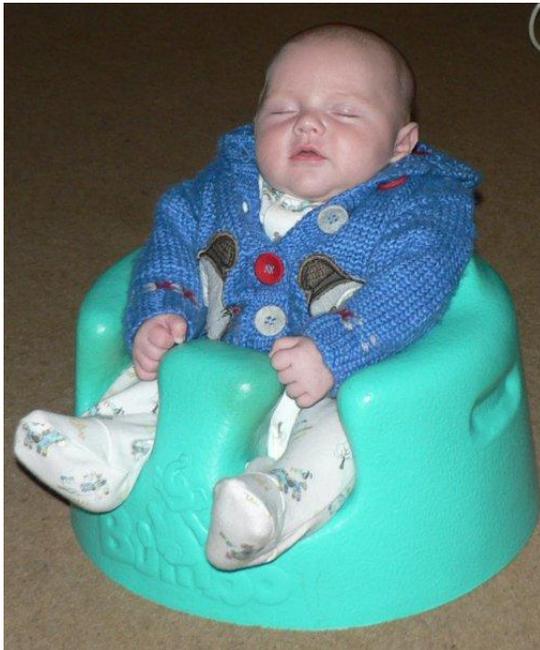




Right from
the start

Good practice in sharing the news
of a child's additional needs

NORFOLK
DIAGNOSIS SURVEY REPORT 2011
EXECUTIVE SUMMARY



The Full Report

is available from NANSAs website,
www.nansa.org.uk

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BACKGROUND

Right From The Start (RFTS) is a national scheme which promotes good practice in sharing the news with parents that their child has additional needs.

It began in 1992 with research by the National Scope Association which led to a report in 1994 highlighting the experiences of parents at the time of diagnosis. The report identified both good and bad practice and drew attention to the legislative framework and recurring theme of working with parents. In Norfolk the then Special Needs Liaison Group, which consisted of 20 voluntary organisations and self help groups, also produced a report in 1995/6 and again in 2001, which echoed the findings of the Scope report (1994).

From the 1994 report a national working group was formed to promote good practice in sharing the news. The working group consisted of key members of the voluntary sector, parents, disabled people and professional organisations such as the Royal College of Paediatrics and Child Health, Royal College of Midwives, Royal College of Nursing. The main achievements of the national working group have been to produce a template (Scope, 2006 edition) which is a framework to support those involved in sharing the news and a parent charter (Scope, 1994) together with promoting continued professional development in the form of RFTS training and a Service Review and Audit document (Scope, 1994).

The three key principles in the template and good practice are, valuing the child, respect for parents and families and support for professionals. Valuing the child includes the recognition that all children are unique and that they are a child first with their disability second. It includes using the child's name and keeping discussions about the child positive whilst avoiding making predictions. Respect for parents and families includes supporting and empowering parents by treating all concerns seriously, listening to them and sharing information sensitively and honestly in plain language with ongoing support and information. Support for professionals includes acknowledging personal and professional developmental needs, participating in training, opportunities for supervision, team sharing and debriefing (SCOPE, 2006 edition)

The principles of Right From The Start were incorporated into Together From The Start (DfES/DH, 2003) which led to the Early Support programme (2002) for which Norfolk was a pathfinder. The template has been included in The Sure Start Guide (DfE, 2004) and adopted by the professional organisations involved in the working group. The principles of RFTS are in echoed the National Service Framework (DH, 2003), in the Equality Act (2010) and of course in the Education Acts and Children's Acts. More

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recently the principles can be seen in Aiming High for Disabled Children: Better Support for Families (DfES, 2007) and in Norfolk's Disabled Children's Strategy (2009 – 2012) as well as the most recent SEN green paper, Support and Aspiration (DfE, 2011).

Norfolk has not always had a lead for RFTS. There have been some years where funding has been obtained and training delivered, but there have also been gaps in training. This report came about when funding was gained for a RFTS Co-ordinator from January 2011 to March 2012. Part of the remit for the RFTS Co-ordinator was to undertake another survey looking at parent's experiences around the time of diagnosis since the last survey in 2001.

Work began on the survey in March 2011 with the forming of a working group which included representatives from, Early Years inclusion and training, the Voluntary Sector, Health and the RFTS Co-ordinator who is also a parent. The group decided to use the questionnaire (see appendix 1 in full report) from the RFTS Service Review and Audit document produced by National Scope on their website and also to use the model letter to parents (see appendix 2 in full report) from that document. It was agreed to include children in the survey who had been given a diagnosis and who were aged 8 years or below at the time of completing the questionnaire.

The survey gained approval from the Research Governance Framework Department of Norfolk County Council on the 28th June 2011. A number of Voluntary Organisations, Parent Partnership, Family Voice Norfolk, SEN Network, Children Centres and Child Development Centres/Units were contacted by e-mail and telephone asking them to participate by identifying parents that were eligible to complete the questionnaire. These organisations and services were then asked to let the co-ordinator know how many questionnaires they required. Covering letters and stamped addressed reply envelopes were also included.

A flyer promoting the questionnaire was included in some voluntary sector newsletters and websites and from this some parents contacted the co-ordinator to be sent a questionnaire. The co-ordinator also gave out some questionnaires to members of various steering groups for them to give to parents. A list of all those who were sent or given questionnaires to pass on to parents can be found at appendix 3 in the full report. The cut off date for the return of questionnaires was the 31st October 2011.

A total of 656 questionnaires were given out. 66 questionnaires were completed and returned.

A meeting of the diagnosis survey working group was held on the 1st November. Those attending were the RFTS co-ordinator, NANSAs training officer, NCC Early Years Support Training and Development Officer, Autism Anglia Norfolk Family Services Co-ordinator, Specialist Health Visitor NCH &C. The group went through the returned questionnaires and agreed upon a main

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diagnosis for each one. Questionnaire no.15 was discounted as sleep problems were not felt to be a disability. Questionnaires 27 and 47 were discounted because there had not been a diagnosis given yet. Questionnaires 22 and 34 were completed for two siblings each and so these were separated and given the references of 22b and 34b so that each child was counted. This made the final responses a total of 65.

The information in this report and the key recommendations will be taken to the Norfolk Early Support Steering Group, and once agreed will be shared with Norfolk Health and Overview Scrutiny Committee, ASD Steering Group, Children's Services Research Governance Framework department and consultant paediatricians for consideration. The report will be placed on NANSAs website and will be shared with NANSAs Executive Committee and in a newsletter for national SCOPE. A variety of sharing events will be planned to disseminate the information and recommendations with professionals and parents.

Recommendations

	Recommendation	Reason	Action
1	Training in RFTS principles and good practice continues to reach multi agency groups of professionals who work with children and families.	<p>The RFTS template states that all parents' concerns should be taken seriously and that they should be listened to and responded to in a respectful manner. There were a large number of comments and 32% of parents that suggest that this is not happening for all parents. This was also one of the areas that the 2001 survey raised as needing attention.</p> <p>The RFTS template suggests that professionals should participate in training, clinical supervision and debriefing. This research shows in all areas around the time of diagnosis that professional skills and qualities were a vital element in the parents' experiences.</p> <p>Although the RFTS template suggests that discussions about the child should be positive and avoid making predictions this report shows that this was not always the case.</p>	<p>Continued funding for a RFTS Co-ordinator be considered by the Early Support Steering Group (and if necessary taken to a commissioning body) in order that RFTS training can be delivered for at least another year and more preferably be a rolling programme of training to continually capture new professionals.</p> <p>Funding for a further year (2012/13) now obtained</p> <p>Long term funding to be considered by the Additional Needs & Disability Partnership</p>
2	An Action Plan and Early Support materials (DfE, 2002) are shared with parents at and around the time of diagnosis.	<p>The RFTS template suggests that parents and families are given support and empowerment. In order to do this parents need information, therapies and interventions. The lack of information, lack of support, lack of therapies and interventions were key themes throughout this research. Portage, Early Bird and Key Working were mentioned by parents in the research as being very positive.</p> <p>The Good Practice Framework in the template suggests that time and space should be given to parents at the time of diagnosis so that questions can be asked. Without this time parents often look to the internet for information especially when they have not been given appropriate information at the time of diagnosis. It can also be distressing to tell other family members when no information has been given in writing that can be shared.</p>	<p>The Early Support Steering Group look at the continued roll out of Early Support training and include the importance of information for parents.</p> <p>RFTS training emphasises the need for clear and concise information for parents making reference to the Early Support materials.</p> <p>RFTS and Early Support training to include the promotion of the Joint Children with Disabilities Register, which gives access to information for parents and assists planning for services.</p> <p>Services like Portage, Early Bird and a Key Worker service continue to be included in pathways of care by Health Trusts and that the roles of these services continue to be developed and funded within Norfolk County Council and</p>

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			Health Trusts. Health Trusts consider the role of a Specialist Health Visitor or similar role and the need for such a role in order to share information with parents and work closely with the voluntary sector.
3	Professionals involved in the planning of sharing the diagnosis with parents include the need to have their partner, friend or family member with them.	The 2001 survey stated that parents wanted to be told in private and to have their partner, friend or family member with them. This survey found that most parents were told in private but that 25% did not have anyone with them. The Good Practice Framework around planning for a meeting with parents to share the news that their child has additional needs should include planning for both parents to be there or to include a family member or friend. When this is not the case another meeting should be planned to share the news with the parent who was unable to attend as soon as possible.	Health Trusts consider the need for this planning within pathways of care. The role of the Specialist Health Visitor where applicable, or similar role where this is not the case, be considered by the Health Trusts as one way of meeting this need where a parent does not have anyone to come to the appointment to share the diagnosis with them and to also visit the family at home.
4	Parents be given a choice as to whether they wish the child to attend the actual sharing of the news and follow up appointment.	Although most parents felt it was appropriate to have the child with them when they were given the diagnosis, there were some parents who did not feel it was appropriate as they felt unable to concentrate on what they were being told. This was mainly when the news was shared with parents of a child that was no longer a baby. The RFTS template and good practice suggest that this should be optional.	Health Trusts allow for this choice within their pathways of care.
5	Professionals consider the impact of a long wait for a follow up appointment	In the RFTS template the Good Practice Framework suggests that an early follow-up appointment should be arranged at the end of the initial diagnosis meeting. This research shows that this only happened in just over half of the cases. Parents often find it difficult to think of all the questions that they might need to ask at the time of diagnosis and need a prompt follow up appointment where further questions can be asked and parents can be reassured of what will happen next.	Health Trusts consider the role of a Specialist Health Visitor or similar role. This role should include working closely with the voluntary sector.

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Good Practice From This Research

This research has shown areas of good practice in Norfolk that can be shared. and that are in the Good Practice of the RFTS Template.

At the Time of Diagnosis

The majority of parents in this research received the diagnosis in a face to face meeting. There were just 8 parents that received the diagnosis in writing and 1 parent who received the diagnosis over the phone.

“Being told in person about the possible diagnosis instead of by letter.” (Q50, Dev delay).

The majority of parents also felt that the arrangement in the hospital or Child Development Unit/Centre was comfortable, helpful and appropriate. Many mentioned that they were in a quiet room and that having all the professionals in one place worked well.

“All professionals were in one place and it felt very supportive.” (Q18, ASD).

53 out of the 65 parents felt that they understood what they had been told at the time of diagnosis.

“The doctor is and was very good and will answer any concerns no matter how small and he explains things so I understand. He doesn't just talk in medical terms. Or try to bamboozle me.” (Q66, RC)

After Diagnosis

There were 44 out of the 65 parents whose follow up appointment was with the same professional when they were told of their child's additional needs.

“Very reassuring told us all the professionals involved with my son's care meet weekly so all decisions around his needs are joint.” (Q55, ASD)

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Professional skills and qualities

Those that were very satisfied with their overall experience mentioned the skills and qualities of the professional as being a key element in a more positive experience.

“I felt they were respectful towards my son and us at what was a very difficult and upsetting time for us.” (Q55, ASD)

“The consultant was very empathetic...” (Q61, CP)

Qualitative analysis

Right From The Start Diagnosis questionnaire

(shortened executive summary version)

Previous research around the time of diagnosis has shown that how the news is shared can have an effect on how parents bond with their child and how they relate to all the professionals that they see afterwards (Scope, 1994).

This research aims to highlight the experiences of parents at and around the time of diagnosis using their words to illustrate the key themes. Throughout the questionnaire there were sections that allowed parents to make comments or add to the information on the form apart from the statistical data.

For ease of reading the experiences have been grouped into sections relating to the time before the diagnosis was given, the time that the diagnosis was given and the time after the diagnosis was given. Within those sections several themes developed for which example quotes have been provided to give a feel of the experiences of the parents.

Before Diagnosis

There were three themes around the time before the diagnosis was given that reflect the comments that parents made. The first was knowing that something was wrong, the second was not being listened to or not believed and the third was where the parents felt they had been listened to and that their concerns were taken seriously.

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Knowing that something was wrong

These comments below from parents reflect the 89% of parents in the survey that felt their child was not developing as he/she should have been. The Right From The Start principles include having respect for parents, treating all parents' concerns seriously and listening to parents.

"I knew there was something wrong as I couldn't control him..." (Q1, ASD aged 3 yrs at diagnosis)

"I knew from an early age just took till then to get anyone to listen." (Q19, ASD aged 5 yrs at diagnosis)

"I knew from the first week of his life." (Q44, Dev Delay aged 1 yr at diagnosis)

Not being listened to or believed

The comments below reflect the 32% of parents who felt that their concerns were not taken seriously. It can be seen from the comments that a wide range of professionals from education and from health were reported not to listen or not to believe the parents. Some of the comments reflect the feeling of chasing or asking several times before being listened to. There are also comments which demonstrate how this disbelief or not listening to parents may affect future relationships and trust of professionals.

"I knew instantly she had down's but they didn't believe me." (Q13, DS)

"Not at first as they thought I was comparisons with my other child who was aspergers, also my partner speaks another language and they thought my son getting confused between the two languages." (Q38, ASD)

"As Health Visitor after 2 visits still would not accept what our concerns were and we was told it was just developmental delay to leave for 6 months which not prepared to accept." (Q40, ASD)

"Was seen by the physio and told everything fine when 2 yrs old and to leave her alone." (Q42, CP)

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“Went to see 3 different GPs and Health Visitor before finally being referred to paediatrician – but 18 months follow up special care baby unit was where it was picked up.” (Q61, CP)

Those who felt their concerns were taken seriously

Although 58% of parents felt that their concerns were taken seriously there were only a few comments below. When parents are happy with a service they may be less inclined to make comments.

“GP was helpful.” (Q6, CP)

“The speech therapist was great from the beginning.” (Q31, ASD)

“Asked for extra scans during pregnancy because first child’s disability. More scans provided.” (Q49, CP)

At the time of Diagnosis

Most of the parents received the diagnosis for their child either in a hospital or a child development centre or unit and the majority felt that the arrangement was comfortable, helpful and appropriate. RFTS promotes face to face sharing of the news in a quiet room. The results from the survey show that the majority of parents did receive the news in a face to face situation but there were 8 parents who received the news in writing and one who received the news over the phone. The parent who received the news over the phone had been referred to a London hospital as well as a local hospital. The majority of comments showed that parents were mostly in a quiet room when given the news.

Parents commented on how comfortable and helpful the arrangement was when being given the diagnosis

The positive comments included having all the professionals in one place for multi disciplinary assessments (MDA). This may reflect the fact that these parents were less likely to have to repeat the news to other professionals and in accordance with the principles of Early Support.

“In the MDA there was all that were dealing/helping with my son at the time. Health Visitor, Special Needs Play Teacher, Music Therapist and his Consultant.” (Q1, ASD)

“All professionals were involved and it felt very supportive.” Q18, ASD)

Other positive comments referred to the relief of being given the news or that the news was expected. This may have been after a long wait or many other appointments.

“I felt at long last someone could see what I saw.” (Q6, CP)

“A relief, as we had already researched and asked friends who were health professionals and knew he either had CP or MD.” (Q61, CP)

Some parents expressed how helpful it was to have another trusted professional with them at the time of diagnosis that they had built up a relationship with.

“The Health Visitor was with us. She was like our family liaison person and was excellent.” (Q9, ASD)

“The nurse in the Intensive Care Unit who had been immensely helpful and warm and supportive was present. This made a real difference to me as I felt she was far more able to empathise than the consultant was, as well as encouraging us not to be too devastated by the news.” (Q43, CP)

The skills of the person giving the diagnosis were also one of the positive aspects mentioned by parents.

“The paediatrician was very supportive and sensitive.” (Q53, ASD)

“I find it always better face to face but also to have in writing to refer back to.” (Q35, E)

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Some parents said that they did not find the arrangement comfortable and helpful when being given the diagnosis.

Those who did not find the experience of being given the news very positive referred to student professionals being involved, a lack of planning and the lack of help after the news had been given. Right From The Start promotes good planning, ongoing support and information and the skills and qualifications of the professional to be continually developed.

“A student doctor was present at the appointment. The student asked the questions without the GP present. GP came back in later to hear the student findings and ask further questions and then expressed her concerns.” (Q5, RC)

“The consultant walked in side room with a registrar and student carrying chairs. I knew then something was wrong. He stated they had known at birth but waited 2 days to tell me.” (Q7, DS)

“No further help after diagnosis just passed to clinic.” (Q34, ASD)

AFTER DIAGNOSIS

Very Satisfied

Those that were very satisfied with their experience of being given the news that their child has additional needs resulted in 28%. They mentioned three key elements. The first was around the skills and qualities of the professional sharing the news, the second was around co-ordinated services and the third was around the support or interventions that were put in place.

Professional skills and qualities

“The speech therapist was especially helpful and encouraging.” (Q28, ASD)

“I felt they were respectful towards my son and us at what was a very difficult and upsetting time for us.” (Q55, ASD)

“We were listened to and dealt with professionally.” (Q56, ASD)

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“The doctor is and was very good and will answer any concerns no matter how small and he explains things so I understand. He doesn’t just talk in medical terms. Or try to bamboozle me.” (Q66, RC)

Co-ordinated Services

“Every stage of the process felt very co-ordinated.” (Q18, ASD)

“A lot of professionals involved in assessment, report writing, diagnosis. We appreciated the way they all worked together.” (Q23, ASD)

“Very reassuring told us all the professionals involved with my son’s care meet weekly so all decisions around his needs are joint.” (Q55, ASD)

Support and intervention

“...Sure start and their special needs mother and toddler. I was with people who had children with disabilities and knew I wasn’t on my own and they told me about claiming such things as DLA and Carers Allowance. I also had somebody to talk to and cry at without feeling silly or alone.” (Q1, ASD)

“The Child Development Centre/Unit and the hospitalkept us informed throughout the diagnosis process. Gave us phone numbers and emails so we could easily get in touch if we had any questions.” (Q55, ASD)

Satisfied

The 31% of parents who were satisfied with their experience had comments that reflected an element of feeling let down in some way which affected the overall experience. These have been grouped into five themes. The length of time being the first theme, the second is lack of information, the third is around lack of support or intervention, the fourth is confusion and the fifth is not being able to concentrate with the child present at the diagnosis.

Length of time

“Felt a bit lost and alone between initial visit to the Child Development Centre/Unit and diagnosis. There was a 6 month interval...There was a long wait to receive the feedback letter from the initial meeting, which was hard as it is difficult to retain information during the emotional rollercoaster we were on.” (Q24, ASD)

Lack of Information

“...more information or pack of information could be given for parents...” (Q17, ASD)

Lack of Support or Intervention

“...we feel that we have just been left to get on with ourselves with no help at all now, we were told speech therapy would be ongoing but we haven't seen a speech therapist for about a year now.” (Q39, ASD)

Confusion

“At the MDA staff were saying all the autistic things he was showing, but his own nursery manager only noticed his speech was different and wanted to delay diagnosis. But I said no he is autistic so we voted and everyone apart from Nursery voted.” (Q31, ASD)

Child present

“I did not always get the full benefit. I feel my son should not have always been present. For assessment reasons yes, but explaining no. I could not always fully concentrate as he likes one to one. He also asks questions. Especially if he picks up on new words. So it sometimes felt uncomfortable.” (Q30, ASD)

Other responses

24% of parents were dissatisfied with their experience around diagnosis with 12% saying that they were neither satisfied or dissatisfied. These comments have been placed together because they come under the same four themes of professional skills and qualities, information, support and intervention and length of time. The comments show again that the ongoing relationship with all professionals may have been affected and also that the bond between parents and child could have been affected.

Professional skills and qualities

The comments within this theme clearly show how the ongoing relationship with professionals may have been damaged. The knock on effect of this can lead to the *child not receiving the help that they need*.

“...unhelpful staff who do not keep their promises. We have had enough.” (Q2, ASD)

“Went for a routine hip appointment. Then called neurologist into room who did a few short tests and then told us our child had been brain damaged and had Cerebral Palsy. No discussion and very insensitive.” (Q42, CP)

Information

“The hospital provided no information and I believe this is awful as this could be the difference between parents keeping a child and giving them up for adoption simply because they do not understand and think they can’t cope.” (Q3, DS)

“Left to find out almost everything myself.” (Q54, ASD)

“Too stunned to ask questions, or know what to ask – a small information pack would have been useful with details of relevant organisations and maybe other parents to contact when we felt able. We felt we had to start fighting for information and guidance from then onwards and are still doing so.” (Q61, CP)

What worked well at diagnosis

The comments around what worked well at the time of diagnosis can be linked to the Right From The Start Template good practice(2006 edition). They included believing the parents and listening to them, promptness in getting the diagnosis which involved a continuity of professionals, the skills and qualities of the professionals and planning and preparation so that they had someone with them and so that services were co-ordinated with ongoing support and intervention. The following comments show this experience.

Being believed and listened to

“Someone listened to us and didn’t say it was ‘normal for a child to do that and all children go through that stage’.” (Q24, ASD)

“Doctor listening and responding to questions/fears...” (Q49, CP)

Promptness

“That the developmental delay issues were recognised immediately.” (Q5, RC)

Continuity of professionals

“...there was not one person there that didn’t know my son and wasn’t involved with him.” (Q1, ASD)

“The caring way the consultant...followed up the case and handover to the next one when the time came.” (Q13, DS)

Professional skills and qualities

“They made my child feel relaxed and they dealt with my shock too.” (Q10, ASD)

“The expertise, understanding and care shown by the consultant.” (Q23, ASD)

Planning

“Was done in a familiar environment and sympathetically.” (Q8, ASD)

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“Having someone with you. To this day I would not have coped with the news we got on my own.” (Q22, RC)

Support, intervention and information

“I was very lucky I got a fantastic team who helped get a lot of information...” (Q63, CP)

What could be improved at time of diagnosis

Parent comments suggest that time was a factor when being given the diagnosis. Having questions answered and being given information was another area that parents mentioned as needing to be improved. Some comments were around the need for support, and intervention to help the child and some around the emotional support needed for parents. Other parents mentioned the need for a better planned handover from one professional to another and some parents would have preferred not to have the child present at point of diagnosis. Parents also commented on how the skills or qualities of the professionals could be improved and how it would have been better if they had someone with them. The comments below reflect the improvements that parents would like to see.

Answering questions and being given information

“People taking the time to answer any questions and give us information.” (Q3, DS)

“Well I just thought I was going to be told my son needed grommets and then found out he was autistic, could have been given more information.” (Q10, ASD)

Support and intervention

“We could have been referred for practical help...” (Q35, E)

“Being put in touch with people that could help.” (Q42, CP)

Emotional support

“...additional emotional support.” (Q18, ASD)

Handover

“If I had been given some warning by the Health Visitor that this was what she was concerned about and the reason for her referral. It would have been less of a shock and I would have asked my husband to come with me for support. As it was I was completely on my own when the consultant broke the news. I feel angry that the Health Visitor didn't let on to me at all what she suspected ...” (Q23, ASD)

Not having child present

“A member of staff to take my child out of the room so me and my husband could talk openly about his difficulties.” (Q26, ASD)

Professional skills or qualities

“GP appointment should not have been scared to death by GP and then left to wait for 10 weeks.” (Q5, RC)

“More awareness of the impact of choice of words on parents who are already in shock.” (Q43, CP)

What worked well at the follow up appointment.

Parents mentioned that being given time at the follow up appointment worked well. They said that effective procedures which led to co-ordinated services were important as well as good information, support and interventions. The skills of the professionals were mentioned to have a factor in a good follow up appointment.

Being given time

“The paediatrician spent a lot of time asking questions and watching our daughter.” (Q5, RC)

“Giving us time to ask questions.” (Q42, CP)

Effective procedures and co-ordinated services

“Just being prepared, reading notes, so you don’t have to go over history from two years ago.” (Q17, ASD)

“All professionals that assessed my son were there so I could ask about anything from their reports that I didn’t understand.” (Q55, ASD)

Information, support and interventions

“Got to meet other parents and was given some great information.” (Q19, ASD)

“The therapy and portage provided.” (Q44, Dev delay)

Professional skills and qualities

“The consultant’s words ‘they are still my boys, they haven’t changed because of a label. They are still lovely boys.’ (Q22, RC)

“...an ability to listen to me, validate my concerns and reassure me that help is available.” (Q46, CP)

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What could be improved at the follow up appointment

The comments made on the improvements that parents would like to see at the follow up appointment were around being given more time, an individual approach, information, support and intervention as well as emotional support, professional skills and the continuity of professionals.

Time and an individual approach

“More time and more individual approach rather than a 10 minute slot in a general outpatient clinic.” (Q7, DS)

“Post diagnosis follow up should have been offered which 1 month of diagnosis...too long a gap.” (Q26, ASD)

Information

“To be given list of websites, organisations and charities, self help groups if missing from initial diagnosis.” (Q54, ASD)

Support / emotional support and intervention

“Expectation that everything would change and be easier after diagnosis but in reality nothing changed – empty feeling...” (Q24, ASD)

“Asked if we would like to make to make contact with other parents in similar circumstances and given contact details or helpful organisations.” (Q61, CP)

Professional skills and qualities

“Bothered to read notes from previous appointment to avoid giving contradicting advice.” (Q12, ASD)

“Paediatrician didn’t mention developmental problem to new agency because wanted them to assess him but then I felt I couldn’t be open with the new agency without getting the paediatrician in trouble.” (Q51, Dev, delay)

RESULTS

These figures represent the results from 65 questionnaires

63 of the questionnaires were completed by mothers, 1 was completed by the father and 1 was completed by the foster carer.

48 or 74% of the children were male and 17 or 26% were female.

59 of the children were white British. 1 child was Middle Eastern and 5 children were from other mixed ethnic groups.

Main Diagnosis

Percentage	Main diagnosis	Average age when diagnosis was given
53%	Autistic Spectrum Disorder.	3 yrs
14%	Cerebral Palsy.	6 months
8%	Developmental Delay	2 yrs
5%	Downs syndrome	6 months
5%	Epilepsy	6 months
15%	Other rare condition	2 yrs

Before Diagnosis

89% of parents said that they had concerns before they were told about their child's additional needs. This consisted of 34 out of the 35 parents of a child with an Autistic Spectrum Disorder, 7 out of the 9 parents of a child with Cerebral Palsy, 5 out of 5

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parents of a child with a developmental delay, 1 out of 3 parents of a child with Down's syndrome and 2 out of the 3 parents of a child with epilepsy, and 9 out of 10 parents who had a child with a rare condition.

52% requested a diagnosis with 46% being offered a diagnosis. One parent did not respond to this question.

Those who requested a diagnosis consisted of 21 out of the 35 parents of a child with an Autistic Spectrum Disorder, 4 out of the 9 parents of a child with Cerebral palsy, 4 out of the 5 parents of a child with developmental delay, 1 out of the 3 parents of a child with Down's syndrome, 1 out of the 3 parents with a child with epilepsy, 3 out of the 10 parents of a child with a rare condition.

58% of parents felt that their concerns were taken seriously with 32% stating that they felt their concerns were not taken seriously. Six parents did not respond to this question.

Those who felt their concerns were not taken seriously consisted of 13 out of the 35 parents of a child with an Autistic Spectrum Disorder, 3 out of the 9 parents of a child with Cerebral Palsy, 1 out of the 5 parents of a child with developmental delay, 1 out of the 3 parents of a child with Down's syndrome, and 3 out of the 10 parents who had a child with a rare condition.

The sharing of the news

60 parents were given the news by a consultant/paediatrician.

1 parent was given the news by a GP.

1 parent was given the news by a nurse

2 parents were given the news by a Speech and Language Therapist and 1 parent was given the news by a trainee doctor.

The news was mostly shared in a face to face meeting with 86% of parents. 12% were given the news in writing and 2% were told over the telephone.

55% said that other staff were present and that 34% knew the other member of staff but 28% did not know the other member of staff.

66% had a partner or friend with them at the time of diagnosis but 25% did not with 9% not responding to this question. Those that did not have someone with them consisted of 12 out of the 35 parents of a child with an Autistic Spectrum Disorder, 1 out of the 9 parents of a child with Cerebral palsy, and 3 out of the 10 parents with a child with a rare condition.

57% had their child with them and 32% did not with 11% not responding to this question.

Results about where the news was shared

Percentage	Where	Was it private	Was it comfortable	Was it welcoming
48%	hospital	YES 96%	YES 91%	YES 74%
38%	Child Development Centre/Unit	YES 96%	YES 87%	YES 70%
2%	GP Surgery	YES 100%	YES 100%	YES 100%
3%	Other = Sure Start Centre Home	YES 100%	YES 100%	YES 100%
9%	No response	YES 33%	YES 50%	YES 33%

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Results about understanding what was said and whether written information was given

Where	Did you understand what you had been told	Was written information given to you at the time	Was written information given to you at a later date
Hospital	YES 23 out of 31	YES 9 out of 31	YES 17 out of 31
Child Development Centre/Unit	YES 23 out of 25	YES 12 out of 25	YES 18 out of 25
GP surgery	YES 1 out of 1	0	0
Other	YES 2 out of 2	0	YES 2 out of 2
No response	2	9	9

Those that did not understand what they had been told consisted of 8 parents including 1 parent with a child with an Autistic Spectrum Disorder, 3 parents of a child with a rare condition and 4 parents of a child with Cerebral Palsy.

The follow up appointment

56% said they were offered a follow-up appointment immediately. Those who were not offered a follow up appointment immediately were offered an appointment as the table below shows.

Less than 1 week after diagnosis	2%
Between 1-2 weeks after diagnosis	5%
Less than one month after diagnosis	8%
Other	32%
No response	54%

At the follow up appointment 47 parents had their child with them.

52% said that tests or investigations were undertaken at the follow up appointment and that 46% had those tests or investigations explained to them with 5% saying that the tests or investigations were not explained.

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Being put in touch with others who could help

62% were put in touch with others who could help. See table below.

Who	Very Helpful	Helpful	Neither helpful or unhelpful	Unhelpful	Total	%
GP	13	14	12	5	44	18%
Health Visitor	9	13	8	12	42	17%
Parent	26	4	2	2	34	14%
Portage	17	6	2	0	25	10%
Social Worker	7	2	4	3	16	6%
Therapist	21	12	2	2	37	15%
Voluntary Group	28	9	5	0	42	17%
*Other	9	0	0	0	9	4%
TOTAL	130	60	35	24	249	
%	52%	24%	14%	10%		

No response = 13

*The other group consisted of the following:

Community Nurse, Specialist Health Visitor, Autism Nurse, Epilepsy Nurse, Surestart Centre, and Child Development Centre/Unit.

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The overall experience

	Total	Percentage
Very Satisfied	18	27%
Satisfied	20	31%
Neither satisfied or dissatisfied	8	12%
Dissatisfied	16	25%
No response	3	5%

Those that were dissatisfied consisted of 7 out of the 35 parents of a child with an Autistic Spectrum Disorder, 3 out of the 9 parents of a child with Cerebral Palsy, 1 out of the 5 parents of a child with developmental delay, 2 out of the 3 parents of a child with Down's syndrome, 1 out of the 3 parents of a child with epilepsy and 2 out of the 10 parents of a child with a rare syndrome.

Those that were very satisfied were 14 of the 35 parents of a child with an Autistic Spectrum Disorder, 1 of the 3 parents of a child with epilepsy and 3 of the 10 parents of a child with a rare condition.

Those that were satisfied were 10 out of the 35 parents of a child with an Autistic Spectrum Disorder, 3 out of the 9 parents of a child with Cerebral Palsy, 4 out of the 5 parents of a child with developmental delay, 1 out of the 3 parents of a child with epilepsy and 2 out of the 10 parents of a child with a rare condition.

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