortunate or luck or bad luck or whatever but the resources that you put in place, I had the resources to do all this. So I can go along, I can take time off. My wife again is a stay-at-home mum so we had a huge amount of time, free time. I went on effectively I'd say eight to nine months of courses. *Focus Group D ((P4))*

People who have services have fought. *Focus Group F ((P1))*

Other Parents as a Source of Information

In order to cope with having a child with an ASD and its associated behavioural or emotional problems, parents searched for information from a variety of sources. The majority of parents reported that other parents of children with ASDs and the Internet were their greatest sources of information and/or emotional support. The general

consensus among parents was that they valued the information and emotional support from parents who had similar experiences or concerns. Although a vast amount of practical and useful advice including tips on how to handle problem behaviours came from other parents, participants felt that this information needed to be backed up or appraised by clinicians. For example, one parent reported receiving a particularly helpful information pack through a Speech and Language Therapist which was previously developed by another parent and reviewed by the clinician prior to the information pack being offered to other parents. One parent emphasised the difficulty of dealing with information from the Internet, without help or feedback from professionals.

Because it's the only way that most of us have gotten information is other parents have told us, somebody who has been there. *Focus Group A ((P2))*

So with regards to information and where to go and what to do, it didn't come from official resources, it came from people. *Focus Group C ((P2))*

The grapevine I suppose is a way of describing it. *Focus Group C ((P1))*

That should be part of the package that they give you because it's amazing how people only find out what they are entitled to because you hear about it from another parent - By the way I got the home tuition or I got the whatever it was, domiciliary allowance or I don't know. God, there's a pile of them. *Focus Group C ((P1))*

There's all these grants that schools can apply for, for all sorts of stuff and the only way that you find out is if somebody else tells you. *Focus Group E ((P4))*

And we had also the information from the web, information photocopied from books. The do's and don'ts. It's putting that into practice without any help is the problem. *Focus Group D ((P3))*

Well you want a sounding board. You want somebody to say 'this is what I think. What do you think?' *Focus Group A ((P9))*

I probably learned as much from the parents, if not more, than from the professionals. Now the professionals were lovely, don't get me wrong. But the parents have lived it or whatever. *Focus Group C ((P3))*

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Because it's the only way that most of us have gotten information is other parents have told us, somebody who has been there. *Focus Group A ((P2))*

Even your financial entitlements I found through chatting to mums. *Focus Group B ((P5))*

Accessing Information on the Internet

There were mixed feelings reported by parents in terms of accessing information on the Internet. For many parents, the Internet was a major source of information. Before the diagnosis, some parents used the Internet to look up various websites for information on the signs and symptoms of different DD, in order to confirm their suspicions. On the other hand, there were parents who had no access to the Internet and therefore found it difficult to locate and appraise the information.

So when he was assessed in [hospital], I think I'd already researched so much on the Internet that I wasn't surprised that that was the diagnosis. *Focus Group E ((P1))*

And the big problem is, even if you do look on line, you need to be able to use a computer quite well. You need to be fairly proficient. So you have to have the skills in order to get the information. *Focus Group A ((P9))*

You're probably very good, as you say at looking up the Internet and all the rest of it. But probably some people are better at actually gleaning information, like, you know, I found I didn't ask the right questions. *Focus Group A ((P1)1)*

Although the Internet offered parents access to a vast volume of information, this was often unhelpful. Moreover, parents felt that attempting to deal with so much information often left them feeling exhausted. There were numerous sites claiming to have 'cured' ASDs and offering expensive treatments. Parents in the present study felt that other parents who had a child with an ASD were often so desperate that they were deceived of large sums of cash on websites for treatments and therapies that lacked any credibility. Furthermore, parents in the present study felt that other parents depended on the Internet for support because of long waiting lists and a lack of services. Therefore, some parents may feel that they have no alternative but to go down the Internet avenue.

The Internet has been very scary because you read lots of stuff. *Focus Group B ((P6))*

I spent three months on the Internet after the diagnosis and went down about twenty different paths. ABA was just one I went [and] out of the other nineteen. Four or five were useful as well. But I probably dug up a lot of rubbish too. Probably wasted my time you know. *Focus Group F ((P2))*

And I know thousands, like there's thousands of people going [to the US] and those people are paying mortgages, double mortgages for something stupid that never worked for their kid because they're so desperate [when] things slow down or [the] parent is left waiting, they become more and more desperate. *Focus Group C ((P4))*

Parent Education or Training Programmes

In general, education or training programmes for parents were received with mixed feelings. Some parents found them to be highly informative while other programmes or events were criticised for their irrelevance, especially if the information was considered to be culturally unsuitable (i.e. American-based) or idealistic. One parent felt that a particular course she attended was too prescriptive and was not presented in a manner that allowed the concepts to be applied in a variety of contexts. On a more positive note, attending training programmes offered parents an opportunity to meet other parents with similar experiences. However, parents felt that educational courses should be more flexible in terms of when they are offered and the level of commitment that is required from parents.

One thing that I found very helpful ... [was that] we met other parents and that was a huge help meeting other parents. I actually think meeting other parents, even if their child was inevitably different from yours because they're all individuals. ... That's a huge help meeting other parents. It really, really is. I can't stress how much that is. *Focus Group D ((P2))*

And put loads of groups of parents together, which all along we've all learnt loads from each other. *Focus Group A ((P6))*

There were a lot of things talking about puberty and that. All the kids in this group were seven to nine. But they were also American questionnaires as far as I could understand and they were just different. You were just going, this is so irrelevant. [I] think an awful lot of probably the research in the area is American-based so is a lot of the literature. So maybe the social stories are,

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they're not quite relevant to us you know. I don't know how people find that.
Focus Group C ((P3))

But I find that I had the senior social worker come out and she does these you know the Marte Meo, the videos. Then she goes through them with you. So a friend from [child's] school came home and played with him and you know she got me to videotape us having a meal and playing board games and just playing spontaneous games and stuff like that and it worked fine and I got great help but it was far too structured. I need her to go out; I need her to stand at my garden and videotape [child] out on the green because that's the real [scenario]. *Focus Group E ((P8))*

Many parents stated that they spent a considerable amount of time and effort attending training courses on offer at home or abroad in the belief that such courses would be of benefit to their child. While some parents considered themselves fortunate enough to live close to where these courses usually took place, others stated that they had to travel long distances in order to attend a parent education event.

But even the time we went to Belfast we were like two lunatics because there was a whole series of lectures on the next day, and you could pick what you wanted and we were like well if you cover this, and I cover this, we should get it all. Like to try and get as much. And then they are all plugging their own.
Focus Group A ((P3))

It's always difficult and I was lucky I don't live too far away. Some people can live miles away. I shuddered after when I heard people coming from Wicklow. But you're tired. You have three other kids but you say oh I should go tonight and then I come home and I'd be delighted because it was so informative.
Focus Group B ((P5))

We're going to a parents' social group, a thing down in [Co. Meath]. We drive. We've just done a six week module where. We're doing another six weeks starting next week. It's every Tuesday night for six weeks. Drive down to [Co. Meath] straight after work. Get babysitters. It's not a case that people aren't trying. We're going down there. *Focus Group D ((P3))*

We went to everything. Every conference [every lecture].*Focus Group D ((P2))*

Information Needs

Parents were asked to identify their information and education needs immediately after the diagnosis as well as their current needs. There was some cross-over in terms of the type of information they sought. Fifty-six information topics were identified under eight broad themes. These were:

- Dealing with the diagnosis
- The next step
- Health services
- Education
- Financial entitlements
- Legal issues
- Explaining to the child or significant others and
- Future concerns.

Sourcing Information

When a diagnosis was obtained, it proved very difficult for parents in this study to source information on where to go, what to do in terms of the next step, who to contact, what to expect from the child, what was available in terms of current and future services including schools, how to access these and what were the child's abilities as well as their disabilities. The majority of parents identified a number of significant questions for which they found no information or practical advice from professionals or service providers.

You're kind of there on your own in terms of what's the best way of dealing with it; what's the best way to go forward . *Focus Group C ((P1))*

Well what do I do now? Just tell me where to go? *Focus Group B ((P1))*

It's just nobody would tell you. You could sit down and ask them straight in their face. You deal with this on a day-to-day basis. You work in an area where you are seeing autistic kids everyday. In your opinion, if a child came in with similar symptoms, what happened to this child? Will that child go on to finish school? Did they go to mainstream? *Focus Group A ((P4))*

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You have this beautiful baby and then you're told this baby has autism. We're not sure where, you know, life is going to take this baby, you know what I mean? The parents don't know where they're going then. They don't know what to expect. What does it mean is the first thing you're going to say. What will it mean in three years time? What will it mean in ten years time? Twenty years time? You know, will the child be able to look after themselves? Will they be self-supportive. While specialists won't be able to give you those answers, they can provide you and say well with the right intervention you know what I mean. [But] you know, you're just told but that child has autism, classic autism. *Focus Group F ((P4))*

We just saw the education was a problem and social skills was a problem and we wanted to find out well what exactly, what's the reason for the social skills problem? What's the reason with the learning problem? Why is this child memorising everything? *Focus Group B ((P2))*

Information about Entitlements

Similarly, many parents reported that they were unaware of their child's entitlements or of the fact that that they needed several psychological reports in order to access specific disability services. Instead, parents found out about these issues through other parents who were currently in, or had been through, the service mill. There was also very little information available to parents in relation to health, educational or financial entitlements and how professionals and service providers arrived at decisions with regards to who was awarded with what. For example, many parents stated it was quite some time before they learned about the July grant or domiciliary care allowance, despite there being an obvious and immediate need to be informed about such matters. Furthermore, one parent advised that she had to negotiate with several professionals before she found the right information.

The thing is they're looking at; ok you have to send in all the reports. They're not going sit there and go through all the reports and say 'ok, they need eight hours [of a specific intervention]', go through that one and say 'ah yeah, they need seven'. So how they come up with it I don't know. *Focus Group A ((P7))*

It should be a list of schools or if you can't get into those schools, you can go into mainstream and [see] what you can do. All your entitlements. Just give you a list you know what to fight for. *Focus Group B ((P4))*

And you sort of say apply? No. Just send me out the form. I'm actually going to the extent now anything I hear about, I ring...send me out a form or any kind of information and once you get the information, you're inclined to work

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away and maybe if you're lucky. But some, you come up against so many people. Oh but I don't know, he only has AS. He's only? *Focus Group B ((P1))*

They said you were entitled to it, they never said when you'd be entitled to it...or even when it'd be available. *Focus Group A ((P3))*

Nothing is organised. There's no one place that you can go and say 'listen, I have this problem. What am I entitled to? *Focus Group E ((P4))*

Information about Development

In relation to the child's development, many parents were concerned about puberty and sexual matters. Some parents were also worried about their child's ability to maintain a relationship with the opposite sex in the future. In terms of the future, they wanted to know what support services were available to their child following secondary school, for example, if the child was unable to live independently or if parents could no longer take care of their child. Parents in the current study stated that they would have appreciated hearing stories and experiences from parents who had gone through or were in the latter years of the service system. They perceived that by depicting a positive outlook, in terms of the child's future and what they might achieve with appropriate support and resources, may have eased their concerns.

[Just] under the long-term planning. We know under the constitution there's schooling until they are 18. So you kinda [sic] think 'alright, he's occupied until he's 18. *Focus Group A ((P2))*

What I'd like is like just [child] is at moment and he's progressing to some degree and we have ideas that he's either going to make progress or he's not and there's a range of levels that he's going to [and] then to have the information to know well if he makes it to this level, what is the future? What are the options? I mean anything from some element of residential care to some kind of being able to look after himself. You know we don't know where he's going to finish up but we'll do our damnedness [sic] to make sure that he maximizes his potential. But to know what the options are and where. *Focus Group F ((P2))*

Information about Legal Issues and Related Matters

Several parents reported that they had legal concerns in relation to making a will for their child with an ASD as well as issues around guardianship. One participant stated that she was advised to consider carefully the legal and financial implications

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that making a will for a child with an ASD might incur. On hearing this, a number of parents were surprised especially as many of them never considered the financial and long-term care implications of making a will for their child with an ASD. Therefore, parents wanted practical advice in relation to their immediate as well as future concerns.

Because when we were making our wills our solicitor said to us well you may need to come back and look at disinheriting him completely, because you could be doing damage by leaving him anything. *Focus Group A ((P2))*

Oh yeah, there's a landmine. He'd be rich and he wouldn't be entitled to anything. *Focus Group A ((P4))*

See people who left their children their house when they died, the child then had a house and was not entitled to [it]. You know really practical things you know that thinking long term for the child. *Focus Group C ((P4))*

Information about how to communicate with others

Information was also requested on how to approach the subject of a child having an ASD with others, especially with friends and family. Some parents reported choosing not to disclose their child's diagnosis to anyone, including their immediate family. Reasons for doing so included protecting the child from negative attention, especially if parents perceived there might be some improvement in the child's behaviour over time. An interesting finding is that one parent felt that not informing others was associated with her own acceptance of the diagnosis. Other parents felt that it was necessary to inform all parties, including their wider social circle, in the event of an urgent issue concerning the child that needed to be handled carefully. A number of participants stated that information on how to tell the child's siblings or the child that she or he had an ASD may have been helpful.

Even how to handle friends and things. Like I was told should I tell everybody? Like your pride is hurt. You're grieving. You've lost the child that you don't have. And you say we're not going to tell anybody. That's your first. That's natural. But it's the most ridiculous thing. People have to know 'cause [sic] they can't deal with your child unless they know. *Focus Group B ((P5))*

The way I feel about [the child] is because it's so vague, that I feel that I should protect his privacy now for his future. I don't want people saying [the child] has an ASD or [the child] has this because I don't know what way [the

child] is going to turn out when he's older. It may like just, he may adapt better. *Focus Group E ((P8))*

And [my husband] just thought, God if he got rid of the American accent, it wouldn't be so obvious whereas I was laughing because I was going I don't think you'll be able to get rid of that that easily. But he was. And I know where he was coming from on that you know that you just want to make your child as less obvious as possible you know. But he's never going to be brilliant socially but it's just the cruelty of other children that you're trying to protect him from or whatever and trying to make him blend in. [It's] just a worry you know. *Focus Group C ((P3))*

The idea was that we wouldn't divulge that there was anything wrong with [the child] and we did it on a need to know basis. The teachers know obviously. But we felt that if the other children knew, if the parents knew, they might stigmatise him and we weren't prepared to run that risk. And we said well if it reaches a point where it's obvious, well then we'll have to say, but we always managed to avoid that. Now I'm sure the parents might think [the child] is a bit strange or a bit odd. *Focus Group D ((P2))*

Information Related Costs (financial, child and family-related)

Parents highlighted some of the hidden costs incurred by searching for information and services in relation to their child and family. Financial costs included those related to telephone use, postage, travel to and from appointments or parent training programmes and those incurred by childminding. Personal and family-related costs included not being in a position to spending quality time with the child and other family members. The issue of additional financial costs in relation to ordering books or equipment from the UK and the US was also identified.

I had to find out about the home tuition. I had to find out about the schools that were available. All of that I had to actually find out about on my own. I don't know how many letters I had to [post]. *Focus Group A ((P4))*

And I spent about three weeks on the phone finding out who has to get the report. *Focus Group E ((P4))*

I found the stress of trying to get the appointments, you know, to deal with professionals, to get to where we wanted to go. I used to say that if I didn't have to deal with all that I could enjoy my child. *Focus Group C ((P2))*

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But I think it's a waste of time, you know, because I often found that I spent an hour and a half following things up. Like I work mornings and I used to feel that that was the children's time, and [my husband's] time, and I shouldn't like. *Focus Group A ((P2))*

Yeah and it's emotionally draining because you're there trying to push all the time, you're going why, why isn't this happening for us at this point of time and you're, it just takes an awful lot out of you. It just took me away a lot of the time from actually dealing with [the child] and actually enjoying him. *Focus Group C ((P2))*

(P1): And then (name of service provider) run PECS courses, and they're very good, because they are only €30, so I did that, and found they were all brilliant
(P2): Yeah, because you could be paying a fortune for some of these courses.
Focus Group A

Several parents reported finding it unhelpful when a professional advised them that parents were the experts in terms of knowing how to manage their child or what was best for their child. Although parents felt that it was said with the best of intentions, it often left them feeling overwhelmed and lost, especially when they were looking for answers from professionals.

Well you know your child very well, now explain the situation, you sometimes hold the answers. [That's] frightening I think, 'cause [sic.] you want them to give you the answers really. *Focus Group A ((P4))*

Basically what you're told is it's your choice what you do next. And because you've just been given a big you know...when you're told your child has an ASD, you're kind of like, this is big news and then you're left to your own devices and you're told this is your, this is your choice. You're the parent. You're the expert. *Focus Group C ((P3))*

3.3 Educational and Health Services

The primary focus of the present study concerns parents' information and education needs, their level of satisfaction with information provision as well as their preferences for sources of information; these three issues are explored within the context of service provision. The following section describes the primary experiences and concerns of parents in relation to the service system and how these experiences or issues may have impacted on their needs, level of satisfaction and preferences.

Gaps in services

The foremost difficulty that parents reported after the diagnosis was that there was no next step. In other words, there was little or no indication from professionals as to where to go or what to do subsequent to diagnosis. Once the diagnosis was given, the majority of parents reported being left on their own. Moreover, this lack of support continued for many parents right through their child's primary and secondary school years. Parents felt that much of the responsibility for securing appropriate educational placements and services fell to them. For example, one participant described the difficulty she had in trying to keep her child's file active as the service provider took a decision that the child did not need any further help or support. In contrast, this parent argued that she could foresee the problems that might arise in the immediate future. In line with this, another parent expressed the belief that certain service providers were not interested or concerned about those children who were attending in mainstream schools.

[But] we called in just after Christmas because they wanted to close her file and I said oh is she cured? Well there's nothing more that we can do for her. And I said hang on a second, I'm not happy with this. I can see things that are going to appear later on. Like she is a very depressive child and I can see in teenage years there's going to be major problems and eating problems etc, etc [sic] and these are all escalating. But we're dealing with them ourselves at the moment. And I said no no this just isn't good enough. Oh no well we have to. We've got so many children on our books that we can do things for, that we can't keep you on. I said no that's not acceptable because I can see these things happening in the future so we came to a compromise after they had a big meeting. The whole team had a big meeting. They said right OK, the compromise was they were closing the file for the moment but if we do need to see them again, get a letter from the doctor and they'll see us with the next available appointment rather than waiting 18 months to 2 years. But I mean it's a compromise but I can't see why. You know this is a child with a label. I mean I had the same problem with my youngest with autism. [Name of service provider] closed her file. There's nothing we can do for you. We can't do anything and they closed her file. *Focus Group B ((P4))*

The lack of effective interagency and interdepartmental communication evident to parents in this study caused or exacerbated their feelings of stress. In effect, parents perceived the gaps in services to lead to gaps in information. Several parents stated that in their experience, each agency or each department dealt with the child and the family without any input from other service providers or key agencies; parents were effectively repeating the same processes in terms of form-filling and looking for information.

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There's no continuity between the diagnosis and the next step.
Focus Group A ((P7))

What it seems like is, the professionals, they deal with their own area. There's no kind of path forward after you leave them you know. *Focus Group C ((P2))*

Each individual parent is ringing about an individual child in the department. There's absolutely no blueprint. There's no template...everyone's [sic] like re-inventing the wheel every time. *Focus Group B ((P7))*

Departments of Health and Education don't work together. So if you have a child with a health need and an educational need, you're dealing with, or social welfare or whatever you're dealing with. And there's no one department that will bring all those things [together]. *Focus Group E ((P5))*

There just isn't the backup...[name of service provider] won't see any of our children because they're mainstream. Once you're mainstream, you're history.
Focus Group B ((P5))

Several parents of children with Asperger's Syndrome were concerned that as their child's disorder was mild or the child displayed very few symptoms, they did not receive the same attention or level of support as those who had children with more severe behavioural problems. These parents reported feeling continuously worried about their child's services and the possibility that she or he might fall through a service gap.

But our problem is that she is not bad enough. We keep falling between all these different stools because she's such a low priority with the service.
Focus Group E ((P5))

My view is, and I suppose for once I've seen some kids that have fallen really badly between the cracks, you get a service when there is an emergency. You get a service when the child is expelled from school. *Focus Group F ((P5))*

This may sound weird but we were lucky that [child] was kind of severely AS when he was very young in that it was very diagnosable. *Focus Group D ((P2))*

A further interesting finding was that several parents in this study suggested that parents of younger children with ASDs who may be new to services were being

influenced by approaches parents of older children may have undertaken in order to access services. For example, some parents reported being influenced by the outcomes of court cases as highlighted in the media.

So then it was the usual fight with the department of education implementing this report. We're happy to go to court over it to get something but I mean not everybody has the resources to go to do that. And that was what was needed. *Focus Group C ((P1))*

But it's so depressing. You always think well it was so bad for me you know it will be fine for everybody that comes after me and it isn't. *Focus Group C ((P4))*

Education

Parents' information and education needs may be examined at various levels. Bearing this in mind, the following section addresses parents' concerns around their child's education, health and other significant factors which are thought to influence their education and information needs. Education was a major concern for parents especially in relation to secondary level education. Parents of older children reported encountering problems mirroring those they previously encountered around the time of the diagnosis. For example, it proved difficult to find a place for the child in an appropriate school setting and in some cases, parents had to travel long distances with their children in order to ensure that they received suitable schooling. A particular concern for parents was the obvious lack of funding and resources for Special Needs Assistants (SNAs) in primary school and their absence in secondary school. Parents were concerned for their child's well-being especially when there was no obvious support offered. Similarly, parents discovered that schools were unable to accommodate children with ASDs without psychological reports.

We had an awful problem with preschool, like we had no place until July last year, it was a nightmare. *Focus Group A ((P3))*

I was knocking on doors to find a primary school for him. *Focus Group B (P7)*

I suppose the whole next year was about trying to get him a SNA for him and getting him in the right environment and try to get him the right help. *Focus Group C (P1)*

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Scrum to try to get your kids a basic education [but it's not necessarily the most appropriate]. *Focus Group A (P4)*

And again in our school, certainly, they cannot put in resources unless they have a report. So they have to demand it. *Focus Group E (P1)*

But a big issue for us is he's going into secondary school. He's not at that stage yet but clearly in secondary school, there is no SNA. Maybe he won't need one going into secondary school but we all know; certainly I know just from going to secondary school, that secondary school is a tough sort of thing. *Focus Group C (P1)*

Several parents raised the issue of competing with other parents for places in schools; some reported parents who registered their child's name for a place in more than one school. They discovered that as most schools have no formal relationship with other schools and are also inclined not to share information on a formal basis, the majority of schools are often unaware if a child is offered a place in another school. As a result, a child could occupy a place on several waiting lists, taking up additional places. By the time this factor is resolved, the school year has commenced and a child falls through another gap in the system. In terms of secondary school, parents were aware that they had very few options available to them. They perceived there was a significant bottleneck in terms of children being ready to move on to the next stage but not having anywhere to go. Every year, parents expected to face a new set of challenges in relation to their child's education.

The schools aren't talking to each other and they're not sharing the information. *Focus Group A (P9)*

They recommended four schools and from there we followed up and we got [name of school]. *Focus Group B (P2)*

It's very unfair because you don't know where your child is going to end up. *Focus Group A (P9)*

Where do we go? Like once they're out of primary school, our kids are going to be left hanging. *Focus Group A (P2)*

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You make progress and think thanks be to God. But you know six months, a year down the line, you're going to be coping with something all over again. Something else is going to come up. So you take your sort of breathers where you can and then you know. I know going to secondary school is going to be a huge [issue] so, you know, we're sort of going a little but easier on ourselves this year and sort of concentrating on our other children and other things in our lives. *Focus Group E (P5)*

During the present study, parents differed in what they felt was appropriate for their child in terms of education. For example, some parents preferred to place their child in a special class for children with ASDs while other parents chose to send their children to mainstream schools. Parents proposed several reasons to account for these preferences. One such reason was wanting the child to mix with typical versus similar peers so as to reduce the likelihood of the child developing or acquiring what they perceived as additional ASD habits. However, parents who preferred to place their child in a classroom with similar ASD children felt that while the child might be good academically, they may have poor social skills. One parent was of the belief that having poor social skills could increase the likelihood that the child may not have many friends and could be vulnerable to bullying. A further parent was upset at the thought of her child being placed in a large classroom in a mainstream school, particularly as the child had poor social skills.

Now I know it's very subjective so I'm only talking about my child. We took a decision many years ago that the only way that [the child] was ever going to be normal was by allowing him to mix with so called normal kids because we felt, now as I'm saying it's very subjective and it's our decision and I know that every child is different and you can't really compare. But we felt we found for [the child] that if we had put [the child] in with other AS kids when he was very young I'm talking about now, he would never really have learned to cope. *Focus Group D (P2)*

[A] child being placed in class of 30 is like two steps forward, ten steps back. [I] went through three days of tears and crying at the thought of this. I knew in my heart and soul 'this is wrong' and I said to myself, what are these people? Why are they suggesting this? [And] to me, all the work that we've achieved with him, he might as well be taking two years back for the two years progress that he's made. It just seems to be fighting ... teacher says he's bright. We all know he's bright. You're not looking at the other side of the coin. *Focus Group A (P5)*

3.4 Parents' Psychological Wellbeing

Feelings of Isolation

Several parents reported feeling lonely and isolated in their experiences. For example, not knowing other parents of children with ASDs, having a child with different needs, having family or friends who did not understand, facing professionals who were reluctant to validate their concerns and having an impoverished social network were just some of the reasons for parents feelings of loneliness. One couple felt particularly isolated as they had a pre-adolescent daughter with an ASD and found it difficult to meet other parents with similar experiences.

I have an added difficulty because ours is a daughter and I was really hoping that when we came tonight - and it's no offence to anybody here - but I was really hoping that at last I'd find some parents with a daughter and that's an extra isolating factor for us and our daughter... I went to an [name of voluntary organisation] a few years ago and it's interesting, the information was very interesting and so on, so on, so on. But talking to the parents at the table, they all had children who were profoundly autistic and I just thought here I am again. This is not me. This is not my daughter. I couldn't find anybody with a daughter. Nothing. *Focus Group E (P5)*

And you know, there were couples and people there with children and in some cases an only child or [it] could be a single parent, whatever the case is and sometimes the greater family support is just not there to help as in trying to get a babysitter. *Focus Group D (P3)*

Parents emphasised the importance of meeting other parents with similar concerns or experiences in order to feel less isolated. For example, one mother was of the belief that when her child misbehaved within a therapeutic group, other parents in the group were less likely to judge her on the basis of her child's misbehaviour. In addition, another parent felt that not every house is ASD-friendly. Being able to take the child shopping was rare or impossible for many parents. In other words, parents felt that they were unable to do typical, everyday activities with their child. Furthermore, it prevented some parents from mixing with other families and with the wider community.

We found because of a lot of the courses we went on, or we know a lot of the parents here because of the courses that we have been on...basically we got as much information sharing our stories...like how our children were, how

they were developing. And all of a sudden we didn't feel like our children were alien towards the rest of the race. Basically there were other children out there who were similar. *Focus Group A (P9)*

We were lucky again we met loads of parents along the way and talking to other parents. You don't feel alone. *Focus Group D (P3)*

And you see, as a parent of an autistic individual, if you can talk about an impoverished semantic network, the family end up with, very easily, an impoverished social network because you can't go out because you can't get a babysitter. You can't go out because you're tired because you've been up all night...So we don't have. We end up quite isolated. *Focus Group F (P1)*

And we kind of learnt, after the Early Bird group, like one child goes mad one day, which the first time we ever met it was mine, and it was fine, you know, it didn't matter that he ran off, he did this, he did that, the next week it was someone else's, that's fine too, everyone just kind of turns a blind eye and lets you deal with it. *Focus Group A (P2)*

We end up quite isolated. This is a group through [name of ABA school], you have that linkage but within your own community, it can be quite isolating because you're not able...you can't go to houses and you can't go to people. *Focus Group F (P1)*

Sympathy was extended to the parents of children with ASDs from minority ethnic families, for example, the Travelling community and non-indigenous communities, such as asylum seekers and refugees. Parents in one focus group highlighted the plight of a refugee family. In both cases, these parents were attending a training course and while the father spoke some English, the mother had very little English and found it extremely difficult to support her child's learning. The parents in the focus group suggested that this was likely to have exacerbated this mother's feelings of stress and social isolation. During another group interview, one father stated that this study should examine the perceptions of parents from rural areas in Ireland; he was of the belief that parents living in rural areas were less likely to have access to the same level of services as parents who currently resided in or close to towns and cities.

(P2): Like Traveller kids, I'd say they'd be put on the absolute scrap heap [that's] what's scary.

(P3): That's what's scary.

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(P2): And also, I know, one of the little boys that we see out sometimes. I know, his parents are black and I don't think the mother speaks English, and you just see her there, she's so isolated, she can't, and she's just standing there by herself, and it's just terrible to look at her...and I do think, 'oh my God' you know.

(P2) His father did come to the course, and they did come to the parenting groups, and he has English, but she doesn't.

(P3): And then that child is trying to learn, and she has no support to try and help him, and she's the one at home with him. *Focus Group A*

Current Feelings

At this stage, several years after the diagnosis, some parents reported feeling overwhelmed by having a child with an ASD. One parent described it as being a tough road. A further parent stated that there were times when she just wanted to relax into the maternal role without always having to be the principle member of her child's intervention team. In light of this, a number of mothers were concerned about their own psychological well-being and in particular, how they would manage now and in the future with having one or more children with an ASD.

Even when they get good, they teach you to be a nervous parent that watches. You watch those incremental gains. You're ever watchful. You never relax into being a mammy. *Focus Group F (P1)*

But my whole relationship with him is totally negative. I've been told by several people and they know what they're saying and they mean well and it's like I'm walking towards the edge of a cliff. I know that there's a drop there but I can't stop myself from going towards it. I react badly to him. It's a horrible thing to say you know maybe you grow to dislike one of your own children and it's not easy to say it. But I'm beginning to think that if I'm honest with myself, I have huge difficulty in dealing with him and I don't feel that there is any real help out there. *Focus Group D (P3)*

I've got another worry which for me is an immediate worry but it's not going to happen for some years yet. I have exactly the same worries as everybody else. But I was an older mother. I'm nearly 50. I have two children on the spectrum, one who will be eleven at Christmas, the other who is nine. And [it's] a very, very big worry for me. It's probably selfish. I feel where am I going to be when I'm 65? Other people are looking forward to their retirement. I'm still going to be stuck with my two children and there's no help out there for me. [I] mean I can honestly say as a 50 year old parent with two young children with disabilities, I am worn out... but when my oldest is 20, I'm going to be 60. In the normal run of things, that's OK. But I'm worn out now at nearly 50. What the hell am I going to be like when I'm 65; and I worry very much about that. *Focus Group B (P4)*

I think stress in the family is a big thing over the years. I think that was a huge thing for us, for the rest of the family. *Focus Group C (P4)*

There's [sic] not enough SLTs. Well, give us the means to help work out groups otherwise the prison service will be picking up the pieces. This is what I'm scared of. *Focus Group D (P1)*

But I think we can sit back and say, you know my son is this and my son is that and I've done this and I've done that and I'm at this stage. As you go along, every two or three year gap, there's a new battle to be faced and sometimes you just might find that you're not up to the battle and that's human. *Focus Group D (P3)*

And they say parent power. I mean we'll leave here tonight and we're all individuals again. *Focus Group B (P1)*

Several parents worried about having to continuously face new challenges in relation to their child problems, particularly in light of the lack of services, especially when they may not be ready for them. Another concern for parents was the possibility that their child might regress and that progress made over the days or months may be lost in a whim:

In an ideal world, you want to lose the word 'regression'. You'd love to think that that phase will never form part of your son's or daughter's education from here on in, that where they have achieved now, that they won't drop down below it. They can only go another step. Now whether it's a huge step or a little step, it's a step and they never keep dropping back and you'd never fear that they're going to lose what they have which is what most parents of children with autism fear, that they'll lose. That they'll start to regress that little bit and it may steam roll or snowball and you've lost the lot. And you live in fear of that and you live in fear of hearing that word. You hope that you're never going to have to hear that word or know what it feels like to have a child that was working their way up the ladder, their own little ladder it may be, and then they start to drop down. So I mean that's what I hope for the future - that we don't need to hear that he's regressing. *Focus Group F (P4)*

3.5 Recommendations Made by Parents during Focus Group Meetings

A number of observations were made by parents during the focus group interviews concerning what would have been helpful. Suggestions for improvements were also made, especially in relation to lessening the impact of the diagnosis on parents or

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families who had yet to experience the difficulties that they so frequently encountered.

Follow-up

Parents recommended having some form of professional follow-up in place during specific stages of the child's development. For example, many parents found it difficult to assimilate verbal information during or immediately after the diagnosis. In fact, the general agreement among parents was that follow-up would have been particularly helpful and may have allowed them time to reflect on the diagnosis, gather their thoughts and come back with specific questions or information needs.

[Because] we found you could be told things again and again. But it's not sinking in [because] I think when he was small, the brilliant SLT that we knew, [I'm] sure she told us so many things that maybe a year or two later sunk in. [But] it was so much to take in with the first fella. *Focus Group C (P4)*

I was just thinking, if you do get a diagnosis, on the day you get the diagnosis you should get, you know, be let go away to think about it and then be called back in a week or two to say now these are your options because you're taking it in and you're... and you've got questions. And you want to know and you'll have had time and space to be able to go away and think about the questions and what to ask. *Focus Group C (P2)*

To me, in an ideal world, for my child with autism, I think that would be just brilliant, that every time I have a problem with [child], or you know I'm anxious about him, that I can just lift the phone...even sometimes... say like with a teacher. If he was in a special unit, that that unit would be like answerable to somebody else, and they would nearly deal with it before I find out about it. Do you know that sort of a way? Like this is what I see in [name of service provider]. Everything is dealt with and nipped in the bud straight away. *Focus Group A (P5)*

Information Pack

Several parents proposed that an information pack should be provided to parents at the time of the diagnosis through assessment centres and local health centres. In an ideal world, this information pack would contain the following:

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- A list of important phone numbers of professionals and service providers, including things to do after receiving the diagnosis
- Information collated from parents who have recently gone through the system including information about the positive aspects of raising a child with an ASD
- A list of local and special national primary and secondary schools inclusive of children with ASDs and
- A five-year plan of what the child may potentially receive in terms of services and entitlements and details of contact numbers for parents of children with ASDs in their locality.

In addition, the information should be paced to coincide with significant life stages, for example, the diagnosis, starting school, the transition from primary to secondary school, puberty, the transition from child to adult services and, where applicable, long-term care.

I definitely think that would be a huge improvement if you get a diagnosis just apart from you know...a sheet of paper with some information or whatever. But like if they had a way of, if they were going to give a diagnosis to somebody, then [to] sort of bring in a couple of people and sit down with you and spend two hours with you. Maybe not on the day but a week later, to say this is what you need to do ...we've culled this from other parents in terms of the way they dealt with things. Here are some sort of helpful things to get you started you know. *Focus Group C (P1)*

You're not told. I mean surely when you think about it, how easy would it be to put some kind of portfolio or package together, to list all of these things, [at] least get the basic things down there. *Focus Group A (P6)*

[It would be helpful to have] an appointment to go out to a functioning school with children either mainstream or a unit or whatever to see that your life hadn't, the orbit hadn't literally dropped out of your world. That life goes on, children improve and this is what happens. *Focus Group B (P6)*

The immediate experience after diagnosis is not necessarily a negative one. It will have to have an element of negativity. Nobody could go through that. But at least the tunnel doesn't grow very narrow and long and dark. You can keep an eye focused on the light at the end of it. *Focus Group F (P5)*

[T]here's no one. Well, your family know but they don't really understand...and you were always funny as a child anyways you know. But definitely emotional support. Somebody else who knows what you're going

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through. Somebody else who's in the same position...who's not going to say oh stop making a mountain out of a molehill. *Focus Group B (P4)*

Appraise and Pace the Information made Available

Parents proposed that information pertaining to various treatments, therapies and tools should be critically appraised by professionals or service providers in order to ensure that these are based on concrete evidence and do not lead to a waste of parents' resources. This was considered to be especially important in relation to the safety of the child. At the same time, the information should be paced according to the child's and parent's needs. This is essential so that parents are not overwhelmed with too much irrelevant information. However, one mother suggested it was often helpful to gather useful hints and tips in preparation for the future.

I think that's where you could do with it. Like when you get the diagnosis you know 'cause [sic] there is a lot of crazy stuff out there in my mind in terms of the different avenues that you can go down and you really have to think very carefully. You have to get someone that you can trust to look at your child and say look you should go slowly on this in terms of the right way. So definitely that would be sort of the package of telling you these are the options but be careful of how you select it. *Focus Group C (P1)*

We just came out of this social skills programme in the [clinic]. It was on for four months and it was very good. A lot of the stuff, the experience of parents was more for the future but that was brilliant in terms of, at least we can refer to it when they're that bit older and all that. *Focus Group C (P3)*

Parent education or training programmes

Many parents reported stumbling across information on parent education or training programmes, rather than being directly targeted by professionals and service providers. Parents emphasised the need to offer training courses on a range of topics including general parenting, the different types of educational approaches available to their child, communication and social interaction, practical everyday advice, sibling relationships and financial planning. Furthermore, this information should be delivered using a variety of formats, in order to deliver the information or the content of a programme as effectively as possible. For example, those parents who considered themselves fortunate enough to be in a position to attend an EarlyBird training programme suggested that current and future training courses

adopt a similar format as it was reported to be extremely effective in terms of delivering information. Alternatively, one father suggested employing a framework analogous to the framework used in handling and sharing information with cancer patients. Parents also suggested that a national ASD centre would be helpful in terms of effective information provision where information could be easily accessible, on 'practical issues like that, what you might do. Legal wills and entitlements. Focus Group E (P2). Other comments included the following:

(P9) I think everybody is different in relation to how they are going to take information...some people are going to read something and get a lot, some people basically can't. Some people require one to one, they require [sic] to be told. Some people might go to a workshop. They might get what they want from it. They might require demonstration. Even the way we learnt, it's different, so

(P4) well probably workshops, like workshops like the Early Bird

(P7) depends on the audience, workshops over here, stands over here, videos tapes over there. *Focus Group A*

Like the information we got from the Early Bird, I found it clarified quite a lot...like there was a lot of information coming at us, and it kind of focused on the real pertinent information that we needed, so it kind of got rid of a lot of clutter. *Focus Group A (P9)*

Now whether we can all afford it or not or whether the state can afford it I don't know. But I mean there is that gap between getting the diagnosis. The thing is you're all kind of left on your own to sort of, with the best resources that you can and at your disposal, you know, try and network and find out as much as possible. But I definitely think that if you could sort of package it up so at least you know someone's giving you some very positive things to do. I mean I'm sure if you talked to someone who got cancer or whatever, there probably is when they get a diagnosis, the doctor is very much up front telling you this is what we're going to do, this is the treatment, you have to go on chemotherapy, you don't or this is the way we are going to go forward. So there's a whole programme set out for you. *Focus Group C (P1)*

Parent Support

A support service specific to the psychological needs of parents should be set up to counteract the impact of the ASD on the family as recommended by parents in the present study. In addition, parents across all focus groups agreed that it would have

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been helpful if professionals offered them some positive messages at the time of the diagnosis. For example, one parent suggested that it would have been helpful to hear that there are people walking around today who might never have been diagnosed but who still manage to live independently. Parents felt that giving them a positive outlook or a message of hope may have helped them to cope more effectively; knowing that other parents managed to cope with the diagnosis and that life moved on and could get better would have made a difference. Several parents stated that they might have appreciated being told about their child's abilities as well as their disabilities so that the diagnosis or assessment was not all negative. One parent felt that during the diagnosis, the professional consigned her child to the 'bin' before the family left the office. A number of parents reported that some form of emotional support or counselling would have been beneficial, particularly after the diagnosis or when the family were faced with challenges with which they may be unable to cope.

I suppose one of the first things you would like them to say is that this is not the end of the world. I mean there are things that you can do. There are interventions that can be done and particularly obviously the younger your child is or whatever, when you hear [that], it helps. And certainly giving you that positive message in that if you can do these things, if you can get this help, it will make a big difference in terms of intervention. So that's like a huge message of hope. *Focus Group C (P1)*

While specialists won't be able to give you those answers, they can provide you and say, well with the right intervention - you know what I mean - and all things going well, we hope that, or studies have shown that children with autism will learn and they have X, Y, Z and all the support that they need have moved on to live ... very, very challenging and rewarding lives. But you knowing, you're just told but that child has autism, classic autism. *Focus Group F (P4)*

But definitely emotional support. Somebody else who knows what you're going through. Somebody else who's in the same position. *Focus Group B (P4)*

And you're on the positive. And I think maybe that part of the diagnosis of that, they should say 'we've looked at all the things this child can't do, but look this child is good here, and they're very visual. *Focus Group A (P3)*

Media

PARENTS OF CHILDREN WITH ASD

Interestingly, a number of parents stated that it might have been helpful if the media and newspapers reported more positive stories about families and children with ASDs. Current references to ASDs tended to be reported in relation to parents having to fight for services in court and the costs involved in these actions. Parents suggested that negative stories in the media might further isolate families or cause parents who are newer to services to be disillusioned with the service system. Similarly, parents felt that it is important that the general public also have access to positive images of families and people with ASDs so that people might gain a greater understanding of ASDs and the challenges that families face over their lifetime. .

I'd like to see when you look at all the programmes that have been shown recently about autism; they've all been on the negative side. I'd love to see something positive. [I'd] love to see the profile of autism being raised but in a positive way...good news doesn't sell. *Focus Group A (P7)*

[Because] when Channel 4 did about the family of seven where there were four boys, that was about how to get on with life and deal with it. *Focus Group A (P2)*

And I think people are looking going 'oh my God, my child is going to end up like that'. And 95, 99 per cent are not, you know what I mean? That would be a small percentage that would be that tough. [I] think sometimes when you're seeing you know a lot of dramatic sob stories on TV. On Nationwide, I saw a school down in Galway and it was these twins that were integrated so you know that wasn't blasted on the news everyday which was a shame because there was a lot of really good stories and a lot of positive stories. *Focus Group C (P4)*.

Chapter Four *Discussion*

There is little documented research in relation to the information and education needs and preferences of parents of children with ASDs. The findings of this study, therefore, provide a valuable preliminary insight into what parents want in terms of information, education and support before, during and after the diagnosis.

While most parents in the current study had young children aged between four and eight years, there was a number of parents who had children aged between eleven and 14 years. In light of this, it is important to note that the latter group of parents were reflecting on a time when services may have been relatively new or not yet developed. There was very little knowledge of ASDs at that time and even fewer experts working in the area. Despite this, parents of younger children experienced similar problems to parents of older children.

The difficulties and stress associated with having a child with an ASD have been well documented in the literature (Bouma and Schweitzer, 1990; Coulthard 2001). In this study, parents were particularly honest and forthcoming in terms of describing how they felt around the time of the diagnosis. In addition, research found that parents of children with ASDs experience further stress and frustration because of the delay in obtaining a diagnosis (Stoner, 2005), which was supported by findings in the present study. In this case, parents attributed the delay to professionals discounting parents' early concerns about their child's difficulties. Furthermore, the overall lack of information and support described by parents in the present study compounded this already stressful experience.

The diagnosis was perceived by parents in bleak terms, particularly since very few professionals considered the positive side of the child or the ASD. However, not every parent reacts in the same way. Positive reactions to the diagnosis may occur on their own or alongside negative feelings. Diagnosis came as a relief for a number of parents as it confirmed their suspicions that something was not right in terms of the child's behaviour. However, whether a parent was relieved, shocked or surprised by the diagnosis, all parents wanted to know how this disorder would

specifically impact on their child's life. Faced with this uncertainty and with very little reliable information or answers offered by professionals, parents reported that it was their responsibility to search for information and services in order to meet their child's and family's needs.

According to Stoner (2005), having to fight for a diagnosis encourages parents to continue with this pattern of persistent behaviour. Furthermore, the way in which the diagnosis is handled by clinicians may continue to influence the behaviour of parents for several years. Information-seeking behaviour may be a way of coping after receiving a serious diagnosis (Stoner, 2005) and previous research examining coping behaviours suggests that information-seeking behaviour is associated with positive psychological well-being (Folkman, 1997)

Parents in the current study emphasised their dissatisfaction with the level of information and practical advice provided by professionals and service providers. This was frequently mentioned in relation to the complete absence of such support for parents, immediately after the diagnosis. They also described the continuous struggle to access reliable and pertinent information beyond the diagnosis which supports previous findings by Murray (2000).

Furthermore, parents in the present study reported that they were unlikely to have received useful information or advice from health care professionals and more specifically, from their GP or their public health nurse. What often happened was that parents stumbled across information in relation to entitlements or services by chance and usually through informal sources. Moreover, there was an evident lack of collaboration between different service providers, especially the primary service providers, which resulted in parents finding it difficult to ascertain which needs were met by which services. For example, one parent was of the belief that it came down to knowing the right questions to ask or making the loudest noise. Overall, parents in this study reported that parental support in the form of information, instrumental or emotional support was not forthcoming and felt particularly dissatisfied with information provision.

Pain (1999) proposed several reasons for parents seeking information. They included helping parents to accept the diagnosis, to adjust to the impact of the

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developmental disability on the family and to manage their child's behavioural problems. Consistent with previous research, parents in the present study searched for information in order to answer specific and often immediate questions. Parents used the information to obtain services and entitlements for their child, to inform their decision-making about appropriate treatment and to help them plan for their child's and family's future. In other words, information was used by parents in this study to gain a greater sense of control over child and family outcomes.

Previous research stated that it is imperative that information be made available to parents in order to realize the long-term goals of empowerment for parents and their families (Beresford, 1995). It is evident from the present study that a dearth of information may encourage some parents to pay for treatments or therapies that lack any evidence or credibility. Parents in this study also suggested that information from other unreliable sources, especially from the Internet which can offer parents access to a large volume of information, may have a negative impact on the well-being of families as well as the child with an ASD. For example, too much information may be just as stressful as too little information which supports previous assertions by Goore et al. (2001). Therefore, there is an urgent need for professionals and service providers to critique the information being accessed by parents so that parents are not being deceived out of time, effort and money. Moreover, the Internet may also provide parents with access to too much information which may prove to be overwhelming.

In the current study, parents reported having significant information and education needs before, during and after the diagnosis. Indeed, education was a high information priority for parents in this study. Parents also reported wanting practical advice on how to apply what they learned from books or training programmes to everyday living with their child. In terms of the child's future, many parents were concerned about the child's level of independence and their ability to maintain relationships. Parents were also worried about what would happen to their child if they themselves became ill and could no longer take care of them.

The following nine themes that were identified in this study informed the content and format of the Information Needs Assessment Questionnaire (INAQ). This questionnaire will be developed and piloted in a future study.

- 1) *Diagnosis* (e.g. What does a diagnosis of an ASD mean for my child in terms of future development? What are the positive outcomes for my child with an ASD?)
- 2) *Services* (e.g. Should I access health services/ what do I need to do in order to access these services? How the different areas of expertise are defined, for example, neurology, occupational therapy, behaviour analysis?)
- 3) *Intervention/ practical strategies* (e.g. What are the practical things that I can do to help my child with an ASD? What is the Hanen programme/ Who offers this training course?)
- 4) *Educational issues* (e.g. What does an Individual Education Plan (IEP) mean for my child? How can I help my child make the transition into secondary school?)
- 5) *Concerns* (e.g. How do I know when my child with an ASD is being bullied? How do I approach the subject of puberty and sexual matters with my child?)
- 6) *Financial and legal issues* (e.g. What are our entitlements to state funding, for example, domiciliary care allowance, tax allowance, transport allowance, etc? What factors should I consider when making a will for my child?)
- 7) *Informing the child and others* (e.g. How do I go about informing the child that s/he has an ASD? How do I go about informing family and friends that my child has an ASD/ Should I tell everybody?)
- 8) *Resources* (e.g. How do I complete all those forms? What are suitable books and websites?) and finally,
- 9) *Future concerns* (e.g. What resources are available for the care of a person with an ASD when parents are too old? What are the options available to my child in terms of independent living?).

Most parents searched keenly for information prior to and following their child's diagnosis. This included attending as many lectures and seminars related to ASDs as possible. However, after this initial intense period of information seeking, some parents became less active and only sought information at critical transition points.

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This may indicate that while all parents searched intently for information prior to and after the period of the diagnosis, only some parents remain active information-seekers, which may support previous research by Miller (1992). Parents in this study may have wanted and benefited from different levels of information. Therefore, professionals and service providers need to be aware of the potential variability in parents' information coping styles if they are to effectively meet the information and education needs of parents.

Parents in this study reported that other parents of children with ASDs were their greatest source for information and emotional support. They frequently described attempts to access information from individuals who had similar past or current experiences. However, meeting other parents with similar experiences was described as being down to luck. Other sources for information included printed materials such as books, the Internet and attending training courses or seminars. A significant advantage of participating in parent training programmes, one that was perceived by the majority of parents in this study, was that training courses also provided parents with the opportunity to meet other parents. Furthermore, the actual focus group interviews emerged as an additional source of information for some parents who discovered that their child was entitled to drop Irish as a subject from their curriculum as early as primary school; this news came late however, since the parents' child had already started secondary school.

The dearth of appropriate services available to children with developmental disabilities was highlighted in earlier research by Kohler (1999). Despite it not being the main focus of this study, it was anticipated that parents would comment on the efficacy of services in Ireland for children on the ASD spectrum. For example, parents in this study observed very little intra- or inter-agency collaboration; this increased the likelihood that a child with an ASD would not receive the appropriate services to meet their needs.

It was anticipated that concerns about services would influence information and education needs, and this was confirmed during the analysis phase of the study. For example, parents of children with mild behavioural, social or learning problems were concerned that their child might fall through gaps between services, especially if the

child had a dual diagnosis or was attending a mainstream school. These parents were eager to know what type of support was available to their child during their transition from primary to secondary school. Another parent described her fear of not being capable of taking care of her children when she and her partner grew older and in light of this, felt that information in relation to emotional support as well as information on the potential support services available to the family in the future might be helpful. This supports previous findings by Doherty, Fitzgerald and Matthews (2000) who claimed that parents are concerned about the continuity of service provision and future care for their child with an ASD.

Several recommendations were proposed by parents in this study for improving the information and education support available to parents of children with ASDs in Ireland. For example, an information centre specific to ASDs should be set up. This could help to support, develop and encourage a constant flow of information between families, professionals, service providers and key shareholders. Information should be screened by professionals who are experts in their field, in order to ensure that parents receive pertinent and legitimate information. Information should be offered to parents in a variety of printed or visual formats as soon as it has been tailored to each family by the relevant professionals. Given that the diagnosis had a significant impact on these parents, they proposed that an information pack be made available to parents of recently diagnosed children through various health centres, so that these parents know the next step. Finally, follow-up after the diagnosis was arguably something that parents in this study felt might have helped them cope more effectively with the challenges and problems that they were yet to encounter.

4.1 Conclusion and Relevance for the Sector

This study highlights the problems that arise when professionals and service providers fail to work together to deliver effective information and education services for parents of children with ASDs. The provision of accurate, reliable and relevant information should be based on a multidisciplinary approach where it is shared and made accessible through health, educational and legal organisations. Information may equip parents with the knowledge, skills and confidence to advocate for their child with ASDs. Although it cannot guarantee that families will be allocated

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appropriate services and support relevant to their child's needs, it may help them to face potential challenges and problems with a greater sense of empowerment.

Many of the concerns and information needs expressed by parents involved a need for more information about educational provision for their children, while other concerns related to more general provisions. It is imperative that those involved in education should be aware of these concerns and needs. It is intended to disseminate this information through conference presentations and peer reviewed publications.

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