



Irish Parents' lived experience of learning about and adapting to their child's autistic spectrum disorder diagnosis and their process of telling their child about their diagnosis

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**Irish Parents’ lived experience of learning about and adapting to their child’s
Autistic Spectrum Disorder diagnosis and their process of telling their child about
their diagnosis**

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For Peer Review Only

Irish Parents' lived experience of learning about and adapting to their child's Autistic Spectrum Disorder diagnosis and their process of telling their child about their diagnosis

Little is known about the lived experience of Irish parents in learning about and adapting to their child's diagnosis of Autistic Spectrum Disorder (ASD) and the process of disclosing this diagnosis to their child. Semi-structured interviews were completed with seven Irish parents of children with an ASD diagnosis to gain an in-depth understanding of these experiences. An Interpretative Phenomenological Analysis (IPA) revealed key themes affecting the process of adjusting to the diagnosis and communicating this diagnosis to their child, including difficulties obtaining a diagnosis and parents ambivalent feelings upon receiving a diagnosis; challenges accessing appropriate support and resources, and attempting to maintain a 'normal' family life; and finally a feeling of needing to protect their child, the realisation that non-disclosure is a poor strategy in the longer-term, and adapting communication style to facilitate their child's understanding of their diagnosis.

Keywords: parents, caregivers, ASD, autism, Asperger's, diagnosis, and IPA

Introduction

Parents act as cognitive and emotional filters to their children (Todd & Shearn, 1997). This is more so the case when a child is vulnerable or has a disability. Parents manage the process of receiving a diagnosis of their child's disability and assimilate this news at their own individual pace (Todd & Shearn, 1997). Research pertaining to life threatening illness and learning disability has demonstrated that parental experiences of their child's diagnosis shapes the meaning they ascribe to it and subsequently their feelings towards sharing this diagnosis with the child (Todd & Shearn, 1997; Claflin & Barbarin, 1991). Whilst parental experiences of assessment and diagnosis of Autistic Spectrum Disorder (ASD) has received a large amount of attention in the literature (e.g. Midence & O'Neil, 1999; Huws & Jones, 2008; Mansell & Morris, 2004), no published research has examined the experiences of those who have had to disclose a diagnosis of ASD to the individual concerned, and what factors influence their decision to do so.

Howlin and Asgharian (1999) described how the time elapsed between when

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parents first began noticing concerning signs or symptoms and diagnosis could take up to four years for children with an autism diagnosis and up to eight years for those with an Aspergers syndrome. Siklos and Kerns (2007) suggested that the shorter the time period between parents first concerns and diagnosis, the better it is for the coping process of the child and parents. The better this process is facilitated, the more trust the parent can have in the system of emotional and instrumental supports available (Siklos & Kerns, 2007). It appears important to develop and standardise guidelines to improve this process. Howlin and Moore (1997) found that nearly half of their sample of 1200 families of children with an ASD who had gone through a diagnostic process found this process to be unsatisfactory and burdened with delays. This finding has been replicated in other studies (e.g. Stirling & Prior, 1999).

A sample of Scottish parents of children with an ASD who were asked about their experience of diagnostic disclosure, found that parents who felt that their opinions, observations and anxieties were listened to and taken seriously by the professionals, were then better able to cope subsequently with the diagnosis (Brogan & Knusse, 2003).

Parents on receipt of the diagnosis can move through a myriad of emotional responses; from relief to anger and from vindication to sadness (Nissenbaum, Tollefson, & Reese, 2002). Professionals need to be mindful of the best ways to communicate with each and all of these reactions and also to be aware of how much information people can cognitively assimilate when in a state of anxiety (Bartolo, 2002; Clarke, Davies, Jenney, Glased, & Eiser, 2005; Sloper & Turner, 1993). Receipt of diagnosis is often the start of a long journey (Murray, 2006). In particular with ASD, the added lack of an obvious physical syndrome with clear facial or physical features can make this adjustment more difficult for some parents (Midence & O'Neill, 1999). There is often a vacillation between more hopeful feelings on receipt of diagnosis, to those of despair, which can appear much akin to a bereavement process (Mansell & Morris, 2004).

The empowering use of support groups has been found to be of benefit to both parents, the children with the diagnosis and their siblings alike (Huw, Jones, & Ingledew, 2009). Huw et al.'s (2009) qualitative study of nine young people with high functioning autism found that knowledge of the diagnosis actually increased some of the individuals' self-esteem. The process was seen as a clarification of previous life experiences and a way to legitimise their behaviour(s) to others. Many children are aware of their difficulties and can report feeling marginalised if they do not have a

means of validating their experiences (Young, Dixon-Woods, Windridge, & Heney 2003).

Whilst there is a body of international research on the lived experiences of parents receiving and adjusting to their child's diagnosis of ASD, there is a paucity of published research in the Irish context. Furthermore, no study has explored the process of parents sharing this diagnosis with their child. The current study aimed to address these issues through one-to-one interviews with Irish parents of children with ASD. The analytic method used was Interpretative Phenomenological Analysis (IPA)

Method

Design

A qualitative research approach was employed. Semi-structured interviews were conducted with seven parents of children with Asperger's Syndrome or high functioning autism. The interviews explored the parents' experiences of receiving the diagnosis, living with a child with ASD and how the parents experienced communicating with their children in relation to their ASD. Interpretative Phenomenological Analysis (IPA) was used to analyse the data (see Smith & Osborne, 2008). The University Research Ethics Committee approved the study.

Participants

The first author used a snowballing method to select participants i.e. a parent of a child with ASD acquainted with the first author recruited participants who in turn recruited future participants from among their acquaintances (Penrod, Preston, Cain & Starks, 2003). Ten parents of children with Asperger's Syndrome or high functioning autism were invited to participate; six mothers and one father agreed to take part. Parent's ages at the time of participation ranged from 33 to 52 years. All parents had a son with a diagnosis of high functioning autism or Asperger's syndrome. The child's age at diagnosis ranged from two to five years. At the time of interviewing, children were aged between eight and 16 years. All children lived in the family home and were attending mainstream education. Five parents had explicitly disclosed the diagnosis to their child. The child's age at the time of disclosure ranged from eight to twelve years. The two parents who had not disclosed felt that their child's maturity precluded them developing an understanding of their disability.

Materials

The IPA method was chosen as the method of analysis. The semi-structured interviews were seen as a ‘conversation with a purpose’ (Smith, Flowers & Larkin, 2009, p. 57), the aim being to facilitate an interaction that permits access to the personal lived experience of the phenomenon under investigation (Chenail, 2011; Smith & Osborne, 2008). An interview schedule was prepared, which outlined a loose agenda of topics to be discussed and the order in which they were to be discussed. Questions were designed

Key themes	References supporting inclusion
Meaning ascribed to diagnosis of ASD	(Todd & Shearn, 1997; Howlin & Asgharin, 1999)
Experience of receiving child’s diagnosis of ASD	(Bartolo, 2002; Brogan & Knussen, 2003; Mansell & Morris, 2004; Siklos & Kerns, 2007; Sloper & Turner, 1993)
Experience of sharing diagnosis with others	(Howlin & Asgharian, 1999; Todd & Shearn, 1997)
Impact of diagnosis of ASD on family life	(Huws, Jones, & Ingledew, 2001; Midence & O’Neil, 1999; Murray, 2006)
Attitudes and feelings towards sharing diagnosis of ASD with child	(Huws et al., 2009; Young et al., 2003)
Considerations when sharing diagnosis of ASD with child	(Claflin & Barbarin, 1991; Huws & Jones, 2008)
Perceiving impact knowledge of diagnosis would have on child’s life	(Huws & Jones, 2008; Murray, 2006; Jones, 2001)

around a number of key themes that had emerged from the literature (table 1).

Table 1: Key themes included in interview schedule

Data Collection Procedure

Interviews took place from March to June 2010, and were conducted in participant’s homes. Written consent for participation was obtained. An interview schedule was used for all interviews. All interviews were audio-recorded. Interviews lasted between 30 and 90 minutes, with an average length of 42 minutes. Notes were made after each interview, summarizing key points and initial impressions of any information relayed. All interviews were transcribed verbatim.

Data Analysis Procedure

All interviews were analysed using IPA as per Smith and Osborn (2008). The first step involved reading and re-reading each script a number of times. The audio-recordings were also listened to when rereading the transcripts. For the second step, the left hand margin of the script was used to record initial thoughts and to summarise

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3 responses or make interpretations about the data. The third step involved the reading of
4 the transcripts again and using the right hand margin of the script to record emerging
5 themes. Initial notes were then transformed into concise phrases. Related themes were
6 clustered together and theme headings were created. The analysis then returned to the
7 transcripts to confirm or refute the applicability of the themes. The fourth step involved
8 developing a list of super-ordinate themes and sub-themes.
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13 A number of different strategies were adopted to test the rigour of the qualitative
14 analysis. Issues of subjectivity were addressed through a bracketing interview (which
15 illustrated the researchers understanding of the subject matter and any values or
16 preconceptions which could affect data collection or analysis), and a reflective journal
17 and analytical diary (which both served a similar purpose). The research supervisor
18 checked the credibility of any analytical interpretations made by ensuring that there was
19 sufficient supporting evidence in the data. Furthermore the researcher left an audit trail,
20 which enabled an external auditor to conduct checks whether a plausible and coherent
21 argument ran from data collection to analysis.
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28 29 30 **Results**

31 Three super-ordinate themes emerged from the IPA. These were (a) Diagnostic
32 Experiences, (b) Adaptation and Acceptance, and (c) Sharing the Diagnosis. Each
33 theme had subordinate or sub-themes that will be explored in more detail in the
34 following sections.
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39 40 *Diagnostic Experiences*

41 The experience of receiving a diagnosis was described by the parents in relation to two
42 main sub-themes; (a) difficulties obtaining a diagnosis and (b) having ambivalent
43 feelings about receiving the diagnosis.
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47 48 *Difficulties obtaining a diagnosis*

49 All the parents reported having suspicions that their children were not typically
50 developing, particularly if they had previous children without this type of behaviour.
51 One mother noted their child's lack of normal language development, another noted
52 their child's passivity and non-engagement with others. Both of these mothers had
53 noted their child's slower learning rate and some of the more unusual behaviours. They
54 had other children in their families to benchmark their concerns against:
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P7: *He'd run up and down the hedge outside looking into the hedge running forward but his face turned sideways...because he was the third we had something to go on*

Parents noticed how their concerns were brushed off by professionals and that despite repeated sharing of these concerns, they felt their comments fell on deaf-ears:

P2: *... we were told by the time they were two years and three months old, they were probably autistic. In fact the first diagnosis we got on (child) was that there was absolutely nothing wrong with him, that he was a very bright child, but the second diagnosis said that he had severe autism*

The difficulty of attaining a diagnosis was experienced as an exasperating task, which was made the more futile due to the fact that most parents felt they knew that the child would receive the diagnosis:

P1: *I was kind of going 'is he, isn't he'. I was very depressed. But then I'd had a new baby. But I was devastated over him, absolutely devastated over him. But I think I was more devastated because I was afraid to relax and think he didn't have it, because in my heart and soul I knew he had it*

Ambivalent feelings upon receiving a diagnosis

Receiving a label appeared to vindicate original suspicions. It helped to resolve their confusion and guilt. It gave an explanation for the child's behaviour. It allowed the parents to 'get-the-ball-rolling' in relation to instrumental supports needed:

P7: *Sheer relief knowing that there was a name to it, that we weren't imagining it, because we had been brushed off by so many professionals and that now we knew this is what it is let's do something about it*

The manner in which people were told did not necessarily contain the emotional reality for some parents:

P6: *That psychologist in particular was a very stern person, and maybe that was the best way to be, but I just felt there was no emotion with her. So it was very matter of fact and I went home and I bawled. I have to say I cried my eyes out*

The reality of the diagnosis also reflected the different journey the person was now on.

This resulted in feelings of loss and a sense of what might have been?:

P2: *...they had all their own perfect families and I felt a knife-in-the-heart sort of thing. It really was that. Even at that time, I don't suffer from it as much anymore, but you'd see a man walking around a park with three or four kids and you do say 'Why Me?'*

The majority of the parents reported that they had no prior knowledge of, or understanding of ASD:

P4: *It would depress you to no end. You'd be in tears after reading it, because you'd see this child who is in a world where they are completely traumatised. I guess it does identify some children, but it was very negative and gave the worst-case scenario. You'd be thinking, well I might as well shoot myself now*

Adaptation and Acceptance

This theme had three sub themes of (a) journeying in the dark, (b) negotiating normality, and (c) oscillations between hope and reality.

Journeying in the dark

The first years following diagnosis were the most challenging for the parents. Obtaining support was difficult and when they received it, it was often inappropriate to their needs:

P2: *We're in the difficult position that (service) won't provide us with services and no one else will provide us services. You know (service) say (child) has an intellectual disability so they won't go near him, the other services say (child) has autism, so they won't go near him*

The struggle to attain appropriate services on this journey was a quest that reaches both exasperation and an exhaustion point:

P3: *I rang every single day, every single day looking for someone to work with (child) or do something with him, but there was just nothing, nothing. It was only that I broke down one day. I just couldn't take it anymore*

And

P5: *You're just constantly battling. I mean the teachers don't have a clue. The secondary teachers just don't have the time, the interest, or the training. If the children need it in primary, then they're going to need teachers like that in secondary level as well. It's just ridiculous what's going on*

Negotiating normality

Most of the parents identified their child as a child first and having ASD second. Parents, as best they could, strived to treat their child who had a diagnosis in the same way as they treated their other children:

P7: *We say the house rules are there, you can't break them but everyone is different within that and (child) would be included within that. He'd be pulled up the same as the rest of them. There are times when it would take him a little bit longer...and we have to work a little harder to explain it, but he's still included*

The majority of parents expressed concerns over the impact having a sibling with an ASD diagnosis might have on the other 'normal' children:

P6: *I mean (brother) has always had that role, but he has great patience with (child), they could fight and (brother) could forgive him within half an hour. It's taught (brother) a lot as well*

Oscillations between hope and reality

The reality of the struggles and joys of everyday parenting were mixed in with fears for the future:

P4: *You worry more, thinking how are they going to survive or how are they going to do stuff. My sister was like 'that's not specific to autism. That's any child... You just don't know what's going to happen so stop worrying about it'. And it did put it into perspective for me, that you don't know what is around the corner so stop worrying about the worst case scenario...we take it one day at a time*

In general the majority of parents' future views were hopeful, but tempered with a good dose of reality. Parents described how they focused on concrete moveable goals for their child, with the expectation that their parental protectionism will be withdrawn as much as it can as the child grows in confidence:

P6: *I don't want to be just making life easier for him...I don't care what marks he gets in his junior cert, I don't care what he gets in his leaving cert, but if I pull him out of school what's the next thing he's going to say to me; 'I can't cope with that', you know you're protecting him coping*

Sharing the diagnosis

This final superordinate theme broke down into three sub-themes: (a) to tell or not to tell, (b) managing the communication, and (c) impact of disclosure.

To tell or not to tell

Parents wrestled with the idea of telling their child about their diagnosis. Most were concerned about the emotional impact of the diagnosis on the child. In addition, two of the parents refused within themselves to ever tell their child:

P1: *No I feel at some stage he had a right to know who he is because everything about our genetics is who we are...Because he is odd. He does odd things. He is socially awkward still and I think when he's older he may well want to understand more about that and he needs to understand what I think*

And:

P2: *I think it would go over the (child)'s head, he's a clever boy, but I don't think, right now anyway, we've no intention of doing it. With (child) he's making such progress where we're hoping we won't have to...*

Managing Communication

All of the parents, irrespective of telling the child about their diagnosis or not, wanted to protect the child's own self image and did not want them to develop a negative view of themselves. Some of the parents couched the disclosure process within the uniqueness of having Asperger's syndrome:

P5: *I find that about a lot of things that I need to tell him. I come at it from a different angle because there are ways you just can't explain it to him. And you might be explaining exactly the same thing, but it's just the way he handles emotion and how you present the thing. So I probably did the same about Asperger's. I went through the positive things. I kind of said do you know the way you are good at this, and do you know the way your brother isn't afraid of music, and you are...*

In order to protect the child, most parents had a tendency to use euphemisms rather than describe the reality of the situation. Respite care was described by one parent as 'the holiday house' (P5). Parent 6 described how they had a tendency of 'twisting things' in order to avoid hurting the child's feelings. The highlighting of differences in others and how we are all different was one important way of reframing the child's diagnosis in the context of normality:

P7: *...we'd always say 'well none of you are the same', in a natural environment highlighting that people are not the same, and you know to feel the way you feel*

The impact of disclosure

All parents wanted the diagnosis to result in some form of relief or validation for the child, as well as a sense of normality- in that there were others out there like them:

P1: *I did want him to have it to explain to himself if times were difficult, that it wasn't anything that he was doing wrong, that sometimes there's nothing you can do about things*

And:

P5: *'There's nothing wrong with having Asperger's?' that's what I always get from him. I say 'not at all'. I always try to be positive about it, like 'look at all the really intelligent people like Einstein who've said they've had it'. He loves to hear about other people that have it*

Parents were acutely aware of the prejudice and downsides to a label which others can hang pejorative connotations on. A good example of this was in Parent 5's interview, who felt that it was of no benefit to their child having a label, if the label was accepted as an excuse, as life would not be so forgiving:

P5: *He has really excelled and come into his own and his confidence. He's getting himself from A to B and he is grand...I think he has developed an awful lot maturity-wise since going into secondary school. I think as well they don't tolerate it...They don't tolerate behaviour as much...And I like that as well because life won't wait for him. Life doesn't allow or tolerate differences, or not complying with the rules and regulations like the rest of us do*

All of the parents who had told their child cited that disclosure of the diagnosis had mixed implications for their child. They recognised the label as a source of comfort, but also having possible limiting effects. Parents really were careful in the disclosure to minimise the effect of informing them of the diagnosis so that they would be able to use it as a:

P1: *source of comfort if things were tough, that he'd have a label he could investigate further when he was older...*

Discussion

Summary of findings

Parents found the process of receiving their child's ASD diagnosis a difficult one. Many reported significant ambivalence about the diagnosis, both relieved and vindicated, but also sad and unsure about the future and how to access supports. In addition, a number of parents perceived that the way in which they were informed of the diagnosis was on occasion lacking in sensitivity or poorly communicated. This

experience was exacerbated by parents' own perceived limited knowledge of ASD prior to the diagnosis. Differentiating the normal parenting role as distinct from the role of parenting a child with a disability meant that normality needed to be negotiated. The meaning ascribed to the diagnosis resulted in most parents needing to adjust expectations and hopes for their child and to learn how to both protect and also not over-protect the child's developing sense of self and their independence. Sharing the diagnosis with the child appeared to occur when parents felt the child was at the right age and place that the diagnosis would possibly function as a useful versus a stigmatising label for them. The diagnosis was seen as something which could help the child or adolescent normalise their own experiences. Parents tended to reframe some communications in a positive or euphemistic way so that the disclosure would be both more useful and palatable. The disclosure itself appeared to have both positive and negative effects, but parents on the whole appeared to view it as a sign of their child's maturity and growing sense of self. They could also see themselves as a parent who was separating as one would normally from a child without such a diagnosis.

Findings in context

Findings from the current study corroborate the extant literature on the process of receiving a diagnosis of ASD and adapting to its consequences (Mansell & Morris, 2004; Howlin & Moore, 1997). Parental dissatisfaction with the diagnostic process is consistent with findings by Mansell & Morris (2004) who described this process as slow, chaotic and badly handled. Sources of dissatisfaction ranged from difficulties having initial concerns taken seriously to preliminary diagnoses which were inaccurate and vague. Midence & O'Neill (1999) noted that 'not knowing' was the most difficult part of the pre-diagnostic period. Diagnosis was often received with relief, as it helped parents resolve their confusion and guilt, explained their child's behaviours to themselves and others, and enabled access to services and supports. Nissenbaum et al., (2002) also found that parents feel relieved that they are not at fault for their child's difficulties. Diagnosis was also received with shock, devastation, and a sense of loss for the life and child they had hoped for (see also Mansell & Morris, 2004). Similar accounts in the literature indicate that parents move between the 'stages of grief' upon discovery of a child's diagnosis of a disability (Siklos & Kerns, 2007; Siegel, 1997).

Unsatisfactory interactions with health care professionals were reported by most parents at some stage in their journey (see also Brogan & Knussen, 2003). At diagnosis,

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parents expressed dissatisfaction with the professional’s manner and the information they were given about ASD. Similar to Osborne, McHugh, Saunders, & Reed’s (2008) findings, parents in the current study recommended that they be provided with a road map indicating available, appropriate services, and information about the effectiveness of different approaches and the future prognosis for their child (Osborne & Reed, 2008). Furthermore, hope was highlighted as a vital message to be communicated by professionals during the diagnostic process (i.e. that having a diagnosis is a positive thing around which a child’s needs can be structured) though unfortunately in the current study many parents reported the contrary (Nissenbaum et al., 2002). The value of the support parent’s received at this time, both from professionals and family and friends, was determined by the perceived level of knowledge and understanding of the child’s difficulties and needs (see also Sharpley, Bitsika, & Efremidis, 1997). Consistent with previous research, the current study found that inter-parent support is one of the most beneficial ways of helping parents adjust to their of child’s ASD diagnosis (see also Huw’s et al., 2001).

The currents study’s findings on the diagnostic process are reflective of findings from a national survey of families experiences of being told of their child’s disability, which evidenced that the diagnosis was conveyed insensitively or in inappropriate environments; and that their experience of being told the news had caused additional distress (Harnett, Dolan, Guerin, Tierney & Walls, 2007). Professionals similarly expressed dissatisfaction with the guidance and support they received in this task . In response to this feedback, best practice guidelines for telling parents about a child’s diagnosis were designed in association with the Health Service Executive (HSE), and have subsequently been adopted nationally as the standards for diagnosis (Harnett et al., 2007). There is a clear need however, to monitor the implementation of these guidelines.

Implementation of similar existing standards in the UK evaluated to have lacked effectiveness, largely due to poor dissemination of information among health care professionals (Fallowfield & Jenkins, 2004). In the Irish context, one would hope that with the development of best practice guidelines for informing families of their child’s diagnosis a neglectful, dismissive and disenchanting process is less likely, however an audit of progress is clearly needed to ensure gold standards are reached (Brogan & Knussen, 2003).

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3 Parents' views of the diagnosis evolved as the child matured. Parents wanted to
4 enjoy their child's unique personality whilst also coping with the real challenges of the
5 diagnosis (Midence & O'Neil, 1999). Sharing the diagnosis with their child became an
6 issue with parents' recognition of their child's continued development and progress.
7 Goffman (1968) suggests that cracks appear in the 'protective capsule' parents have
8 created around their child as adulthood approaches, and the current study revealed
9 similar findings. All parents felt that a cognitively able child had a 'right to know' their
10 true social identities. Most of the parents felt that disclosure by peers or drawing their
11 own conclusions about their difficulties could have a more negative impact on the
12 child's sense of self than explicit disclosure by parents. Claflin & Barbarin (1991)
13 reported similar findings with parents of children with cancer and suggested that telling
14 less does not necessarily protect more. The act of disclosure was nonetheless
15 approached with ambivalence. Whilst on the one hand, parents wanted to legitimise
16 behaviour and clarify previous life experiences, they were also aware of the shock and
17 disruption to life plans that knowledge of the diagnosis could impose. This array of
18 emotion very much reflected the experiences of people with ASD learning of their
19 diagnosis as documented in the literature (Huws & Jones, 2008).

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Parents employed a range of strategies to protect the child from the potentially
harmful consequences of disclosure. They reported waiting to disclose until their child
had developed an awareness of their disability or explicitly questioned their difference.
Parents wished to communicate positive and hopeful messages to their child about their
disability, though they often reported feeling ill-equipped to handle such discussions
(see also Young et al., 2003). They feared they would overwhelm their child or portray
the diagnosis in a manner which would define them. Consequently, parents carefully
managed when, how and what their child was told about their diagnosis. In the literature
this has been referred to as the executive like role adopted by parents in managing their
child's identity (Young et al., 2003). Young et al., (2003) noted that this role both
facilitates and constrains communication, and the current study reported similar
findings. Parents wished for their child to have an understanding of their disability, yet
their protective communication style may have prevented them from developing a full
awareness of their ASD.

Strengths and limitations of the study

By its nature, this study was an IPA, which had implications for the generalisability of
the findings. The small number of parents involved meant that the findings may not be

representative of the views held by other parents of children with ASD. However as IPA studies are concerned with the in-depth analysis of certain phenomenon within a small selected group, making generalised assertions about larger populations was not the focus of the research (see also Huws & Jones, 2008). Another limitation of the current study was that it did not address the influence of gender, age, socio-economic status, ethnicity or the specific nature of the disability on parental experiences of diagnosis and disclosure. In particular, only one father participated, and not all parents had discussed the diagnosis with their child at the time of interviewing. Whilst the research question was meaningful for all parents who took part, a more homogenous sample may have enabled a greater examination of psychological variability within the group. Despite these limitations, this research had not been completed in the scientific literature previously: understanding the lived experience of these parents allows the development of further research questions which can be tested on larger, more representative populations.

Implications of the findings

Professionals need to become more astute in their communication of diagnosis to families of children with ASD. Professionals need to be empathic about the emotional impact of the disclosure of a diagnosis. Teams need to identify which members of the trans-disciplinary team are most adept at this, and it is not necessarily the psychologist who should step into this role, as all members of the team will have different strengths and weaknesses that should be acknowledged. A map for parents' about available resources and reasonable expectations needs to be provided where possible. The implementation of national best practice guidelines on informing families of their child's diagnosis will go a long way towards improving families experience of the diagnostic process (HSE, 2006; Harnett, Dolan, Guerin, Tierney, & Walls, 2007). Siblings also need to be remembered in this process, as they are likely to have the longest life-long relationship with their brother or sister with an ASD diagnosis, and thus they need to be key-stakeholders in the communication and understanding of the diagnosis. Professionals have a duty to work with parents to develop awareness as to how the diagnosis affects the sibling and how to engage with siblings in relation to it (Egan & Walsh, 2001).

Open communication with the child regarding their disability seems necessary in order to provide them with the tools for dealing with their lives. Nonetheless, sharing information about a disability is a difficult task for many parents. Decisions about what

to tell the child about their disability, and when to disclose evoke a range of anxieties and concerns. Health care professionals play a key role at this time in helping parents overcome their reticence, and offering guidance and advice. Professionals have a responsibility to further their expertise and understanding of this particular domain because of the connections between the support/services they offer, parental adjustment, and disclosure to the child.

The paucity of research which has been conducted on the experiences of those who have received a diagnosis of ASD and those who have had to relay the diagnosis indicates that this is an area which warrants further exploration. Further research should examine what factors indicate a child's readiness for knowing about their diagnosis, how do children experience receiving a diagnosis, and what supports can facilitate a child in processing this information. It may also be interesting to explore the effect of parents' positive and negative attitudes towards ASD on their intention to disclose the diagnosis to their child. With further research, the development of best practice guidelines for disclosure to the child from the perspective of health care professionals, parents and individuals with ASD would greatly ease this process for all involved.

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Dear Reviews and Editor,

Many thanks for the opportunity to address your concerns. Please find an outline below with your comments and concerns restated and a response following each section outlined below.

Reviewer(s)' Comments to Author:

1. The abstract of the paper suggests that the focus of the study will be on parents discussing a diagnosis of ASD with their child. However, the analysis is much broader than this, focusing on parents' own experience of receiving a diagnosis for the child, coping with this, and finally communicating this to their child. The discussion section also focuses on these three areas. This analysis is really nicely done and very informative, but it's not solely focused on disclosure to children. Therefore I think the authors need to decide which focus to take – I feel it should either be framed as a broader and more general examination of parents' adjustment, including telling the child (this is what the title suggests) – or else it should be a narrow examination of disclosure to children (as the abstract suggests) focusing only on those parts of the interviews. I feel the first approach would be stronger and would use the analysis well, but the authors need to decide which way to frame the study.

RESPONSE: The above concerns have been addressed and the paper now reflects a broader discussion

2. In the introduction there aren't enough references to back up assertions such as 'Parents act as cognitive and emotional filters to their children' and 'researchers have asked parents about their experience of being given their children's diagnosis'. All assertions of this kind need to be referenced. The first paragraph should be clearer – the author writes that 'parents manage the process of diagnosis' but does not specify that this is about autism diagnosis.

RESPONSE: References have been added and a new paragraph on page 2 has been added to reflect on this comment (lines 44-55).

3. In the introduction I think the description of Howlin & Asgharian's (1999) study is misleading – from the time parents noticed any concerns to diagnosis may have taken 4-8 years but the diagnostic process itself did not – so I would rephrase this to be clearer.

RESPONSE: This has been rephrased Page 3 lines 11-12.

4. On page 3 the study aims should be in the past tense, and should more clearly set out the focus of the study (e.g. is it to develop understanding of parents disclosing to

children or is it about the broader issue of parents' experience of receiving a diagnosis etc).

RESPONSE: Past tense has been used.

5. In the participants section of the Methods the author needs to specify where they recruited participants. They describe using a snowballing technique – did parents recommend each other for the study? Please use a reference for 'snowballing'. The sentence that begins 'At the time, the parents were disclosed...' needs to be rephrased.

RESPONSE: Page 4 & 5 has been completely redrafted to more clearly outline participants involvement.

6. In the Measurement section IPA is described as the 'stance of the researcher', but I wonder if it should be called the 'method of analysis'?

RESPONSE: Now referred to as method of analysis on page 5, line 28.

7. In the Data Analysis Procedure section the author refers to the 'left hand margin' – this needs to be better contextualised and described – does the author mean the margin of the script?

RESPONSE: Changed to script.

9. The discussion section has some interesting ideas but it's disorganised and would benefit from being better ordered around certain sections. It could start with a summary of the findings, then talk about topics such as

1. Parent's experience of diagnosis
2. The way in which clinicians deliver diagnoses (and please give reference for Informing Families guidance) as well as auditing this process and what after-care is given;
3. Parent's experience of disclosing diagnosis to children, including communication style of parents to children.

RESPONSE: The discussion section has been completely redrafted taking in the above comments.

10. The last paragraph of the discussion does not make sense. I think the author needs to be clearer about what concrete research could come from this – e.g. what factors indicate a child's readiness for knowing about their diagnosis? How do children experience receiving a diagnosis? What supports can help children to process this (e.g. evaluations of support groups for children with ASD).

RESPONSE: The last paragraph has been removed and redrafted taking into account the above comments.

TYPOGRAPHICAL ERRORS HAVE BEEN CORRECTED.

Reviewer: 2

Comments to the Author 1. Perhaps it is clear in Ireland what the professional team On page 4, there is an indication that the participants received the diagnosis from the professional team...this was not clear to me.

RESPONSE: The participants section has been redrafted to be clearer.

2. In the recruitment of respondents, the ages of the children were not clear. Although the authors indicated when the diagnosis was received, the age of the child at the point of the study was not clear. Along with this, since both autism and asperger's have various manifestations, this was not stated. Both age and nature of the disability have implications for disclosure.

RESPONSE: This section was redrafted to address these concerns about clarity.

3. The discussion was both interesting and certainly relevant for families who have children with autism. At times, the authors appeared to go beyond what was presented from the data analysis. The discussion may need to be more contained.

RESPONSE: The discussion section has been completely redrafted based on the above comments and reviewer 1's comments.

4. In the limitations to the study, several major limitations were omitted. Specifically, there was no mention of the small sample size or the fact that it was a convenience sample. There also was no mention of socioeconomic status anywhere in the article. If this information was not obtained, the authors should indicate it was not and perhaps why not.

RESPONSE: On pate 17 a Strengths and Limitations of the study section has been added and details these issues between lines 30 and 48.

Editor's Comments

- Avoide use of acronyms in the Title and Abstract:

RESPONSE: Acronyms removed or stated and acronym placed in brackets following to save on word count.

- Consider changing the title of the subsection Measurement to Materials. I recommend the inclusion of a table showing the key sections of the interview schedule and indicating key references that support the inclusion of each section

RESPONSE: Table included on page 6.

- What did the audit trail mentioned on page 6 consist of?

RESPONSE: Now on page 7, the audit trail is discussed between lines 11 and 24.

- I agree with the first reviewer's comments that there is some variation between the title, the abstract, the findings and indeed the discussion that needs to be addressed.

RESPONSE: These have been amended.

- In discussing the findings it is important to recognise that these are the experiences and perceptions of parents. You comment on p11 that " the way in which parents are informed of a diagnosis was on occasion lacking in sensitivity or poorly communicated" might suggest a more objective assessment of the process rather than a formulation of the parents' reported experiences.

RESPONSE: Findings in context section has been added on page 13.

- The discussion of the findings needs to be more grounded in the relevant literature. While it does not focus on informing children.

- The limitations section should be presented as Strengths and Limitations and should include a balanced reflection on the positive and negative aspects of the study that may have effected the credibility of the findings.

- It might be worth noting that the Information Families project did not just generate a service user leaflet, but rather that they developed best practice principles for professionals which have since been adopted nationally as the standards for diagnosis. This point may be more relevant to the key issue being discussed.

RESPONSE: All the above issues have been addressed in a completely redrafted discussion section .