

# **Families' Experience of ASD Diagnosis in the North West**

**The results of a research study commissioned by the North  
West Care Services Improvement Partnership Children and  
Families Programme**

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## **Families' Experiences of Diagnosis across the North West**

### **Context/ Background**

Following concerns about significant variability in the methods, timescales and auditing of autism spectrum disorder diagnoses (ASDs) in the North West, the Care Services Improvement Partnership (CSIP) established a project to develop a regional set of standards for the identification and diagnosis of ASDs in childhood. A multi-agency Identification and Diagnosis of Autism (IDA) Project Steering Group was convened, and agreed that a 'gold standard' of good practice had already been outlined in the National Autism Plan for Children (NAPC) in 2003. To gain a baseline of best practice in identification and diagnosis of autism spectrum disorders across the region, it was agreed that the group's first step would be to develop a questionnaire which was sent to all Primary Care Trust's (PCTs) to ascertain how closely the NAPC recommendations were being followed in each area<sup>1</sup>. 22 out of the 24 PCTs responded, and the results of the audit were shared and best practice highlighted at a regional event in November 2007.

Whilst this information was very important in terms of ascertaining the current situation regarding the processes of identification, diagnosis and assessment across the region, the Steering Group also felt it was important to expand the project to include the families and carers perception of the process particularly focusing on the *experience and quality* of ASD diagnoses in this case; predominantly of children with autism and Asperger Syndrome.

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<sup>1</sup> See appendix A for PCT audit tool

To elicit more qualitative data about the experience of identification, diagnosis and assessment, the Steering Group proposed a parallel piece of research based on interviews with parents of children who have been through the diagnostic process in the North West in the past 3 years. The interviews picked up on key themes from the National Autism Plan for Children, such as the presence or absence of early detection of alerting signs; the acceptability of waiting times for assessment; the quality of the assessment process and multi agency working; breaking the news procedures, and the availability and relevance of post diagnostic information, training and support for the whole family<sup>2</sup>. The interviews were intended to provide opportunity for the users of services to look back on the long term impact of this experience on themselves and their families: to reflect on what had been helpful and what hadn't. Even negative aspects of experience contain within them lessons to learn and clear pointers to how practice can be improved.

By combining these insights with the results from the audit, the Project group will be able to make clear recommendations for a regional set of standards that encompass best practice from the perspectives of both professionals and the families they work with. This work links to the National Service Framework for Children(2004) which sets out standards to:

- Improve quality
- Reduce variation
- Establish performance indicators
- Support partnerships
- Involve parents and children

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<sup>2</sup> See appendix B for interview schedule

- Break down professional boundaries

The National Autism Plan for Children(2003) was written in consultation with both professionals and parents and expressly believed that, while

*“From the parent’s perspective, the intense distress associated with the diagnosis of autism/ASD cannot be taken away,.. At least the experience can be assisted by a system that works effectively to answer their questions and provide them with the support they need.”* (Dr Sue Bailey, Foreword to the National Autism Plan for Children, 2003).

### **Introduction:**

It is clear from the audit of PCT’s completed in 2007, that many PCTs in the North West now have an ASD referral, or care pathway (64% answered positively to this question). 78% realise the importance of making a diagnosis of children via a multi-agency assessment, and over two thirds of responding Trusts had invested in recognised ASD specific assessment training. The above points were key recommendations of the National Autism Plan for Children, (published in collaboration with the Royal College of Paediatrics and Child Health, and the Royal College of Psychiatrists), and suggest that there has been progress and investment in the rigor of diagnostic processes regionally.

However, such measures of procedure tell us little about the quality of the diagnostic experience from the user – or ‘receiving’- end. Audit questions more directly related to family involvement threw up the lowest scores overall, with key workers rarely available and assessments of the needs and strengths of all family members only routinely made in two PCTs. In the National Autism Plan for Children it says:

*“Assessment should: address the needs of the child in the family context such that the family is given confidence to provide for the health, learning and care needs of their child, whilst understanding that their own needs (including cultural and spiritual needs) are being taken into account.” p32*

Questions we wanted to explore through our interviews included: do we diagnose a child but ignore the family? What is it like to live with a child with ASD undiagnosed? How easy are our diagnostic processes to access? Are systems and services supportive and empowering or not? Has breaking the news been thought through? Is ‘getting a diagnosis’ the end of the story/ the end of professional responsibility? How do we support families to move towards a more positive acceptance and adaptation to their child and their new lives as ‘families with a child with a disability’? How can services work together more effectively to safety net children and families struggling with these considerable stresses and challenges? In short, what are we currently getting right, and what do we need to change.

### **Methodology**

Based on the results of the self-audit questionnaire, 2 PCTs were chosen in which to cluster 8 interviews. The chosen PCTS were rated differently in the PCT audit -one self rated as having a good diagnostic service judged against the NAPC criteria, and one self rated as being not so good. These 2 PCTs were in different regions of the north-west, but are demographically similar.

The remainder of the 31 interviews (23 including 3 pilots) were scattered across the region. Their location was determined by those families who responded positively to invitations to take part in the study.

Requests to take part were sent to 100 families from the NAS help! Database and these were chosen to ensure the most even spread of PCTs, age of diagnosis and severity of additional learning disability. Use of the NAS database inevitably meant that the sample was made up of participants who had already sourced independent and external support. It was therefore not fully representative of the broad range of families receiving a diagnosis. However, given the absence of other sampling frames (few PCTs or local authorities maintain data about children with ASDs in their area) and time constraints, this seemed the best available solution.

All but 2 of the families who expressed interest in taking part were able to be involved, and all interviews followed the same, semi-structured interview format (see Appendix C). The interviews took on average between 60 to 90 minutes and were taped. Detailed notes taken first by the interviewer, then by a second research assistant to try to minimise bias in the selection and interpretation of material. Findings were checked back with all the participants in writing and followed up with a phone call before the final draft report was completed. At the end of the interview participants were offered a gift in recognition of the value of their time and experience, and were invited to take part in the dissemination of findings.

**Sample:**

The families who agreed to take part represented a good geographical mix. Those who responded however, did have a bias towards children diagnosed with ASD and Asperger syndrome who were in mainstream school, and who had received a comparatively late diagnosis. Only 8 had received a diagnosis pre school, and only 6 were now attending special schools. Our average age of diagnosis was 8.3 years, 26 months later than the average identified by Howlin's study in 1997.

**Previous research findings:**

Howlin and Moore's survey (1997) of almost 1300 parents found that the average age first concerns emerged about their child's development was 1.69 years. The average age of a final diagnosis was 6.11 years. Greater satisfaction with the diagnostic process *and* with support received was noticeably higher for those who experienced less delays in obtaining a diagnosis, and where diagnosis was definite (i.e. no mention of 'traits' or 'tendencies' pp 151).

The need for stronger links between professional agencies was highlighted by parents in focus groups conducted by Osborne and Reed (2008). The authors point out that while "the diagnosis of ASD is made within a medical context, subsequent help is mainly provided through educational channels". Through our interviews we found this problem mirrored pre-diagnosis, in that problems were being experienced within the school context but education professionals were not knowledgeable about, or easily linking into, the medical systems of diagnosis.

Other common themes running through recent diagnosis research in the UK are that parents are repeatedly frustrated by lengthy delays (Mansell and Morris, 2004; Oberheim, 1996 etc.); and that satisfaction or otherwise is directly linked to how sensitively parents are listened to and treated (e.g. Knussen & Brogan, 2002; Brogan & Knussen, 2003), and whether comprehensive information is provided at the point of diagnosis (e.g. Whittaker, 2003; Mansell & Morris, 2004).

The pre-diagnosis phase seems to be typified by parents' difficulties understanding and explaining their child's behaviour (Midence & O'Neill 1999), and a lot of self doubt and blame because of this (Rogers, 2007). Given this situation typically goes on for years before a final diagnosis, it would seem clear that professionals need to handle breaking the news with the utmost sensitivity. At this time, parents value a professional manner, the provision of quality written information, and opportunity to return to ask questions (Brogan and Knussen, 2003).

In their pilot study using semi structured interviews with four families, Midence and O'Neill (1999) found that the main response to an eventual diagnosis was one of relief. This finding is replicated in larger sample studies too – for instance, in Mansell & Morris' 2004 survey 90% of respondents agreed strongly with the statement that obtaining a diagnosis had been a relief (thereby the most common and consistent response). Alongside this however, is an enduring sense of loss, with “dashed expectations” as the main casualty, alongside a missed opportunity for the “idealised ‘normal’ parenting” (Rogers, 2007). Mansell & Morris respondents requested post-diagnostic counselling and in our research we found such a service particularly wanted by the participating fathers.

Post-diagnosis support seems very patchy and disjointed with many parents expressing the sense of having been ‘dropped’. As our sample was heavily biased towards school age diagnoses, it was a common experience for families to go through the assessment process at a local hospital or clinic only to be told at the end of it – ‘that’s it, we’ve done our bit, case closed’. Again there was a problem in that diagnosis happened in a health context, Statementing in an educational context, and the whole child and family’s needs often not addressed by any service.

As Midence and O’Neill describe it, there is an inevitable and vital post-diagnostic stage of family acceptance and adaptation that both professional practice, and service design, needs to be guided by. Lietz explains in her study of resilient families:

*‘Working with families needs to capture the whole experience of families, and not just the negative experiences. Service providers, who interface with families of children with disabilities, can communicate to them with a conviction that these families can be resilient, the same way that they could communicate a negative conviction’ (Lietz 2006)*

In order to promote such resilience it is vital that parents feel listened to, that assessments take account of the family context, and that post-diagnostic interventions and support are designed in partnership with families – being designed to empower them rather than leaving them marginalized.

*‘Insensitive professional and official intervention can generate conflict and weakness, instead of strength and mutual support. It is the responsibility of professionals to meet families at their point of need’ (Carpenter, 2005)*

### **Pre-diagnosis:**

#### ***“You know your child but no-one’s listening”***

In our sample we found the average age first concerns were noted was 22.5 months, with a range from 10 months through to 6 years. By far the most common time for worries around development to surface was between 18 months and 2 years. In 63% of cases, these first concerns were raised by parents (usually the mother), and the first point of contact was most often the health visitor, followed by the GP, then nursery staff. In just over a third of cases, initial concerns were raised by a professional. Again, this was most likely to be the health visitor – particularly if the child was under 3. After health visitors, nursery staff were the second most likely to indicate there might be difficulties.

In a third of cases alerting signs were initially missed because of other issues and concerns. These included the fact that four of the families had twins where one or both were later found to be on the spectrum; two children where English was not the only language spoken at home, and other instances where suspected hearing, learning and dyspraxic difficulties led the diagnostic process in a completely different direction.

The most common concern was about language delays or, in a couple of cases, language development seeming to stop completely. Lack of interest in being with other children was mentioned as conspicuous from early toddlerhood for several participants, and fixations with certain objects or routines were also mentioned as apparent early on - sometimes within the first eighteen months. One mother

remembered how, if the day started wrong for her son, the whole family would have to go back to bed and start their morning routines again from the beginning.

In a context of not knowing why their child is acting differently, many difficult and conflicting feelings are stirred up. Before daring to voice concerns aloud, parents (typically, but not always, mothers) have questioned and criticised themselves for having somehow contributed to these problems:

*“All I knew was that it didn’t feel like I thought it would feel... perhaps social services should take him away because I don’t know what he needs – when he cries I don’t know why”*

Added to the self doubt and concern about the adequacy of their parenting, mothers also reported having to face the implicit and explicit criticism of others. One mother neatly summed up the situation this way:

*“I had seen it from a long time back that he was a difficult baby. He was my first so I had nothing to judge it by. At that time, I thought the difficulties were of my own making.....as did the rest of world”*

Many parents expressed the view that others deemed them “neurotic”, “molly-coddling” or “wet”. In cases where such a view was expressed to them in response to initial concerns, some mothers were dissuaded from their early plans to seek further assistance. When one of the mothers was pregnant with her second child the health visitor commented, *“Let’s hope you’re not going to let that one control you as much as the other one does”*. In desperation, the same family resorted to video taping their child self injuring at home in an attempt to get the health visitor and GP to take their concerns seriously and refer on.

Other families mentioned they too had thought of videoing their child in response to the common feeling of being at best ignored, at worst, disbelieved. In 20% of cases, parents were only successful in being referred beyond the GP surgery after serious incident(s) of self harm or harm to siblings, or following a threat of potential harm from parent to child if help wasn't provided soon.

Where health visitors noticed problems, usually at two or three year checks, referral to a paediatrician or speech and language therapist (SALT) typically followed. How useful this was however depended on the expertise of that individual, their willingness or otherwise to refer on for more specialist assessment, and related to this, their personal philosophy regarding 'labelling'.

Many of the concerned mothers were advised to "just carry on", "not to worry" and "(s) he'll be fine". A common addition to this being the admonition "not to compare" their child with other children. But as one parent pointed out, what would be the point of development checks if they didn't seek to make comparisons and identify norms? In a few cases, early assessment was obtained by the determination of a professional diagnosis 'champion': in our study, two of these were nursery heads who made it their "mission" to get the child diagnosed before school, and one was a specialist health visitor (all three sets of parents were extremely grateful for these interventions).

It was rare that a professional raised initial concerns where parents had no prior inkling that something may be amiss, even if they'd not voiced this to anyone. In a few cases nursery staff were the first to observe unusual or difficult behaviour, and in

a couple of other cases pre school speech and language therapists suggested further assessment was necessary. Even though difficult to hear at the time, all of the families interviewed were glad these professionals spoke out when they did. Praise was singled out for those who had been careful to highlight the child's difficulties within a context of overall concern for that child's well-being, and who made sure to mention the child's strengths as well as their weaknesses. Where the focus was solely on difficult behaviour, parent's sense of personal inadequacy was inevitably made worse.

### Good Practice Pointers

- Each area needs to have a clear, multi-agency diagnostic pathway with transparent and easily accessed entry points.
- The pathway should include approximate timescales of response.
- The diagnostic pathway should be in written format and available to all front line professionals and parents.
- All early years professionals need training in understanding the alerting signs that might indicate ASD in a child, particularly health visitors and GPs.
- Professionals should recognise that parents often intuitively know when there is something wrong with their child. Professional training programmes should include how to listen to and work with families, and how to approach the need for further assessment with sensitivity.
- Professionals need to recognise the limits of their expertise and be prepared to refer on when a second opinion is needed.
- Where possible it is better to refer straight onto a social and communication disorders specialist service or professional rather than generic children's services.

### **The undiagnosed child at school:**

*“It is of no benefit to be within the education system without a diagnosis”*

In comparison to other studies in the UK about diagnosis, our sample had a bias towards children now diagnosed with ASD and Asperger Syndrome in mainstream schools. Responses suggested that it was those families whose children had started school without a diagnosis who most wanted to share their experiences (75% of respondents).

As the opening quote to this section suggests, all of these parents spoke of how difficult it had been for their child at school prior to obtaining a diagnosis. Early years professionals may have seen the child and decided that it would be harmful to pursue a label so young, but as many parents pointed out – their children just got stuck with different, more pejorative tags:

*“If you think he’s not being labelled you’re in fairy land: he’s being labelled a naughty boy. I would rather he had a scientific label than an unofficial label”*

In many cases, the schools were aware of ‘a problem’ but categorised that problem as one of bad behaviour. More than one interviewee related how their child spent many hours on the naughty chair, or outside the head teacher’s office, often with little understanding of why they’d been sent there. Four children had been excluded more than once.

In other examples school staff dismissed parents concerns, insisting that the child was “fine” despite evidence that they were significantly under-achieving in some areas, and also evidence of their considerable anxiety and distress about attending school.

In one sixth of cases of a school age diagnosis, parents related that head teachers or

LEAs had only taken action to assess the child's needs when they threatened legal action or wrote to the governing body and/or the local MP. Often parents seemed to meet considerable reluctance on the part of the school to make referrals to educational psychology services and some felt this was an issue of resources.

As with referrals in the early years sector, experiences of educational psychologists varied widely according to their expertise in ASD. In a couple of cases, their involvement and intervention proved to be the breakthrough the child and the family needed for difficulties to be acknowledged, and the correct support and strategies to be put in place. Others came out less well, notably one who said:

*“If you took your child to the local NAS support group all the other parents would laugh at you because their children have got real problems”*

Frequently there seemed to be inadequate communication between local health services and the education authority. In some cases there also seemed to be a culture of conflict between the two that parents and children unwittingly got caught up in with damaging results.

Sometimes it seemed that the relationship between teachers and parents was characterised by a mixture of mutual defensiveness and mistrust that got in the way of pupils needs being recognised and met. Parents who have been questioning and blaming themselves for their child's unusual behaviours are understandably quick to feel further blamed when complaints about behaviour become the daily norm at the school gates:

*“..so it was kind of half way through reception and we'd been in school numerous times. The teacher was constantly ringing us and sending him home .....basically*

*using the words... he was a naughty boy, uncooperative, and I'd kind of go in school and feel quite insignificant and inadequate 'cos of my experiences at school, and I kind of thought the teachers were right. I felt that I couldn't really articulate myself in a discussion and was kind of agreeing with them"*

It was five years and two more schools later that the above child finally got a diagnosis.

Five of the children in this study were taken out of their original school by their parents and placed in more inclusive, supportive (still mainstream) schools. The variability within a small geographical area shows that excellent practice does exist and parents were also quick to praise again the "brilliant" teachers who went out of their way to ensure that children got the support they needed. Two sets of parents could not praise their child's school and head teachers highly enough.

When we asked interviewees what the most useful thing about having a diagnosis had been, many mentioned that it had opened the door to services and support that beforehand had been totally out of reach. Statements of educational need fell firmly within this camp with most children only becoming eligible via their diagnosis. Often the statement and the 1:1 support brought with it proved to be the turning point in the children's educational careers. One set of parents who managed to get a Statement and support for their son after writing to the local MP (he was in secondary school by this point) told us how

*"Now he has support full time and she scribes for him. He's getting A stars.*

*He's just done his mocks and is doing fantastically - for someone who can't even write his name"*

### Good practice pointers

- In many areas a separate diagnostic pathway for school age children will be necessary. This should be multi-agency, in written format with timescales, and easily accessible to all.
- Education professionals require training in the alerting signs of ASD with particular regard to how this may present in the school setting.
- There should be training for education professionals about the diagnostic pathway, and schools should know how and who to refer to for further assessment.
- Good multi agency working is essential – professionals should be communicating with each other and collaborating to ensure the whole child's and family needs are addressed.
- Professionals need to have a better understanding of the combination of difficulties likely to be experienced by a child on the autism spectrum – in particular, behavioural problems should not be dismissed as evidence of a naughty child or a dysfunctional family.
- Ease and timeliness of access to education psychology services needs to be improved in many areas.
- Specialist ASD education advisory services and professionals are extremely valuable once on board.

### **The assessment process:**

*“Ignorance isn’t bliss. You need help as early as possible”*

Many of the parents interviewed had spent years pursuing a diagnosis. The time from someone first noticing concerns to getting a confirmed diagnosis ranged from 1 yr to 12 ½ years with 4 to 6 years being the most common waiting period. The process of getting someone to recognise that their child was experiencing difficulties was described by many as a “fight,” a “battle” and a “struggle”. Because this took so long parents felt a sense of relief once they were finally ‘in the system’. However, being in the system was often not the end of delays and brought about its own confusions and frustrations.

For the majority of families who felt they had a bad experience, this was characterised by the following: long waits; repetition of basic information; not feeling listened to, and the presence of dispute – either between themselves and key professionals, or in several cases, between diagnosticians. One parent said, *“I felt like a rag doll between the paediatrician and the psychologist. We never saw them together.”*

As the presence of other conditions or difficulties is a significant issue for many on the autistic spectrum, the diagnostic process was complicated and lengthened by earlier or additional diagnoses of ADHD, Tourettes and Dyspraxia for a quarter of families interviewed. Still more found themselves sent on alternative routes, and away from an ASD assessment process, by a key professional focusing on one difficulty (eg. dietary or toileting problems), and not looking at the child holistically, or in a properly multi-agency way. That a symptom such as an extreme sensory or anxiety response may signal the presence of a broader social and communication

disorder was often missed and this contributed again to delays. With a focus exclusively on the child, and specifically on particular ‘symptoms’, 97% of families interviewed expressed the view that they did not feel the whole family’s needs had been taken into account as recommended by the National Autism Plan for Children (2003).

Having to repeat the same story over and over to different professionals contributed to the sense of not being listened to: *“Sometimes we felt listened to, but with different staff it felt like a broken record – why don’t they read the notes?”*

When asked what would have made the assessment process better, another mother replied:

*“Maybe acknowledgement that we were talking from a perspective of knowing something – being treated as equals. We weren’t any less knowledgeable, we knew how the ASD affected our child. This wasn’t acknowledged, ‘you’re just a parent what do you know?’.. It was draining - undermining.”*

That such interactions could also be “daunting” or “intimidating” was highlighted by a number of interviewees. More than half the parents interviewed mentioned at some point how they felt that, had they been less ‘articulate’ ‘knowledgeable’, ‘troublesome’ or well-supported by family and friends, they would not have been able to pursue the diagnosis with the persistence they did. Several expressed concern for other families who may not be willing or able to ‘take on’ the system in this way.

A number of parents also talked about the effect of a lengthy assessment process on their child. Problems included the child being talked about in their presence, the stress of having to attend many different appointments at times that disrupted school

routines, and the impact on self esteem of having to take part in an assessment process designed to highlight their weaknesses and shortcomings. One mother said, *“ I watched the play session through the window. It was awful, heart breaking watching him fail”*

Another explained that her son *“ used to end up in tears... because he knew he did that stuff, he'd just never realised it wasn't normal before”*.

Some parents experienced an inner conflict between their desire to receive a correct diagnosis and the feelings of disloyalty the process raised. When describing her feelings on being asked to complete a parental questionnaire about her son's difficulties one mother commented that it was:

*“Awful... I felt like I was signing his death warrant”*

Another mother spoke of how her husband found it really difficult to share the real picture of life at home with the professionals because he felt disloyal to his son

*“ He sees it as a personal failure as a parent for things not to be great and fine, for him not to be coping. He wouldn't tell them what was really going on”*

The 'system' often came across to parents as both hard to access and equally hard to navigate. None of our parents described being given a written diagnostic pathway. As one mother said, *“What would have made it better would have been a clear written map and a list of useful phone numbers...instead of getting passed around a telephone tree.”*

For many it was this sense of being in the midst of a process with no timescales and no information that was particularly stressful.

A number of families talked about how it would have been good to have someone to coordinate the process, to update and explain to them, someone to telephone with questions and concerns. Families felt they needed a key person to be in charge of both providing information, and to be able to offer some emotional support. One family received this service from a CAMHS social worker, another from a charity based family support worker, and one other from a specialist ASD nurse. All three families were extremely positive about this kind of service. Many parents remembered with great warmth and levelled the highest praise on those professionals who listened to them, showed empathy, and expressed a positive view of their child – a view that included strengths as well as weaknesses, and in so doing provided hope for a meaningful and more independent future.

The vast majority however had no one and struggled to answer the question, ‘who would you ring if you had a problem?’ One mother suggested that a fellow parent ‘mentor’ would be useful to guide and support you through the process. Another advised future parents to always try and take someone with them to meetings, both to advocate, and for them to ‘lean on’. In many cases, a key worker would also have been useful to co ordinate the various assessments and to liaise between different agencies.

#### Good practice pointers

- Availability of a clear written diagnostic pathway with timescales would avoid frustration and confusion for many families.
- An accompanying leaflet or series of leaflets, for families should be made available. These could cover .e.g.

- Alerting signs and what to do if you are concerned about your child's behaviour.
  - The assessment process: the professionals you may come into contact with, what their role is, and how they can be contacted
  - The formal assessment procedure: what to expect, how to prepare and how and when results will be shared.
  - Sources of local support and information, including relevant counselling services.
- Families should be allocated a named person to offer support and information throughout the assessment and diagnosis process.
  - Assessments should include regular checking back with parents that they understand and agree with processes and findings.
  - Families should be offered more choice about the timing of appointments - so as to enable both parents to attend, and also to ensure minimum disruption of the child's life and routine.
  - Professionals should avoid speaking negatively about children in front of them. Services may need to plan ways in which children can be supervised while professionals and parents speak together in private.

**Getting a diagnosis – breaking the news:**

*“It was heartbreak and relief”*

Getting a diagnosis was a mixed blessing for many parents. There was nearly always a sense of relief that someone had finally acknowledged and defined the problems.

However this was often also accompanied by feelings of shock, disbelief, despair and

grief. Many of the parents who described feeling not believed now felt vindicated, the diagnosis confirmed that they were not neurotic or bad parents.

*“We could hold the piece of paper up to all the doubting Thomases to say it wasn’t my fault...I’m not a bad mother. Someone else believes me”*

A common fear was that the assessment process would come back inconclusive - meaning either more tests and uncertainty, or the loss of hoped for support.

The effect on parents of receiving a diagnosis of ASD cannot be under-estimated.

Even parents who knew it was coming, and had been prepared for the news, described their conflicting emotions:

*“Obviously you’re expecting it but it still comes as a shock.*

*When you see everything written down and the labels - it’s heart breaking*

*I don’t think you can ever be prepared. You know it’s going to happen but nothing can prepare you for seeing it written that your child has a chronological age of this, and it’s so black and white, so stark and so demoralising, and you just look at this bit of paper and think that’s it then. All these labels and you have to have a cry, have to have a weep and start again.”*

Whilst parents had pushed for some kind of diagnosis, often for many years, several still described hoping that the professionals would tell them that, actually, everything was alright.

*“You are expecting it, but you wonder why it’s quite so shocking – part of you is hoping it won’t be true”*

Some families spoke of immediately starting to worry about what the future would hold. This could lead into a spiral of negativity. One mother spoke of how difficult

her husband had found it, and the fact that he couldn't stop thinking of his son as a teenager and the problems he would encounter. Another remembered feeling:

*"I'm never going to escape this. This is what it's going to be like for the rest of my life."*

Also commonly expressed was a sense of loss for an imagined future:

*"You don't have your children and envisage them going through 'the system'. I have two children, I'll always have two children. I'll never have a relationship with them as adults because they'll always be children"*

For parents having to cope with this range of emotions it's essential that breaking the news is done sensitively, includes time for questions, and at the very least, a follow up appointment offered at a time when the news has had a chance to sink in. Many parents described not being able to take much in at the diagnostic meeting:

*"You come out with a completely scrambled brain ... your emotions have been completely battered...and nobody stops to say are you alright?"*

Parents should know in advance that they will be attending a meeting where the conclusions of assessments will be shared, and offered the opportunity to bring a friend or family members for support. They also need quality written information to take away with them – both about autistic spectrum disorders, and about local services and groups.

Not all of the families interviewed felt that the diagnosis was delivered in a sensitive way. Two families described receiving their diagnosis through the post, and one by telephone. One mother went to what she thought was a routine appointment and was given a diagnosis when she was alone and not expecting it. Another parent found out

from a hospital receptionist that her son was being tested for autism with no inkling of this beforehand. In one other case, the family was told that their child had 'got Aspergers' from his father.

Even parents who had spent many years in the system described how a positive experience of breaking the news made a real difference to their ability to cope. Those who were offered a follow up meeting soon after with a chance to ask questions and have terminology explained felt better about the whole experience. This also gave them another chance to pick up written information. In some cases parents were invited to bring other members of the family to the follow-up appointment, for example siblings and grandparents. This was seen as very helpful. In a few PCTs sessions were arranged with the child to explain their diagnosis to them, but more often this was not available. Thought needs to be given to how this will be handled as one child in our study thought the diagnosis meant he was going to die, and others faced significant struggles in coming to terms with their 'difference'.

Finally, parents expressed the view that, whilst they wanted professionals to be straightforward and realistic with them when breaking the news, they also felt the need to hear someone say something positive about their child.

*“This is my precious little boy you’re talking about. You might be used to this kind of terminology to describe children but I’m not. Every word sinks in your head like a stone – it may be innocuous to them, but it stays with you.”*

Another parent described taking comfort from what was said to her by the psychiatrist when breaking the news. He said,

*“ She’s the same little girl you had yesterday. She’s no different to you.”*

Good practice pointers:

- Professionals involved in assessment and diagnosis need training on how to share the news with families.
- Parents should know they are attending a sharing of findings, and possibly a sharing of diagnosis meeting ahead of time
- Joint attendance at a breaking the news meeting should be accommodated, and where this isn't possible, parent(s) should be encouraged to bring a friend or family member for support.
- Wherever possible, assessment reports should be written in plain English – using terms that families can understand and avoiding jargon.
- Professionals involved in assessment and diagnosis should try to offer some positivity in both their written reports and their verbal feedback to families.
- Families need to be offered the opportunity to ask questions about the diagnosis.
- Clear and accurate leaflets with useful contact numbers should be given to parents at the breaking the news appointment.
- Families should be offered at least one follow up appointment within a few weeks of the diagnostic interview.
- Parents should not be advised to search the internet following a diagnosis. They should be given details of helpful and accurate websites.
- Professionals and parents should consider and agree how information about the diagnosis will be shared with the child.

## **Post Diagnostic Support**

### *“ They tell you and then they drop you”*

As part of the assessment process, or immediately following diagnosis, none of the families interviewed said that they had had an assessment that had taken into account the needs of the whole family as described in the National Autism Plan for Children. Everyone felt that this would have been useful. The type of difficulties experienced by families included:

- Finding it difficult to socialise with others or go on holiday
- Being unable to take their child shopping
- Experiencing regular sleepless nights with their child
- Struggling with children who have toileting problems and restricted diets
- Having to make changes to the physical environment eg locks and needing extra bedrooms
- Having to change or give up employment to fit in with the needs of their child
- Significant strain on the parents relationship
- Difficulties with relationships with the extended family
- Sibling difficulties
- Feelings of exhaustion described by parents worn out by having to be constantly vigilant
- Coping with on going and challenging behavioural difficulties at home and in school
- Having no access to alternative child care
- Coping with periods of depression
- Coping with feelings of extreme negativity towards their child.

What most families said they would have valued was some support with day to day problems. This started with the need for a debrief or follow up interview after diagnosis that also looked at the family's ongoing needs, and that linked into – or at least signposted – to possible sources of help. Both emotional and practical support were highlighted as desperately needed, but could be hard to find.

Some families had the telephone numbers of professionals involved in their child's diagnosis and felt able to telephone them with questions. Others felt that they had no one to call. For some the period after diagnosis was a time when they felt numb and in shock. These families described how having a person who would come round for a cup of tea and organise things for them would have been really helpful.

*“There's a lot of people who can understand autism and can write you a thesis on it but do they understand how difficult it is with the sleep problems and the nappy problems? You know, the actual stuff that affects your life... You need somebody with that practical understanding of day to day life to go out to your house and listen to you moan a lot and go, 'ok, well what can we do to make it a bit easier?'”*

Some families did get this kind of support in the form of an ASD nurse, family support worker or portage worker, and they described the practical support received as invaluable. One of the few families interviewed who did receive such assistance said, *“She was wonderful – she cried with us. We wouldn't have got through without her.”*

All families who had received ASD specific training following diagnosis reported that they had found these sessions useful. In one PCT such courses were regularly provided for families with a new diagnosis, in most other cases parents had referred

themselves to a National Autistic Society help! course. A number of families had been sent pre-diagnosis onto generic parenting courses and these had not been well received: information had not been relevant or useful in managing the child with ASD, and overall the courses added to a sense of being blamed and not listened to rather than helped. Following the diagnosis many parents turned to books and the internet for more information, and a couple had found internet chat forums helpful. Whilst often useful, navigating the quantity of available material and assessing its quality was difficult and time-consuming.

Almost all families interviewed talked about the importance of support from other parents following a diagnosis. Knowing that someone else understands what you are going through makes a real difference. For some families the most positive aspect of the diagnostic process was the support they received from other parents. One mother suggested being paired up with another parent in the area who would be available as a support ( a kind of mentor). Parent support groups were positively referred to by many as providing a place where *'everyone's in the same boat'*, and where they could speak freely and openly about their difficulties. Often fellow parents were also the source of crucial information about services and benefits.

A majority of the mothers interviewed said that they were the ones having to coordinate post diagnostic support. Again they described having to fight to get their needs recognised, and expressed concern for those less able to do the same. Social Services received a particularly bad press with parents describing them as hard to access and inflexible. Direct payments were an option for some families but for others

they felt they did not have the skills or energy to manage their own support in this way. As one mother said:

*“I don’t have the time to find and interview a suitable carer and get them vetted. People can’t or won’t do it. 3 years down the line we’ve had no help from social services. You’d think they would say well we’ve offered them this and they haven’t taken it up ... but we struggle on”*

Information on welfare benefits was often stumbled upon by accident. Parents who had a key worker or accessed post diagnostic training including the help! programme were given this information but others were not. Although not specifically asked about in the interview schedule, many interviewees mentioned how important discovering benefits had been for their family.

*“No one says to you, this is how you contact the National Autistic Society. There was no, ‘you can get Carers Allowance for that’. You don’t need to be tearing yourself in two and living on no money. And you don’t need to feel like a second class citizen – you are doing a really good job.”*

The need for sibling support was mentioned by all families who had more than one child, but offered to only a handful. Many parents worried about how the non disabled child was coping and expressed concerned about the long term effects. Counselling for parents was also mentioned as many families found themselves coping with feelings of depression and despair following a diagnosis.

### Good Practice Pointers

*Preferably throughout the assessment process, and certainly at the follow up interview, a checklist should be gone through to ensure that the following matters have been addressed. Where appropriate, professionals should make direct referrals to support services (with family's consent) and where this isn't possible, clear written information about such services provided:*

- Post diagnostic support/ counselling should be available for parents, the child with ASD, siblings and the extended family
- Training about ASD for parents following a diagnosis is valuable and promotes better understanding of the child's difficulties.
- Signposting and support to access parent support groups and sibling support networks should be offered as a minimum.
- An identified person( key worker/ parent mentor) to follow up on the family and offer support, information and practical guidance on day to day difficulties should be allocated.
- Information about practical issues such as welfare rights, how to obtain help in school, and how to access local social services should be routinely provided.
- Information about appropriate local leisure and child care services, both those provided by statutory and voluntary sectors, should be made available to families.

**Acceptance and adaptation:**

*“I wouldn’t change him for the world. I love a challenge and he’s definitely a challenge. He’s fantastic, the information that he’s got, the knowledge that he’s got is incredible. He teaches me...he’s made me a lot calmer, more patient. I’ve become a lot more understanding and he has opened my mind to other people”*

In their pilot study about four families’ experiences of diagnosis in North Wales, Midence and O’Neill (1999) found a common post-diagnostic theme they referred to as one of acceptance and adaptation. Many of our families felt that the process of acceptance couldn’t really begin until they had a confirmed and official diagnosis. In this regard a diagnosis is far more than a label: it is an explanation for how and who the child is; it can signal an end of continuous self-blame for mothers, and may also become a common cause that previously disputing family members can rally themselves behind.

93% of those interviewed used the word “relief” in response to questions about how it felt to receive the diagnosis for their child, which may seem perplexing to those who have not been through the experience themselves. However in the context of an average delay of more than six years between parents becoming concerned and a reason being given, a sense of relief that doubt and dispute is now over becomes more comprehensible. As one mother expressed it:

*“Having a diagnosis has been a very positive thing...(before) nobody takes you seriously. It opens doors and makes you feel more confident...(it) removes uncertainty.”*

On a more personal level, another mother whose child had been diagnosed very late said, *“I can now say there was a reason for our relationship not being what I wanted from Day One.”*

Expanding on this idea of reaching acceptance about a different kind of relationship with a different kind of child, several interviewees mentioned the need to grieve before they could move on. No matter how sure they had been prior to diagnosis what the outcome of assessments would be, no matter how well prepared by professionals and their own research, relief always came mixed with a heavy dose of “heartbreak” too. As one mother put it, *“you have to let go of the child you thought you had”*. One participant made the point that it would be useful to be told that such responses are normal, that others have gone through this and come out the other side, as – without such reassurance – it’s possible that grief becomes another response to feel guilty about. In terms of acceptance and adaptation, many parents spoke highly again of the support they have gained from other parents, particularly those further down the road from diagnosis than them. As one father summed it up, *“They’re happy. They’ve got a life. That gave me hope”*.

A third of families interviewed highlighted the particular difficulties fathers can face in their process of coming to terms with the ASD diagnosis. Many fathers chose to take part in the interviews and were clearly very involved in supporting their children, but their involvement was arguably less well supported than mothers by services and by wider society. As fathers were more likely to be out at work when children were small, in some cases they did not see the difficulties the mothers were concerned about. Assessment processes were often protracted and this made it difficult for

working parents to attend the many necessary appointments. Mothers complained about having to “drip feed” information back to sometimes sceptical spouses, and pointed out that it is far from ideal that they get placed in the position of having to “train” their husbands about autism.

Several interviewees also mentioned having struggled with feeling responsible, that somehow they have passed on autism to their child. One father felt this so strongly he couldn't bear to stay in the family home and left. In other instances, mothers felt disbelieved and in dispute not only with professionals but with their partners too. For one family, the twelve years it took for a diagnosis took a huge toll on that child's relationship with his dad and his older brother:

*“Given the age of diagnosis there is a lot of ‘undoing’ to do. Where do you start? The damage is done...If there had been an early diagnosis things could have been so different for the family. Everyone in the family is affected and the memories could be so different”*

After diagnosis however, other families commented how this new twist in their life's course had actually brought them closer together. Many positive aspects about having a child with ASD were emphasised by our parents, particularly in regard to how they had personally been changed by the experience. Most commonly noted was having found a new way of looking at the world: one where they had better awareness, particularly of others difficulties and differences. A new way of seeing also encompassed greater compassion for others; changed definitions of what counts as ‘achievement’, and a new sense of their own resilience. As one mother explained:

*“He’s taught me that I am intelligent, capable and incredibly strong. And I wouldn’t have known that otherwise”*

Our interviews suggested that there were ways in which services and professionals could help promote better acceptance, starting with careful and empathic listening. One mother described the encounter below as one of the best things about the diagnostic process:

*“Apart from anything else having someone who listened and didn’t say you shouldn’t be comparing children ...didn’t say I’m sure its just a phase...didn’t tell us he was going to grow out of it ...didn’t belittle our concerns...It was like a huge relief...I felt like someone was listening and after 5 years of not being listened to, it was so good to be listened to”*

Earlier diagnoses, less ‘fighting’ in general, and a process that is perceived as reliable and undertaken by professionals perceived as competent (*“he knows his stuff doesn’t he?”*) also seemed to make positive adaptation easier. Assessment procedures and feedback that emphasised strengths and the possibility for future improvement were highlighted as both helpful and necessary. Running through our families’ recommendations was the ever-present need to convey hope about the future, and reflect back to parents a sense of their own knowledge, competence and strength.

We ended the interviews with a question to parents about the best things about their child with ASD. Here are some of their responses:

*“He’s the best. I wish you could meet him actually”*

*“He’s the light of this family”*

*“He’s the one who cheers everyone up”*

*“She is my life. The apple of my eye. A star”*

*“When she smiles she makes your day”*

*“He is a fabulous boy”*

*“He’s absolutely gorgeous, very loving, very sensitive, he’s an individual with lots of potential, lots to offer”*

*“If someone had a cure...I wouldn’t take it...I don’t want him to be any different, even though he’s difficult at times”*

*“He does bring his own brand of joy into life*

*“The best aspect is how nice he is- how loving”*

*“He lights up the room”*

*“He’s a very pleasant child very honest – strong sense of justice”*

*“An absolute star – I love him so much. The diagnosis hasn’t changed that – maybe it’s made me love him more. I will dedicate my life to him.”*

### **Conclusion:**

In common with previous research in the UK, we found that long waits and the lack of coherent and transparent diagnostic pathways is still a significant problem. Those likely to be the first port of call regarding alerting signs need training about early indicators of ASD, how and who to refer on to, and how to work with families sensitively at this difficult time. This training needs to be extended beyond health visitors and GPs to teachers and other education professionals. Reluctance to label or a ‘wait and see’ attitude was viewed retrospectively by many families as harmful in that it stops appropriate information, strategies and support services being made available both to the child and its family. Parents also need a reliable diagnosis in order to begin the lengthy process of acceptance and adaptation.

There still seems to be a lack of linking together of services resulting in no holistic view of the child's and family's needs. Symptoms may be noted for the purpose of diagnosis, then educational needs assessed for managing the child in school, but no professional or agency assigned responsibility for looking at the bigger picture and supporting families with their often very challenging situations. Provision of information about ASD, welfare entitlements, local services and support groups is hit and miss – again with no professional or service routinely taking responsibility. Emotional support for the whole family - mothers, fathers, siblings and grandparents – is another often unmet need. Formalising parent to parent support in a strategic way could be part of a solution to this.

Despite their struggles, many of the families interviewed were keen to share positive experiences of certain professionals or services they had encountered along the way. In all of these cases, empathic and careful listening to parents was the gift most well remembered and treasured. After this, a practical hand in 'getting things sorted' was valued: people who took it on board to make referrals or source information and support even if, strictly speaking, it wasn't their job.

*“At the point of diagnosis of a child's disability...families are frightened, disturbed, upset, grieving and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward.”*

(Carpenter, 2005)

## **REFERENCES:**

- Bayat, M (2007) *Evidence of resilience in families of children with autism* Journal of Intellectual Disability Research Vol 51(9) pp 702-714
- Brogan, C & Knussen, C (2003) *The disclosure of a diagnosis of an ASD: Determinants of satisfaction in a sample of Scottish parents* Autism 7(1) 31-46
- Carpenter, B et.al (2005) 'Celebrating Families: an inclusive model of family centre training', British Journal of Special Education, 32(4)
- Carpenter, B (2005) Disabled children: the father's role- Inside the Portrait of a Family: the importance of fatherhood [www.fatherhoodinstitute.org](http://www.fatherhoodinstitute.org)
- Dept of Health (2007) National Service Framework for Children Young People and Maternity Services, HMSO
- Howlin and Moore (1997) 'Diagnosis in Autism: A Survey of over 12000 Patients in the UK' *Autism* 1 (2) 135-62
- Knussen, C. and Brogan, C.A. (2002) Professional practice in the disclosure of a diagnosis of an autistic spectrum disorder: Comparing the perspectives of parents and professionals in Scotland. *Journal of Applied Health Behaviour*, 4, 7-14
- Lietz C. A, (2006) Uncovering stories of family resilience: a mixed methods study of resilient families, part 1 *Families in Society* 87, 575-82
- Mansell, W & Morris, K (2004) A survey of parents reactions to the diagnosis of an ASD by a local service: Access to information and use of services *Autism* 2004;8;387
- Midence, K and O'Neill, M (1999) The Experience of Parents in the Diagnosis of Autism: A Pilot Study *Autism* 1999; 3;273
- NAPC (2003) *National Autism Plan for Children: plan for the identification, assessment and diagnosis of autism spectrum disorders*, NAS
- Oberheim, D (1996) *The Support Needs of Adults and Children with Autism and Their Carers in Kent*, Kent Autistic Trust
- Osborne, L & Reed, P (2008) Parents perceptions of communication with professionals during the diagnosis of autism *Autism* 2008; 12;309
- Rogers, C. (2007) *Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities* British Journal of Special Ed Vol 34 (3) p 136-143
- Whittaker, P (2002) 'Supporting Families of Preschool Children with Autism: What Parents Want and What Helps', *Autism* 6 411-26