

**Provision of Occupational Therapy for Children with
Autism Spectrum Disorders
A Comparative Study between Durham & Darlington and
South Tyneside.**

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Introduction

This report was produced to provide information about the nature of Autism Spectrum Disorders (ASD) and the number of individuals within County Durham diagnosed with ASD for the board of the Primary Care Trust (PCT) at Derwentside, County Durham. The Chief Executive of the PCT also requested information with regard to the numbers of children diagnosed with ASD receiving Occupational Therapy with the six PCT areas of County Durham and Darlington Acute Hospital Trust.

Aims and rationale

The aim of this report was to highlight the complexity of ASD and the resultant difficulties individuals with ASD experience which subsequently affect the individual's ability to function in everyday life activities that provide meaning to their life (e.g. self-care, going to school, play, social interaction and independence). The need for this report was generated from a complaint by parent members of the local parental support group to the PCT at Derwentside. Their complaint being that their children having being diagnosed with ASD could not access Occupational Therapy (OT) despite referral to this service because the existing criteria within this PCT specifically excluded children with a diagnosis of ASD regardless of complexity or severity of need.

Local figures demonstrating the numbers of Children with ASD 0-19 years within Durham (no figures are available from Darlington) would be incorporated into this report and families across Durham and Darlington within the six PCT areas of the Strategic Health Authority (SHA) would be surveyed to generate data in order to provide the information requested by the Chief Executive of the PCT at Derwentside.

The author of the report was a member of the core working party for the development of the National Autism Plan for Children (NAP-C). She was aware having being involved in extensive research for this plan of best practice for children with ASD that early co-ordinated intervention had a significant beneficial impact on the lives of ASD children and their families.

Therefore the report also aimed to highlight the need for OT input for children with ASD and the benefits of this therapy/intervention. In order to provide quantitative and qualitative data to inform the study a comparative survey was made of families living within South Tyneside where an ASD specific OT service is in place.

Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is thought to be a neurobiological condition of the brain which impacts on the individual's development (Prior 1992). The resultant difficulties they experience produce a cluster of features which provide the diagnostic criteria for autism (Wing & Gould 1979). These clusters of features are referred to as the Triad of Impairment (Wing 1988) which can be diagnosed using diagnostic criteria used by the World Health Organisation 'ICD- 10' (1990) and the American Association 'DSM-IV' (1994).

The core features of ASD's are impairments in social interaction, delayed, absent or impaired language and communication skills, problems with rigidity of thought and stereotyped behaviours (Richer & Coates 2001, Jordan & Powell 1995). Individuals

therefore have difficulties with social relationships, verbal and non-verbal communication, and development of play and imagination and with change in routine (National Autistic Society 2002).

ASD is described as a communication disorder (Williams 1996) with individuals experiencing difficulties with all communication including non-verbal communication. Individuals have limited use of gestures and body language. They also have difficulty understanding and interpreting facial expression (Attwood 1998). There is an inability to interact with and in some individuals a lack of desire to interact with peers. Individuals display a lack of appreciation of social cues and often demonstrate socially and emotionally inappropriate behaviour (Attwood 1998). Williams (1996) describes this as an impairment of the ability to act socially. Individuals with ASD are described as having a lack of 'theory of mind' (Baron-Cohen 1995) or an inability to understand that others have their own unique view of the world and have different thoughts and beliefs to themselves (Randall & Parker 1999). They also experience problems in recognising and understanding their own emotions (Williams 1996, Attwood 1998, Lawson 2001).

Individuals often have unusual or restricted interests and can display compulsive, ritualistic or stereotyped behaviours (Schopler 1995).

Current studies have also identified additional sensory 'differences' in individuals with ASD's (Myles et al 2000, Bogdashina 2003). They describe individuals as experiencing sensory agnosia or difficulties interpreting their senses. This is linked to bizarre responses to sensory stimulus (Williams 1996). Lawson (2001) also discusses processing problems or delayed processing in individuals with ASD suggesting that they process pieces of information one at a time (Lawson 2003). This is described as being single channelled or mono-tropic (Lawson 2001) or experiencing mono-processing (Bogdashina 2003).

Occupational Therapy and ASD

Sensory differences and ASD have been highlighted in the last few years by individuals with ASD (Williams 1996, Lawson 2001). This is now being extensively researched and has resulted in the availability of literature relating to the sensory differences and subsequent difficulties faced by individuals with ASD and how this should be addressed (Myles et al 2000, Stackhouse et al 2002). Many of the anxieties and resultant behaviours of individuals with ASD relate directly to their sensory differences and inability to process the world around them. Unlike the majority of their peers they are unable to process and use the sensory input they receive (Trott 1993). Frequently they have sensory integrative disorder (SID) a common component of this disorder is sensory defensiveness, in which children are unable to tolerate various kinds of sensory stimulus (Wilbarger & Wilbarger 1991). These sensory integration issues fall within the frame of the scope of OT which has been demonstrated through case study to have value in addressing these specific difficulties (Stackhouse et al 2002).

Some children with ASD also have additional diagnoses of dyspraxia, dyslexia and developmental coordination disorder and a large proportion experience problems with fine and gross motor skills and coordination (Ayres 1989). The College of Occupational Therapists (2003) survey reported these children to be doubly

disadvantaged because they are given low priority by OT services and other services. It goes on to say that these individuals are at significant risk of being socially excluded. They have to compete for OT services against other children with apparently more severe disabilities, however, they deserve the same opportunity to attain their potential and develop the necessary skills required for adult life.

Although the prevalence of ASD has increased empirical data about the role and practices of OT's has not been reported within the literature although more study is being generated. Case-Smith & Miller (1999) investigated the practice of OT's with children with ASD. They found where OT's provided direct services using holistic approaches which included applying sensory integration and environmental modification approaches more improvement was seen in the child's sensory processing. They also reported that where child-centred play was used frequently and competently that there was improvement in the child's sensory integration and play skills. This was also supported in the research of O'Rafferty (2004).

In a further study Case-Smith & Bryan (1999) examined the effects of OT intervention emphasising sensory integration with preschool children. Their results supported descriptions within literature regarding positive behavioural changes that ASD children can make when participating in intervention using sensory integration approach. In a small study Linderman & Stewart (1999) found that participants receiving sensory integrative-based OT displayed significant improvements in the areas of social interaction, approach to new activities, response to holding or hugging and response to movement. They also identified decreases in frequency and duration of disruptive behaviours (high anxiety levels and aggressive behaviours) with an increase in functional behaviours such as spontaneous speech, purposeful play and attention to activities and conversation.

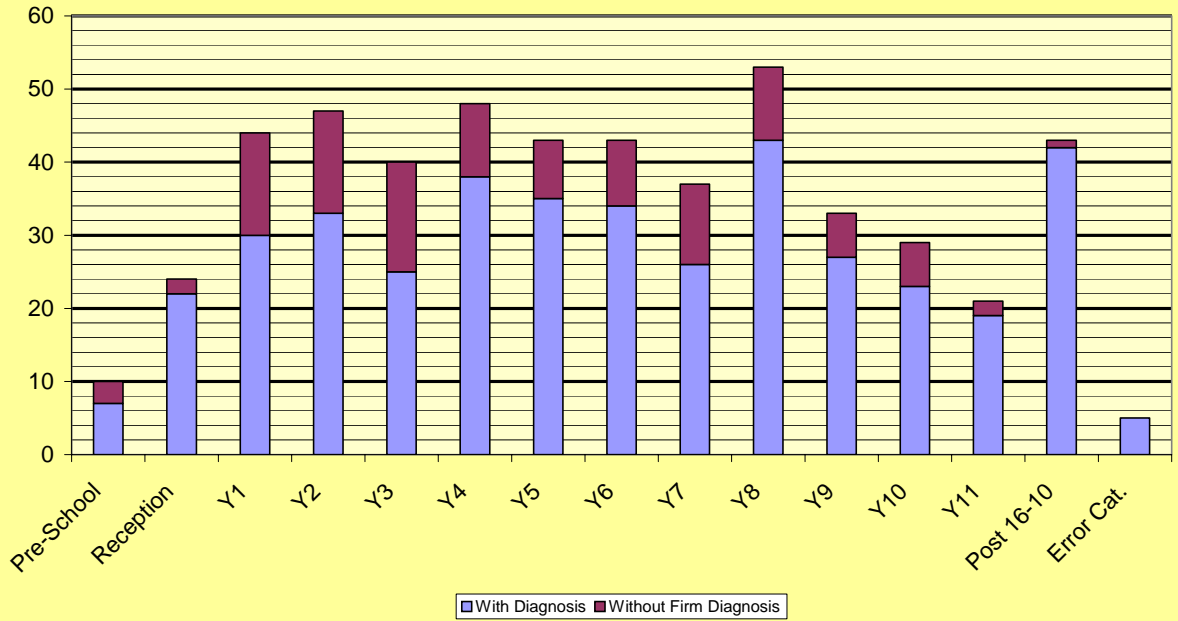
Williams (1996) states that sensory integration does not take place naturally in individuals with ASD as the brain is not able to filter out sensory information on different channels. She emphasises the need for specific therapy and sensory integration programmes which assist the individual to overcome this difficulty and helps them to "pick up the developmental pieces", that is to promote their ability to learn. Myles et al (2000) also reports significant progress in individuals with Asperger Syndrome who received sensory integration therapy.

Bogdashina (2003) concludes that all individuals with ASD have some degree of sensory dysfunction and there is a need for knowledge in this area. There is also a need for specific profiles of individuals and therapy/programmes to address their individual needs. This will assist to decrease their symptoms and help them reach their full potential.

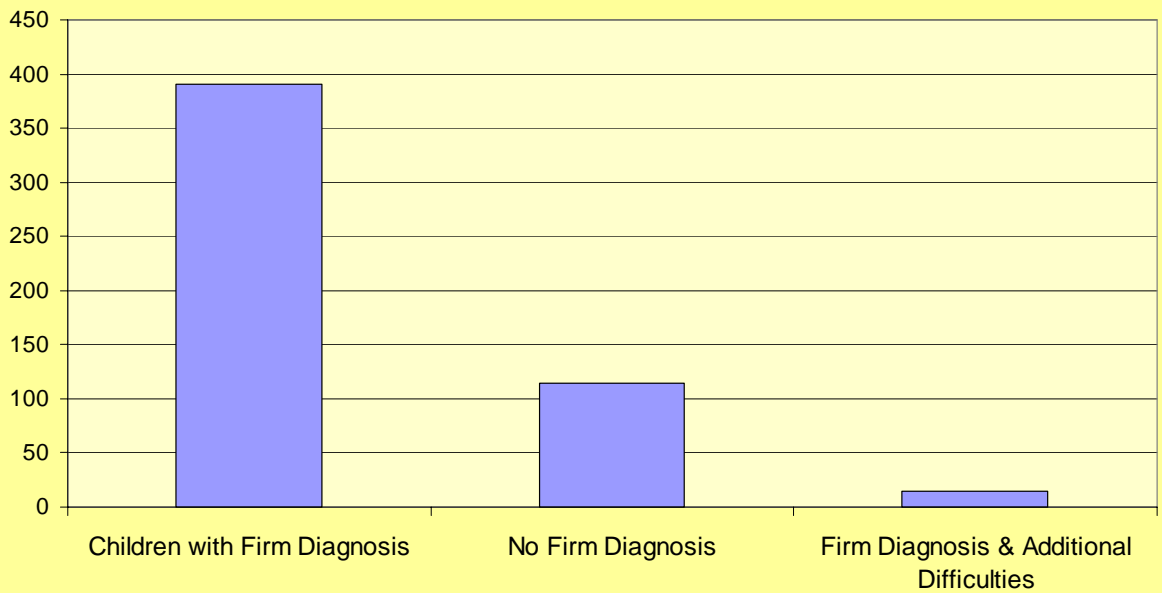
Numbers of children 0-19 years within Durham

The following data in graph form was compiled in 2002 by Senior Educational Psychologist Janet Crawford to inform the Multi-disciplinary ASD Group, Durham. Permission was given by this group for this data to be used in appropriate research 11th May 2004.

ASD - Graph 5



ASD - Graph 1



Methodology and ethics

Data was collected by postal survey. A preaddressed stamped envelope was provided.

A short questionnaire was designed to specifically obtain the information required to inform the PCT. The questionnaire was composed of twelve questions. Question 1 asked the child's diagnosis, questions 2-11 investigated the respondent's experiences of OT and question twelve asked the respondent to indicate the PCT area they lived within.

The respondent was not asked to give identifying information such as their name, address or the age of the child therefore guaranteeing their anonymity. They were however asked to identify which PCT area they fell within and if they were aware or had been told their child did not meet the criteria of OT.

The questionnaire required them to identify their child's formal diagnosis but did not seek information about their child's additional problems if any as this may have produced data which was parental assessment rather than clinical observation of the child's difficulties. However a comments section was included to allow respondents the opportunity to express opinion either of the OT service or their child's needs.

The initial questionnaire was sent to 134 families of children diagnosed with ASD. These families were members of the local support group which is a charitable organisation. The aims of this research when presented to the committee satisfied the charitable aims of this organisation. All recipients of the questionnaire had also previously indicated a willingness to be included within such projects within the charities data base. As the author of this report is the coordinator of the support group she already had access to the confidential data base so there were no further ethical considerations.

A comparative questionnaire (excluding question twelve) was sent to the committee of the support group within South Tyneside who had already expressed an interest in being involved. Similar considerations were made by their committee who then agreed to send the questionnaire to their parental membership for return to the author directly. Questionnaires were subsequently sent to 80 families in South Tyneside.

Only the author of this report had access to completed questionnaires which were considered confidential and shredded on completion of the final report.

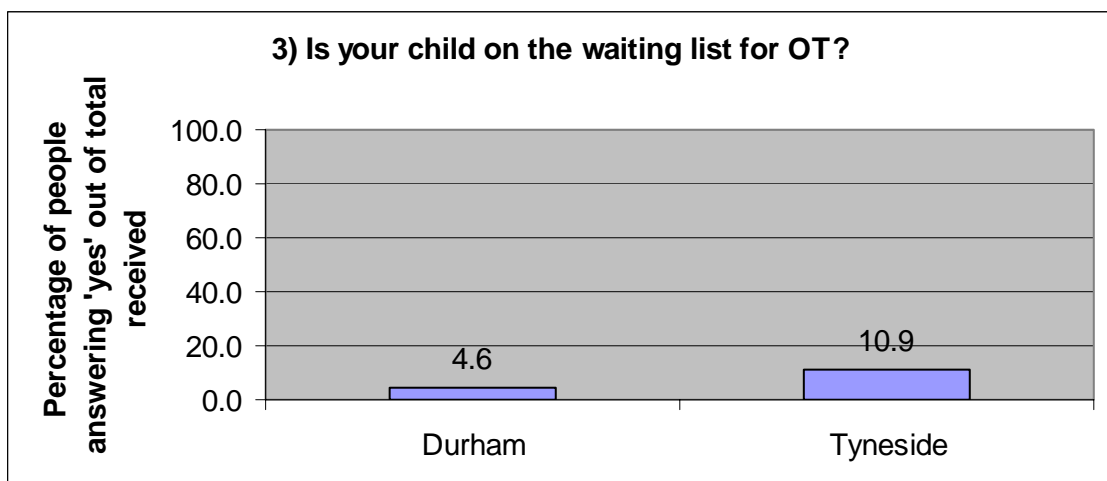
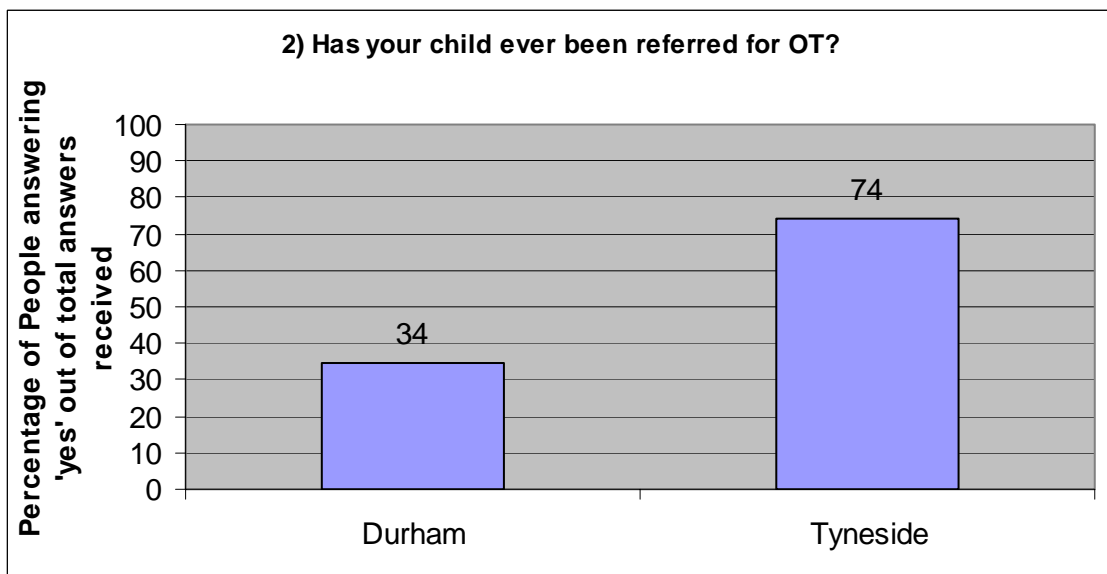
Analysis

On receipt each questionnaire was given a code number. 87 questionnaires were returned from Durham and Darlington (numbered 1-87) and 46 from South Tyneside (numbered 1-46). These were high response rates for postal questionnaires 64.9 % response rate from Durham and Darlington and 57.5% from South Tyneside.

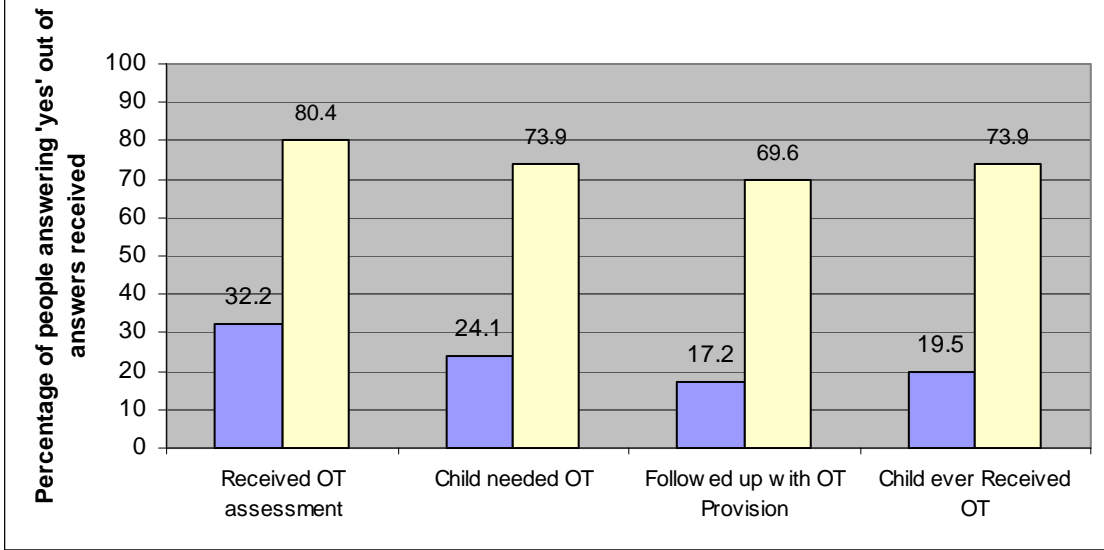
Of the respondents from Durham and Darlington (D&D) all gave their child's diagnosis as ASD, Autism, Asperger Syndrome or a variation of these except for two. Nearly 25% had dual diagnosis including ADHD, dyspraxia, dyslexia, global developmental delay, coordination dysfunction/disorder and/or Semantic Pragmatic Disorder. Respondents from South Tyneside (ST) with the exceptions of two who did

not respond gave ASD specific diagnoses with only two giving dual diagnoses of ADHD and dyspraxia.

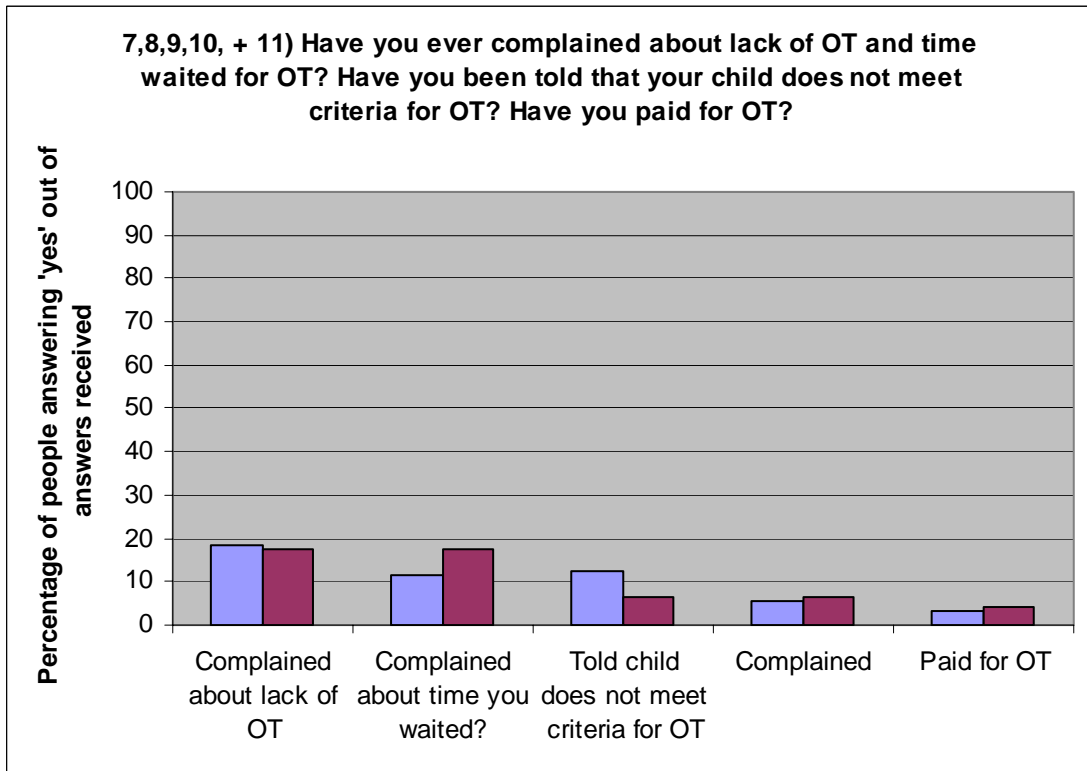
In order to produce a clear and informative report for the PCT the data generated by questions 2&3, 4&5, 7, 8,9,10 & 11 are shown below in graph form and in terms of percentages to aid comparison of the two studies. If required the full data will be provided as appendices. Question 6 was not analysed as this generated the names of individuals who had referred to the OT service rather than their profession which made comparative analysis impossible (in retrospect the question could have been more directly worded).



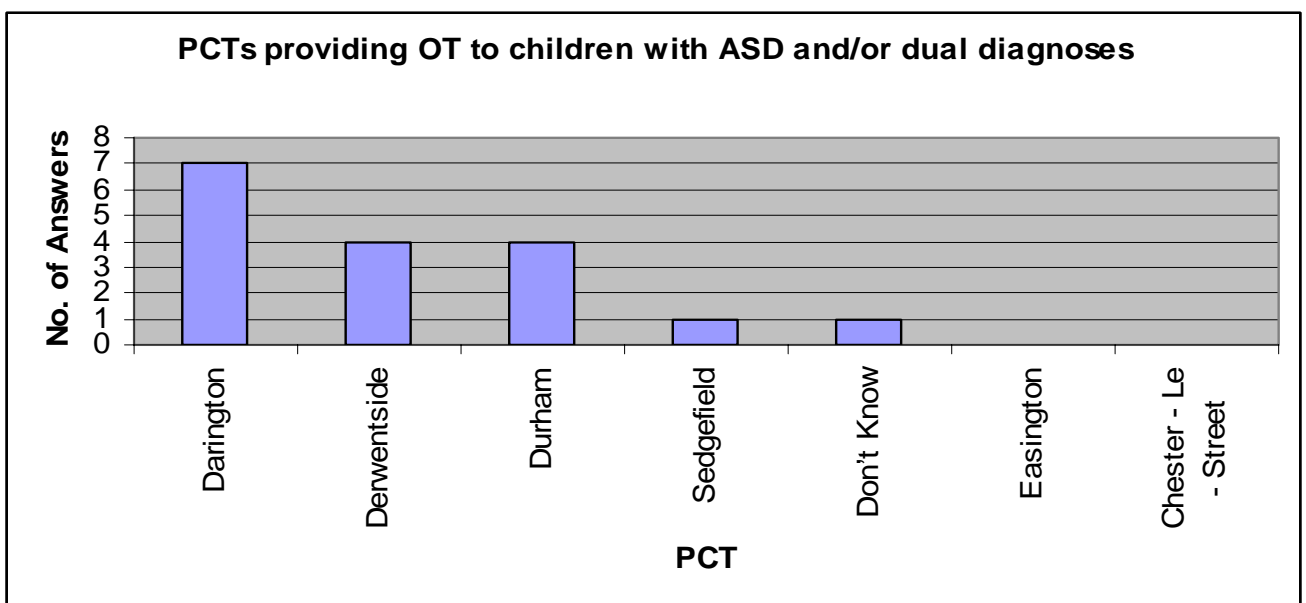
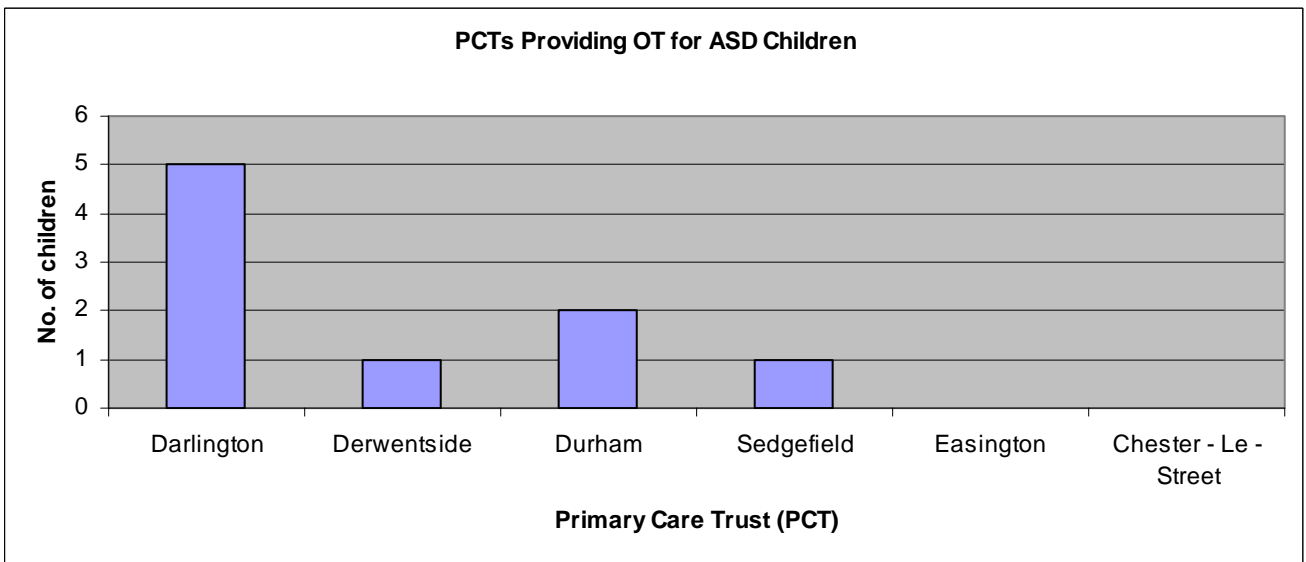
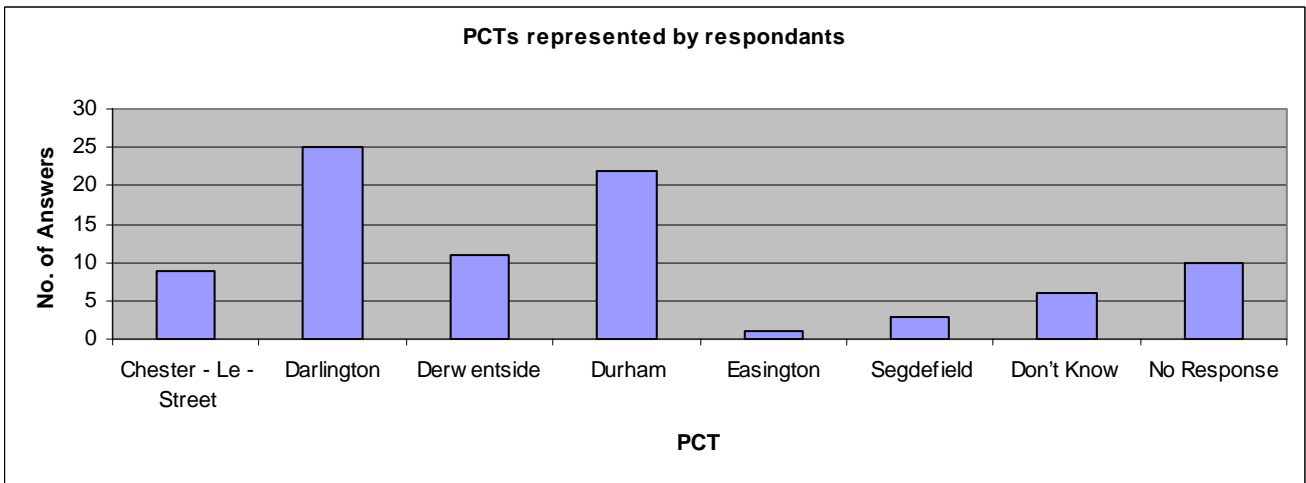
4+5) Did you receive an OT assessment, did it say your child needed OT, was it followed up with OT provision? Has your child ever received OT?



7,8,9,10, + 11) Have you ever complained about lack of OT and time waited for OT? Have you been told that your child does not meet criteria for OT? Have you paid for OT?



The following graphs indicate which PCT's respondents from D&D indicated they came within, which of these had provided OT services to children of the respondents and which had provided OT to children with a single diagnosis of ASD.



Those families (17 in total) within D&D which indicated they had received OT for their child described receiving one block of therapy delivered weekly lasting 45 minutes to one hour in duration. These blocks of therapy varied from six to twenty sessions. Two families indicated they had received more than one block of therapy. One described provision of a school programme but also made comment that this was not monitored or followed up. Another stated that the school had received 2-3 visits (Appendix one).

Respondents from ST described weekly therapy for children at an ASD specific school. Others described blocks of sessions being delivered in various frequencies according to needs with direct access to the service. The service was also closely linked to and worked jointly with speech and language therapy (SaLT). OT included social skills work, exercise programmes, work for fine and gross motor skills, handwriting programmes, movement groups, sensory assessment, social use of language groups (SULP), and provision of home and school programmes (Appendix one).

The comments section from both studies (Appendix two) was analysed to identify any common themes. Noticeably the D&D study generated a higher proportion of and more in depth comment than the ST study. The ST study generated essentially positive comments about the OT service with only 5 respondents complaining about service provision. Where as the D&D study generated predominantly negative comments about the lack of OT service provision, being refused OT due to exclusion criteria or waiting long periods of time to be told they would not be seen.

Families who had received OT for their child both in D&D and ST made comment about the improvement and value of therapy to their child as a result of direct therapy, home programmes, and school programmes.

Indeed the few positive comments generated by the D&D study were made by parents whose children had received OT and described the beneficial effects OT had on their child. These included improved confidence and ability with fine motor skills, improved coordination, improved sensory integration and improved self-esteem.

One parent from South Tyneside submitted a personal statement for this study which she wanted included (Appendix three). This provides a personal description of the service level provision of OT to her two ASD children and her assessment for their progress and the benefits of OT. This parent is in her final year of MA in Education Studies and Autism and has an extensive knowledge of ASDs.

Conclusion

This study highlights the number of individuals with ASD within Durham using previous available data. There were 87 respondents within the D&D study which would represent approximately 20-25% of the families within Durham with children diagnosed with ASD.

Current research is highlighting the benefits of OT for children diagnosed with ASD and supporting sensory integration therapy to promote children's awareness and understanding of the world around them. Reported benefits are a reduction in behaviours and anxiety and an increase in communication and social skills. Neither study asked parents about the benefits of OT for their child yet analysis of the comments section showed parental report of beneficial affects to directly reflect that reported in previous research studies. This would demonstrate a need for OT provision for children diagnosed with ASD as it has a beneficial effect which both research and parental report indicates.

As this was a comparative study between D&D and ST it must be acknowledged that the OT provision within ST is substantially greater than that within D&D with many parents referring to the exclusion criteria for children with ASD within D&D. So not only are families within D&D not receiving anywhere near the level of OT that ST families receive but they will not be able to access services at all due to exclusion criteria. However comment must be made that seventeen children within D&D with an ASD or dual diagnosis had received OT. However it cannot be determined when they received OT as the age of children was not requested nor did the study ask if they had received OT prior to receiving a diagnosis of ASD. Therefore they may have received a service prior to the application of the exclusion criteria or prior to a confirmed diagnosis of ASD.

Current government legislation (DfES 2001, DfES 2002, NAP-C 2002, DfES 2003, DfES 2004, DOH 2004) looks at service quality and equality for disabled children and their families with an emphasis on early timely intervention to meet individual needs so that children can reach their full potential and be included within society. The National Service Framework for Children will include ASD as an exemplar care pathway reinforcing the need for early interventions based around the needs of the child. Currently OT provision within D&D would appear not to consider individual need or severity of need for children with ASD. This study does not suggest that all individuals with ASD would benefit from OT and certainly of the 80.4% of the children assessed by OT in ST only 73.9% received OT suggesting that following assessment 6.5% of children did not require OT. However, 92% of those assessed did receive OT which highlights a real potential need within D&D if a similar percentage of children required OT following assessment. Children with ASD in D&D are therefore disadvantaged compared to children in ST. Assessment is prevented by criteria and this would seem to directly contradict the legislation around disabled children and provision of timely early interventions.

It also reflects the findings of the Audit Commission (2003) which described a lottery of provision with how good services were depending on where you lived and how hard parents were able to 'push'. It found that too little was provided too late and this was because support was not based on the priorities and needs of families. The unacceptable long waits for interventions also meant lost opportunities for children

and families. The Commission recommended that Heads of service in local authorities need to identify what matters most locally in order to improve services as services for disabled children were still Cinderella services. The high response rate to this study would indicate that this service does matter to local families. If the high level of need of ASD children for OT within ST is indicative then D&D are guilty of a huge proportion of unmet need suggesting that many children are being denied the right to services they require to reach their full potential.

This study suggests that research and parental report needs to be acknowledged and investment made to bring OT services in line with this and the requirements of government legislation. This investment has been made within South Tyneside. In order to provide equality of OT services and remove the post code lottery as described in the NHS plan D&D PCTs need to make a similar investment in the future of individuals with a diagnosis of ASD living within D&D.

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