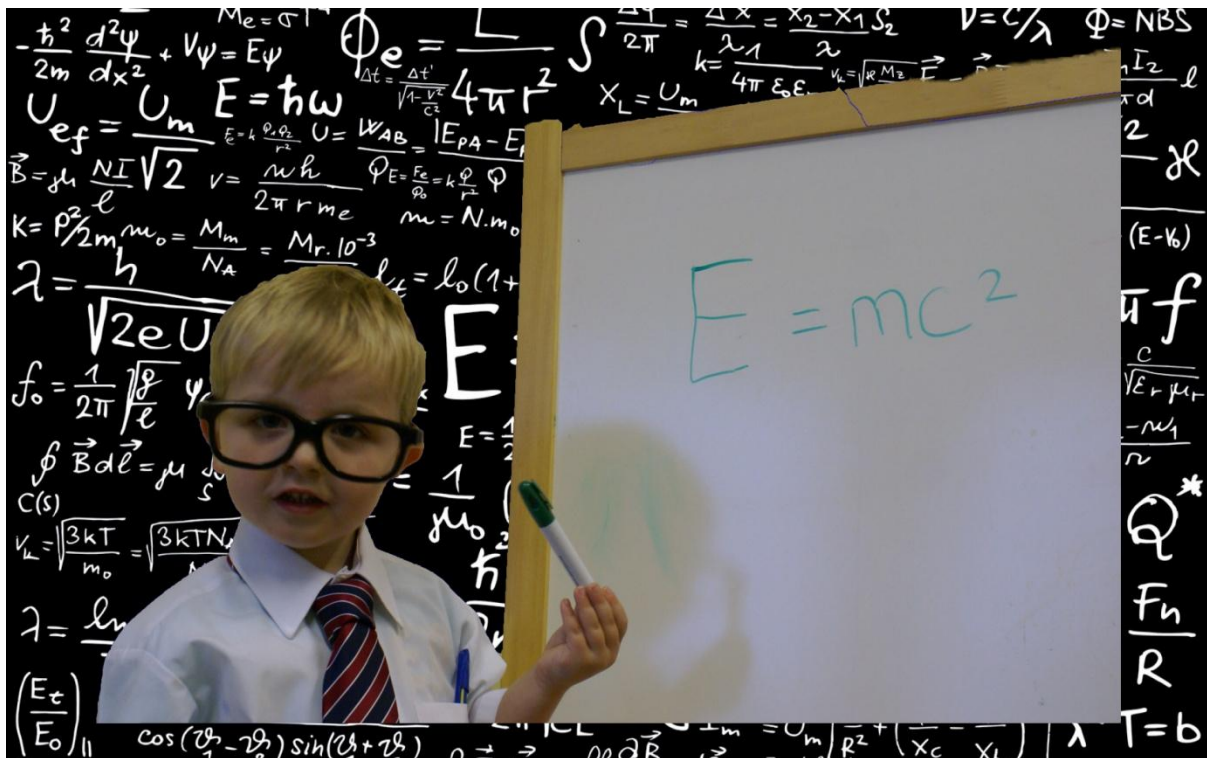




Speur-Ghlan

Parent Survey Responses 2015
Pre and Post Diagnosis Support and Services



Speur-Ghlan Early Intervention Service

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Who we are:

Speur-Ghlan is a registered Scottish charity offering a unique service to families across Scotland. In Gaelic Speur-Ghlan means blue skies, or cloudless heavens which represent hope and future thinking. We provide a range of therapy and support services to preschool children with autism/ developmental delays and their parents/ wider family members. We have been running for almost 5 years and now have the evidence and experience to show that what we do is effective and much needed within the communities in which we work. In spite of decades of research and recommendations, children with developmental conditions including autism and communication delays/ disorders are not receiving sufficient levels of therapy and support. Families are often left with no information or direct services for their child, and many families are waiting over 12 months from their initial identification of their child's issues to receiving any kind of direct intervention or support.

Why We Exist:

We provide a much needed service for children age 0-5 who need a little help to achieve their full potential. There are decades of research showing that children with autism and other developmental difficulties can make significant progress with the right type of support but unfortunately this support is not advocated by or provided in Scotland currently.



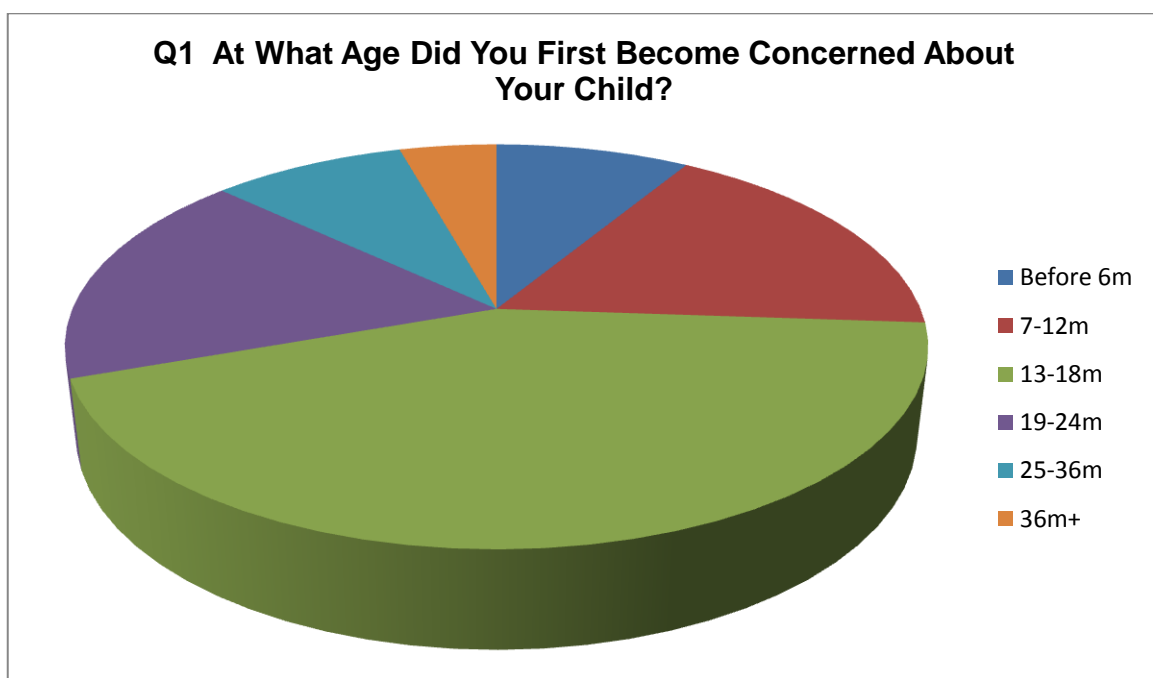
Background

We sent out two surveys to our parent group (32 families) in January 2015. The first asked for feedback regarding experiences of pre and post diagnosis support. The second looked more specifically at access to and levels of services offered to families. These results reflect the experiences of families located across a wide area of Scotland ranging from Edinburgh and Lothian to Fife, Stirlingshire, Clackmannanshire, Lanarkshire, Ayrshire, Perthshire, Angus, Dundee and the Highlands.

Survey 1

This survey focussed on pre and post diagnosis experiences including early identification, support and information given to parents at the early stages of the diagnostic process. As the children that we provide services to have a range of challenges, parents' answers to these questions were varied and reflect the diverse population within our client group. However, the predominant view from the respondents were that although parents had concerns early on in their child's development, diagnosis, access to support and direct services took much longer to be put into place.

Question 1

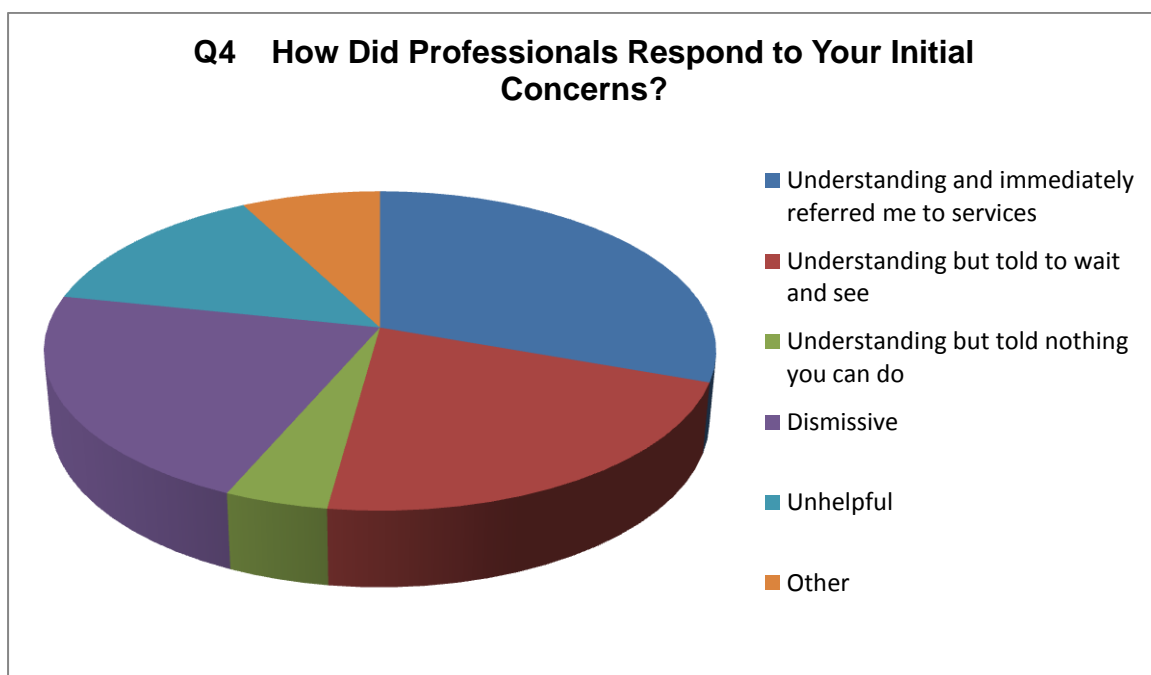


When asked at what age they first had concerns about their child's development, 87 percent of parents stated that this occurred before their child's second birthday. 9 percent of parents first had concerns between 2 and 3 years old and only 4 percent of parents first became worried about their child's development after they turned 3.

Question 2 and 3

In the second question, parents were asked at what age they first became involved with health or education services regarding these concerns. 74 percent of parents reported that they became involved with health and education services before their child's 2nd birthday, with only 26 percent becoming involved after that time. When asked who they first raised their concerns with regarding their child, 72 percent of parents stated it was their health visitor, with only 20 percent choosing to speak to their GP and 9 percent with their paediatrician. This response clearly reflects the importance of the role of Health Visitors in early identification and support for young children with developmental delays.

Question 4



When asked how professionals responded to these concerns, only 30 percent of parents reported that professionals were “understanding and immediately referred me to services.” In contrast, 22 percent of respondents found professionals to be “dismissive” of their concerns and an additional 15 percent found their reaction to be “unhelpful”. 22 percent of respondents were told that there was nothing that they

could do and 5 percent were told to “wait and see”. 6 percent selected the category of “other” but did not clarify. These responses show that over 70 percent of respondents received no initial referral to services from this first interaction with statutory professionals.

Question 5

In Question 5 parents were asked if relevant to their situation “Was autism discussed with you at this initial appointment and if so how was it described?” Of the 32 respondents, only 22 answered this question. No participants responded with the option “in positive terms with reference to the benefits of early identification and intervention”. Only 1 respondent selected “in positive terms but no reference to early support”. 9 participants selected “I was told it was too early to tell” and 12 selected “other”, reflecting a range of responses. These ranged from “I was told I had nothing to worry about” and “I was told at 2 that she was too young and they catch up really fast at her age”, to more detailed responses discussing the perceived lack of knowledge on the part of the professional involved:

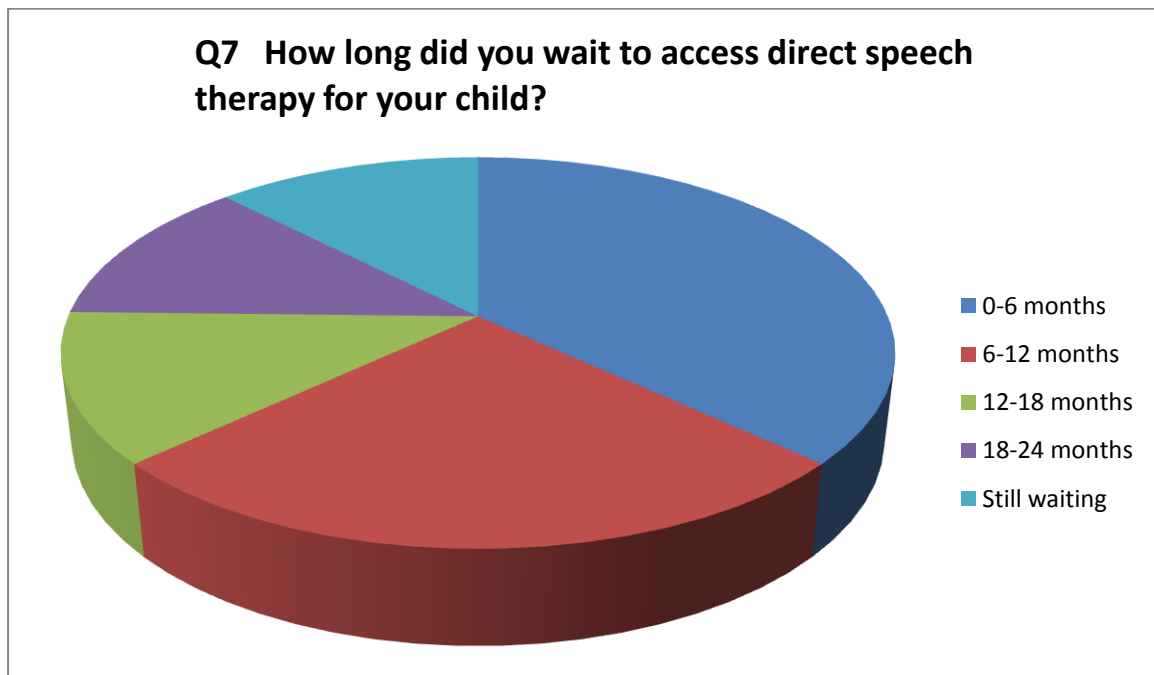
We raised our concerns about autism with our GP stating we felt our daughter’s speech was delayed, her play skills had stalled and stereotypical behaviours were beginning to worry us. After having observed our daughter for approximately 3 minutes the GP advised us that he knew what autism looked like and “this” was not it! He dismissed our concerns and did not make any referrals to other services.

It was never even mentioned. Our Health Visitor didn’t know that J had autism until she turned up at a team around the child meeting when he was 3.5, and even then we had to tell her.

Question 6

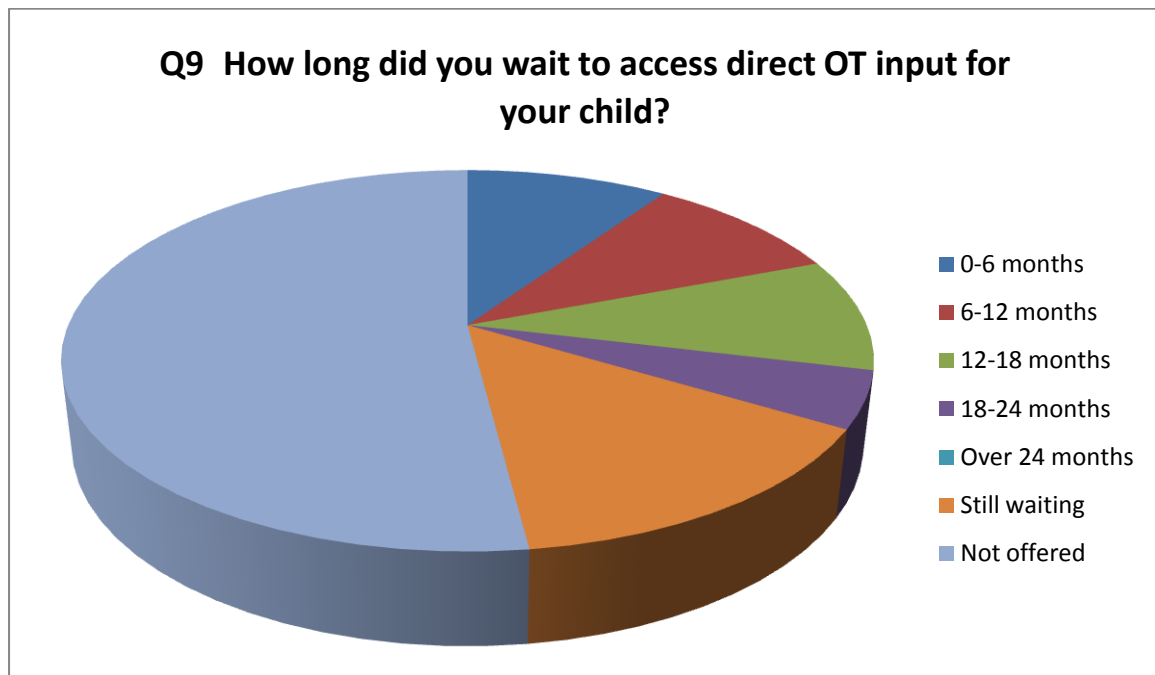
Question 6 allowed respondents to select multiple answers. When asked what support they were offered 68 percent of parents stated that they were offered speech and language therapy, either as direct intervention for the child or assessment. 30 percent of these parents stated that they were offered speech therapy but through a parent training component only with no direct support for the child. 22 percent of respondents stated that they were offered an occupational therapy assessment and 18 percent stated that they were offered no support at all. 22 percent of respondents replied that they were offered parent training (outside of speech therapy) and no respondents were offered any type of parent counselling. Only 10 percent of parents were offered genetic testing for their child and none of these were offered genetic counselling to support this process. No parent was offered any type of bespoke, intensive early intervention therapy based on behavioural principles, such as ABA or PRT.

Questions 7 and 8



These questions referred specifically to speech and language therapy and the time it took between referral and assessment and between assessment and direct intervention. When asked “how long did you wait for speech and language assessment?” only 11 percent of respondents selected “3-4 weeks” and none selected “1-2 weeks”. 28 percent responded that they had waited/ were waiting between 1 and 6 months for assessment and 62 percent had waited between 6 and 18 months. After initial assessment, 43 percent of parents stated that they waited between 7 and 9 months for direct speech therapy for their child, with an additional 43 percent waiting between 10 and 24 months. 14 percent stated that they were still waiting for assessment.

Question 8 and 9



Questions 8 and 9 related specifically to Occupational Therapy (OT) support and waiting times for assessment and direct therapy. 48 percent of respondents stated that they were never offered OT assessment. 11 percent said that they were still waiting for assessment and 30 percent had waited one year or more. 11 percent had waited between 7 and 9 months. In terms of direct OT input 11 percent had waited between 7 and 12 months and 15 percent had waited between 1 and 2 years. 14 percent were still waiting for assessment and 60 percent stated that they had never been offered direct OT input for their child.

Summary:

The responses from this first survey show that even though parents are identifying potential developmental delays early in their child's life, the support available is not appropriate to deal with these concerns in a timely and practical manner. Parents are being given information that is outdated and untrue, particularly regarding the benefits of early identification and early intensive behavioural interventions. In addition, many parents are being told to wait and see as their child is considered too

young at 2 or 3 years old to be considered for diagnosis or support. This is in spite of a wealth of recent research that states that autism can be identified from as early as 9 months. The inconsistency between the services that parents are offered at this early stage shows a clear difference in practices across locations in Scotland and across individual practitioners. There appears to be no consistent response to parents who are concerned about their young child's development, and waiting times for key services such as speech and language therapy are in excess of what could be deemed reasonable in the life of a very young child. Occupational Therapy services appear to be only offered to a small number of parents for initial assessment purposes, but waiting lists for direct support are variable and many parents do not get offered this crucial service as direct therapy for their child.



Survey 2

This survey asked more specific questions regarding the level of services that each child received. In line with the findings from Survey 1, there appeared to be a varied response by statutory professionals across Scotland to meeting the needs of young children with autism or other developmental delays. In addition, service levels offered are far below the recommended UK guidelines of a minimum of 15 hours of per week for preschool children diagnosed with an autism spectrum disorder (NIASA, 2003), and well under international guidelines adopted in the US 25 hours per week for each child (National Research Council, 2001).

Questions 1-3

Parents were asked directly about speech therapy services for their child including hours per week and types of approaches that therapists used. 75 percent of respondents stated that they had a speech therapist assigned to their child, with 10 percent stating that they had no assigned speech therapist and a further 15 percent replying that they had been discharged from speech therapy services. When asked

how many hours of speech therapy their child received per week, only 11 percent stated that they had weekly sessions of less than 1 hour. 5 percent had 1 hour per fortnight and 22 percent had 1 hour per month. Of the remaining respondents, 22 percent stated that their speech therapist worked in a consultancy role only and had no direct input with the child and 28 percent stated that their child never saw a speech therapist. 11 percent of parents selected the 'other' response and replied that their speech therapist either worked directly with the nursery with no direct communication with the family or that their child had less than one hour per month of input.

When asked what strategies their speech therapist used with their child, 35 percent responded that they used Picture Exchange Communication System (PECS), 5 percent used Makaton and an additional 5 percent used Objects of Reference (OAR). 70 percent of parents stated that their speech therapist had never explained any strategies or approaches to them. No parent responded that their speech therapist was using any evidence based behavioural methods to develop speech, such as PRT or ABA.

Questions 4-6

These questions focussed on Occupational Therapy input and asked specifically about the level of direct services children received. Of the respondents replying to this question, only 25 percent stated that they had an OT assigned to their child. Within this group no children had weekly input, 5 percent had fortnightly input of less than 1 hour, and 10 percent had up to 1 hour per month. Of the remaining respondents, 20 percent stated that their OT worked in a consultancy capacity only.

When asked what strategies OTs were using with their child 2 respondents said that they were utilising sensory integration approaches and 1 respondent selected 'other' but did not clarify.

Questions 7 and 8

These questions gave parents an opportunity to comment on a more extended level regarding the support that their child was receiving. Overall, parents were disappointed and disheartened by the lack of practical support and the scarcity of direct services. There were no positive responses from these questions, showing an overarching theme of dissatisfaction within this group of parents regarding statutory input.

Q7: How do you feel about the level of support your child currently receives from statutory services?

- Would like much more intensive input as early intervention is so important
- Some are good and others impossible to access
- Very poor
- I feel my child receives very minimum support. I have expressed my concerns and have been advised this is due to lack of funding.
- It's woefully inadequate and, in cases, inappropriate.
- Feel it's at best ineffectual and at worse a waste of our time. It's never helped progress my child in any way. Therapists changed after one or two meetings therefore never getting to know my child and don't provide me with any suggestions (other than pictures) in how to help my child progress.

- Only practical help has been Hanen programme. Little follow up from speech therapist. Paediatrician was 1 hour and very negative experience for my son and me.
- There is very little support offered. It's so disappointing and devastating for families that have nowhere else to turn
- Completely inadequate
- Very disappointing at this early stage I would expect SALT to be at least once per/week with regular updates/strategies for us to try. O.T again poor she met with me spoke with me re my concerns came back for progress update. Did not work directly with my child then discharged us.
- The support is extremely limited. You attend Consultations when the service provider is sympathetic however the output is usually little to nothing. Sometimes they provide suggestions of activities however I believe the best way to support children with ASD is with a consistent one to one therapy and target based proven system.
- Appalling and inadequate.
- Although we have 30 minutes per week speech therapy we had to fight for this and they are trying to discharge us for a period of 5 months. The support offered in general is nonexistent. Without a private provider such as Speur Ghlan our child would have no support. The people who are meant to help for example health visitors, educational psychologists and speech therapists seem to be very ignorant on how to work with a child with autism. In the 9 months I have been trying to engage with these services there have been lots of meetings but no action taken to help my daughter.
- Don't get any

- They currently don't receive any statutory support.
- It's not enough by any means I have had to fight for speech therapy weekly instead of fortnightly and meeting for other children means my sons sessions are cancelled. I also fought from him to get pre five learning support weekly which was initially granted but due to L progressing well he was put back onto a block system due to a large waiting list. Staff are amazing but just stretched and there are not enough of them
- Very, very dissatisfied. Support is incredibly poor from local council. 2 years on and wee A is only due to start speech therapy. This is not 1-1, this is at his nursery when she will drop in and see him. Services are not structured. Targets are not measurable. A has some speech so feel he is not seen as priority compared to other children.
- Been waiting over a year for speech therapy. Early nursery placement without support offered. No other support offered
- It's very poor to nonexistent

Q8: Is there anything you would like to add regarding support that you currently receive from statutory services?

- Outdated methods used and don't look to the future. They don't see that if they spend money on early intervention they will save a lot more money later down the line.
- I feel there should be more support available and on a more regular basis. This support should also be provided earlier instead of waiting until they are older. More information should also be provided on the support that is available to your child.
- Considering the poor quality of advice received by Primary Health Care providers in terms of our child's needs, we are probably better off not using them at all.
- My child has not been diagnosed but SALT treats her as if she has and regularly tells me she has a communication disorder. They fail to look at my child as an individual to see what interests her and how they can use this to encourage her. After their first meeting with my child they were already telling me they would remove their contact when they felt it was no longer helping. In reality they could have done this already as they've never helped improve my child's speech or language!
- It focuses on diagnosis and they have NEVER mentioned how important early intervention can be. They don't give you hope for the future. We dread appointments with NHS services.
- There is no real early intervention or even speech therapy offered.

- Not enough information to start with. If it wasn't for our input our child wouldn't be getting half of what he gets and even that is atrocious. We have lost all faith in the NHS.
- Very poor since diagnosis met with paediatrician & also SALT for 6 month review only. No parental support.
- More speech and language therapist who offer 1to1 and more training techniques / strategies such as PRT rather than reading from the NHS manual on autism
- It seems that the general attitude of the services is that you child has autism there is nothing we can do for you daughter but we are here if you as a mother needs someone to speak to but don't expect us to do anything with relation to your child. There is no support for children before the age of 5. Our children are being pushed to the side and forgotten.
- Should have early intervention strategies similar to Speur Ghlan. We are lucky to have a place but what about the other thousands that need support.
- There is very limited statutory support available. We have fought to get some for our child with no success.
- Pivotal response therapy, my son receives it privately and it is has changed his life. This therapy should be offered as a statutory service
- More hours needed more one on one therapy. More proven structured therapies.
- Next to no support, very disappointed. Was told when my daughter was 2 that it was too early for any kind of diagnosis and told to return in a year to the paediatrician.
- It would be nice if she got some!!



Conclusions

Unfortunately, in spite of decades of research showing the ways in which children with autism and other developmental difficulties can make significant progress with the right type of intervention this support is not advocated by or provided through statutory services in Scotland. The current level of direct support and therapy provided to families of young children with developmental disabilities is unacceptable. The current world health organisation recommendations, which are also advocated by the UK National Autism Strategies, would advocate a minimum of 15 hours of therapeutic intervention per child per week, rising to 25 or more hours in the United States. In addition, in spite of a huge body of empirical research into a wide range of therapeutic interventions for children experiencing developmental delays, including (but not restricted to) autism, we are currently the only service within Scotland to be providing this type of empirically validated, evidence based intervention model.

Parents with young children with disabilities have long been identified within research as being a group vulnerable to stress and mental health issues, and

parents of children with autism specifically have been identified as having even more significant issues with stress, coping and depression. The parents that we work with have been offered very little (and often no) information on their child's condition and no training in how best to manage their child's needs. To date, after being open for 5 years we know of only 2 families who have ever been offered any counselling services pre or post diagnosis.

Access to key statutory services such as speech and language therapy (SALT) and Occupational Therapy (OT) is extremely limited within our client group, in spite of the overwhelming benefits that these approaches can offer to the child and to the family as a whole. The maximum level of services that any of our children with an autism diagnosis receives is 45 minutes per fortnight of SALT. Communication and understanding of language are key skills that our children need ongoing and intensive support with at this early stage is crucial to their development. In addition, a number of local health boards in Scotland are also refusing OT support and assessments for children who present as being on the autistic spectrum. With new diagnostic criteria which are now implemented worldwide (DSM V) autism now has a sensory processing element to the diagnosis and children with possible autism spectrum conditions should have ongoing and specialist OT support to help address these difficulties. In addition, almost all of our children attend a mainstream nursery, but only 3 children (approx 10 percent of our current client base) receive any level of 1-1 support within this setting.

In conclusion, professional awareness of and commitment to early identification and early intervention for young children with autism and other developmental delays needs to improve significantly across Scotland. Parents who are proactive enough to recognise early differences in their child's development should be better supported

with in depth assessments, early diagnosis and direct support and intervention for their child and their family unit. Intervention needs to be based on well researched approaches that have proven to be effective with this client group rather than an eclectic mix of methods. Waiting times need to be reduced dramatically and access to direct therapy needs to be made a priority for all children under 5 with developmental needs. Intensity needs to be increased to meet the requirements and recommendations at national and international levels. Above all children and their families need to be given the very best start in life, in order to support them to achieve their full potential. In our opinion this is not simply a need, it is their human right.

Early interventions have proven to produce the best returns in investment and better results in terms of developmental outcomes and improvement in daily functioning.

(WHO, 2013:19)



Ruth Glynne-Owen

CEO Speur-Ghlan Early Intervention Service, February 2015

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- World Health Organisation (2013) **Autism spectrum disorders & other developmental disorders MEETING REPORT *From raising awareness to building capacity*** Geneva, Switzerland