Research Article

Parental Perceptions of a Manchester Service for Autistic Spectrum Disorders

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Background. User feedback is now an integral part of both clinical governance and service development, and it also provides a key route to engaging parents and children. Autistic spectrum disorders (ASDs) can impact on all members of a family, and close working between parents and professionals is essential.

Aim. To explore parental satisfaction rates and identify areas in need of improvement.

Method. A postal survey was completed by parents whose children had been diagnosed with an ASD in the past 18 months in a Manchester Child and Adolescent Mental Health Service. The National Autism Plan for Children was used as a gold standard.

Results. Parents were particularly satisfied with the way team members dealt with them and their children during appointments. However, the standard of written information provided about the condition, diagnosis, and support available could be improved. The findings show the benefits of receiving a diagnosis in the recommended timeframe.

Discussion. We discuss ways of effectively using scarce resources.

1. Introduction

Autistic spectrum disorders (ASDs) are developmental disorders estimated to affect 1 in 150 children [1]. They are characterised by social communication impairments, limited imagination, and repetitive behaviours. Learning difficulties are overrepresented, but not always present. Increasing professional awareness has led to higher levels of diagnosis and support, possibly explaining the recorded rise in prevalence over the last 30 years [2]. ASD is commoner in males (M: F autism 4: 1, aspergers 10: 1). Genetic factors are complex, and no single gene mutation or chromosome abnormality has been linked [3], although the condition has the highest heritability of any psychiatric disorder (approximately 90%) [4]; the risk of having a second child with autism is increased by 20–30.

The National Autism Plan for Children (NAPC) emphasises the importance of early intervention and close collaboration between parents and professionals and provides a gold standard for services [3]. Benefits for parents include increased capacity to seek information from external sources and make use of available health services [3].

Diagnosis of children with ASDs requires multiagency and multidisciplinary collaboration. In 1998, an assessment team was established in one sector of Manchester. This service involved sessions from child and adolescent psychiatrists (CAP), community paediatricians (CP), CAMHS practitioners, specialist speech and language therapists (SALT), and educational psychologists (EP). The successful format was established city wide in 2000. The multiagency teams are called Social Communication Assessment and Intervention Teams (SCAITs) [5]. Service provision within CAMHS needs to make the best use of limited resources [5].

In addition to the core symptoms, there are other common features [6], such as abnormalities in sleep and mood. For a diagnosis of ASDs to be made, there must be both symptomatology and an impact on functioning [3]. If there are concerns during developmental screens, specific screening for autism is strongly encouraged. Parental concerns provide vital information for early diagnosis [3]. Specific diagnostic instruments are available and should be used alongside clinical judgement. Most commonly used is the Autism Diagnostic Observation Schedule (ADOS) [3];
however not all characteristics may be demonstrated during the test. Observations should be conducted in different settings including clinics, homes, and schools.

ASD is a developmental disorder; symptoms can vary in severity at different times. Difficulties can become more apparent when changes in routine occur, for example, starting a new school, and this is often when children are referred. The benefits of early identification of ASDs are recognised by parents and professionals alike [3]. The diagnosis of autism, however, is often not made until 2 to 3 years after symptoms are recognized [3]. Evidence suggests that early intervention can lead to improved outcomes for most children [7]. Earlier diagnosis facilitates earlier educational, social, and medical support. It is also important to reduce waiting times from referral to intervention. There are considerable demands on parents as they accept and adjust to their child’s communication and social interaction impairments [3].

Many people seek information on their own, from other parents, websites, books, and autism groups and newsletters [3]. Children and families want accessible mental health services which provide support when needed and involve them as users. They also want to know what services are available to help them support their child [3].

The NAPC guidelines address identification, assessment, diagnosis, and access to early interventions for children with ASDs. It recommends a three-stage assessment framework. Stage 1 is a general multidisciplinary developmental assessment for any child with possible developmental problems. Stage 2 is a multiagency assessment. The assessment should be completed and fed back to the family within 17 weeks of referral. A written report should be produced and discussed with the parents. Stage 3 addresses the need for tertiary referral. The local team may need this for reasons such as specific advice about treatments. The NAPC states that feedback to parents should include information about services, for example, The National Autistic Society (NAS).

In Manchester, all SCAIT professionals receive training in assessing ASDs. Monthly SCAIT meetings involve liaison work with community paediatricians and preschool special needs workers. Direct referrals are accepted from general practitioners and paediatricians. Referrals from educational psychologists, health visitors, and school nurses are accepted if the general practitioner or a paediatrician is informed. The team generate a plan tailored to each individual regarding diagnosis and care.

Parent intervention programmes can enhance interaction with children, promote development, and increase parental satisfaction and mental health [3]. SCAIT offers five 2-hour sessions: Understanding ASD, Understanding and managing behaviour, Understanding and working with the education system, Enabling your child’s communication and understanding, and Further resources for you and your child.

2. Aim

To assess parental satisfaction with SCAIT assessments and compare the service with the NAPC Guidelines.
Table 2: Information provided before the service.

| How well were you informed about the assessment before the first appointment? | Very good | Good | Average | Poor | Very poor |
|---|---|---|---|---|---|
| | 6 | 11 | 1 | 0 | 2 |

| Were you given information describing the assessment process before the appointment? | Yes | No |
|---|---|---|
| | 13 | 7 |

| What information would have been helpful before seeing the clinician? (choose all applicable options) | Name and profession | Questions to be asked | Time it would take | Different assessment parts | Not answered | Time it would take and different parts of the assessment | Name and profession and different assessment parts | Questions to be asked and different assessment parts | Name and profession, questions to be asked, and different assessment parts |
|---|---|---|---|---|---|---|---|---|---|
| | 1 | 1 | 1 | 4 | 3 | 1 | 2 | 5 | 2 |

| Did you know of the name and professional background of the clinician prior to attendance? | Yes | No | Not answered |
|---|---|---|---|
| | 9 | 10 | 1 |

| If you did not know the name and professional background would you have liked to? | Yes | Not answered |
|---|---|---|
| | 12 | 8 |

Table 3: The assessment process.

| Ease of getting to CAMHS? | Very good | Good | Average | Poor | Very poor |
|---|---|---|---|---|---|
| | 10 | 6 | 2 | 1 | 1 |

| Which CAMHS professionals did you see for assessment (not intervention) | CAP | CP | SALT | Child mental health practitioner | CAP and SALT | CP and SALT | CAP and CP | CAP, CP, and SALT |
|---|---|---|---|---|---|---|---|---|
| | 8 | 3 | 2 | 1 | 1 | 1 | 3 | 1 |

Nineteen parents felt they were definitely listened to carefully, with the final patient choosing yes to some extent. Additionally, 18 parents felt they were able to discuss their concerns and give feedback at the time of assessment, and 80% felt the assessment could not have been communicated differently. The family who needed an interpreter reported that the information they were provided with before the appointment was very poor, although they believed the actual process was good.

Notably, 85% of parents would have liked a letter with a plan for further assessment and appointment dates. Most parents had received a report which 65% claimed to definitely understand, with 20% understanding to some extent. Parents would have liked less medical terminology in the reports. Eighteen parents had the opportunity to give feedback at the time of the assessment. However, 59% stated they either did not have any say or only to some extent. All of the parents said they were able to ask questions at following meetings.

With regards to the postdiagnostic workshops, 8 parents received information regarding the aims. When parents are invited to attend the sessions, written information about the course is also sent with the letter. However, the 8 who did not answer may not have been invited.
Every respondent was happy with the assessment process, with 60% reporting it to be very good, 100% of parents said they were definitely treated with trust and dignity. After the assessment, 100% of patients were happy with the level of information they had regarding the process. Although 18 parents received additional information in some form, 6 felt they had not received enough information about the condition and future interventions. With regards to the post-diagnostic workshops, only 15 parents said they were invited to attend. The reasons for this were not explored, although one patient did report moving house. When asked why they were unable to attend, Childcare was a key theme as was timing. Looking at the time interval from referral to diagnosis, great variance was apparent (Figure 2). The average time was 46 weeks with only 6 diagnoses reported in the recommended time frame of 17 weeks.

5. Discussion

One weakness was size, although sampling the past 18 months allowed the collection to be achieved within the allocated timescale. If the study was increased to the past 3 years, the results may show a more significant trend, although parents might find the process harder to recall.

Table 4: Relationship with the professional performing the assessment.

| Question                                                                 | Yes definitely | Yes to some extent | No |
|-------------------------------------------------------------------------|----------------|--------------------|----|
| Did the professional listen carefully to you?                           | 19             | 1                  | 0  |
| Did you have trust and confidence in the professional you saw?          | 15             | 5                  | 0  |
| Were you treated with trust and dignity?                                | 20             | 0                  | 0  |
| Were you given enough time to discuss your concerns about your child?   | 18             | 2                  | 0  |
| Could the communication have been done differently?                     | No             | 16                 | 3  |
| At the end of the assessment did you have enough information regarding the process? | Yes            | 17                 | 3  |
| How was the assessment outcome communicated?                            | Verbal only    | 3                  |    |
| Could the assessment have been communicated differently?               | No             | 15                 | 3  |
| Were you able to discuss the report at the next appointment?            | Yes definitely | 12                 | 5  |
| Did you understand the report?                                          | Yes            | 13                 | 4  |
| Did you have a say in what the report should contain?                   | Yes definitely | 7                  | 5  |
| Were you given a chance to ask questions either in the feedback or following meeting? | Yes            | 15                 | 2  |

Of note, the child with the shortest timeframe from referral to diagnosis was the least satisfied, while the longest timeframe elicited the highest satisfaction score. The results show 2 peaks, with satisfaction higher at the times of school transition (3–5 and 10–12 year olds).
Table 7: Additional information.

| Did you receive additional information regarding your child’s condition at the end of the assessment? | Yes verbally | Yes the written report | Information from early support | NAS leaflets | Multiagency partnership (MAP) leaflets | Not answered | Verbally and written report | Verbally and NAS leaflets | NAS and MAP leaflets | Verbally, NAS and MAP leaflets | Verbally, information from early support, and NAS and MAP leaflets | Verbally, the written report, and NAS and MAP leaflets | Verbally, the written report, early support, and NAS and MAP leaflets |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2 | 1 | 1 | 1 | 0 | 2 | 1 | 2 | 4 | 2 | 1 | | |

| If MAP was recommended to you, were you happy for your child to be referred? | Yes definitely | Yes to some extent | No | Not answered |
|---|---|---|---|---|
| | 14 | 0 | 3 | 3 |

| Did you receive enough information about the condition itself and future interventions? | Yes | No | Not answered |
|---|---|---|---|
| | 14 | 6 | |

| Were you given the opportunity to watch a video about the condition following diagnosis? | Yes | No | Not answered |
|---|---|---|---|
| | 4 | 15 | 1 |

One solution might be administering the questionnaire as a standard part of clinical practice.

Parents wanted more information regarding diagnosis and management. A longer follow-up appointment after diagnostic feedback could allow needs to be individually assessed. During this appointment, professionals could discuss the purpose of the postdiagnostic workshops. The information provided during these workshops is obviously most beneficial when attending the group sessions, as they are interactive and parents have the opportunity to share experiences and strategies. However, if all parents received the written information provided within these sessions, it would be helpful to those who could not attend. As childcare and timing were the commonest reasons for nonattendance, this could be addressed by combining all 5 sessions into 2 days within school hours.

Written communication could be enhanced by a standardised response letter from the SCAIT team. This could include the role of SCAIT, the purpose of the assessment, the appointment time, the assessment structure and timescale, the name and profession of all clinicians, and possible question areas. This should help ease parent’s anxiety and ensure that scarce appointments achieve maximum benefit. Finally, the assessment report needs to be clear and concise. The initial page should contain a standardised format with the outcome clearly stated, the individuals and professional roles of those involved, and the date of the diagnosis.

Although, most parents were happy with the assessment service, satisfaction could be increased by providing more information about the assessment as well as the condition. It is important to actively involve parents in the sessions, allowing them to build a trusting relationship with the health professionals involved as children may need support from
Table 8: Postdiagnostic workshops.

| Question                                                                 | Yes | No  | Not answered |
|-------------------------------------------------------------------------|-----|-----|--------------|
| After diagnosis were you invited to attend the Autism Workshops?        |     |     | 2            |
| Yes                                                                     | 15  |     |              |
| No                                                                      | 3   |     |              |
| Were you able to attend the sessions?                                   |     |     | 5            |
| Yes                                                                     | 8   |     |              |
| No                                                                      | 7   |     |              |
| If you were unable to attend, which reason best applies to you?         |     |     |              |
| Inconvenient location                                                   | 3   |     |              |
| Inconvenient time                                                       | 1   |     |              |
| No transport                                                            | 0   |     |              |
| No childcare                                                            | 3   |     |              |
| Other                                                                   | 3   |     |              |
| Inconvenient location, no transport or childcare                        | 1   |     |              |
| Not answered                                                            | 9   |     |              |
| Were you given any information regarding the aims of the course?        |     |     | 8            |
| Yes                                                                     | 10  |     |              |
| No                                                                      | 2   |     |              |
| Not answered                                                            |     |     |              |
| Did the aims of the course appeal to you?                               |     |     |              |
| Yes                                                                     | 9   |     |              |
| No                                                                      | 2   |     |              |
| Not answered                                                            | 8   |     |              |
| Was the course useful?                                                 |     |     | 10           |
| Yes                                                                     | 8   |     |              |
| No                                                                      | 2   |     |              |
| Not answered                                                            |     |     |              |
| Did the course cover what you wanted to know?                           |     |     | 11           |
| Yes                                                                     | 9   |     |              |
| No                                                                      | 0   |     |              |
| Not answered                                                            | 11  |     |              |
| Would you recommend the course to other parents/carers?                 |     |     |              |
| Yes                                                                     | 9   |     |              |
| No                                                                      | 0   |     |              |
| Not answered                                                            | 11  |     |              |

...the team for many years. Giving each family the time to discuss their concerns will also help tailor individual needs and further increase parental satisfaction. The fact that parents are considerably more likely to have a second child with ASDs emphasises the importance of engaging families.

The study was fed back to SCAIT, and standardized letters and workshop information sheets have already been implemented. Furthermore, the team will complete the audit loop by undertaking the audit again in 18 months time. This study has provided a key opportunity to offer a value-added service with service-user feedback.

References

[1] M. D. Inglese, “Caring for children with autism spectrum disorder, part II: screening, diagnosis, and management,” *Journal of Pediatric Nursing*, vol. 24, no. 1, pp. 49–59, 2009.
[2] NICE Autism spectrum disorders in children and young people: final scope, 2010 http://www.nice.org.uk/nicemedia/live/11826/45433/45433.pdf.
[3] National Initiative for Autism: Screening and Assessment, *National Autism Plan for Children (NAPC): Plan for the Identification, Assessment, Diagnosis and Access to Early Interventions for Pre-School and Primary School Aged Children with Autism Spectrum Disorders (ASD)*, The National Autistic Society for NIASA, London, UK, 2005.
[4] A. Raznahan and P. Bolton, “Autism spectrum disorder in childhood,” *Medicine*, vol. 36, no. 9, pp. 489–492, 2008.
[5] L. Hackett, S. Shaikh, and L. Theodosiou, “Parental perceptions of the assessment of autistic spectrum disorders in a tier three service,” *Child and Adolescent Mental Health*, vol. 14, no. 3, pp. 127–132, 2009.
[6] Diagnosis of autism spectrum disorders—a guide for health professionals—NAS, 2010 http://www.autism.org.uk/working-with/health/screening-and-diagnosis/diagnosis-of-autism-spectrum-disorders-a-guide-for-health-professionals.aspx.
[7] P. A. Filipke, P. J. Accardo, S. Ashwal et al., “Practice parameter: screening and diagnosis of autism. Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society,” *Neurology*, vol. 55, no. 4, pp. 468–479, 2000.