

IMPROVING DIAGNOSTIC AND ASSESSMENT SERVICES FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

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Summary

Various studies have highlighted parental dissatisfaction with the diagnostic and assessment services available for children with autistic spectrum disorders. In N. Ireland these appear to be poorly developed compared to other regions of the United Kingdom.

A consultative research project was undertaken with the main stakeholders, namely parents, professionals working in education, health and social services, representatives from provider Education Boards and HSS Trusts and commissioners of health and social services.

Focus groups involving nearly 100 parents and professionals were held throughout the province along with written questionnaires that were completed by over 100 service personnel. The emerging consensus was validated through an iterative process of meetings and comments on draft documents produced by a selected reference group.

Ten principles underpinning assessment services were identified and recommendations developed for improvements to services. Particular attention focused on the provision of local services; developing staff skills, the form of home-based supports and the nature and role of specialised services.

Introduction

Autistic spectrum disorders are estimated to affect between 5 and 11 children per 10,000 (depending on the inclusion criteria used) with indications that the incidence is rising (Gillberg, 1995). The main diagnostic indicators are based around the triad of impairments proposed by Wing (1979); namely deficits in social relationships, communication and imagination, and typified by an onset before 30 months of age. A consensus has also emerged for a continuum of disorders (Wing, 1988; Happe, 1994); at one extreme children present with very low levels of ability while at the other, individuals may have exceptionally high levels of intellectual functioning. These disorders are included in both ICD-10 (WHO, 1992) and DSM-IV (APA, 1994).

Delays in obtaining a diagnosis are a particular source of distress for parents (Quine and Pahl, 1987; Howlin and Moore, 1997). Siegel et al (1988) reported that parents most often expressed their initial concerns to paediatricians, noting delays in language and social behaviour by the age of eighteen months. By age 2.5 years, most parents had sought a diagnostic evaluation but their child was aged 4.5 years on average before they received a diagnosis of Autistic Spectrum Disorder.

In the United Kingdom, children appear to be older before a diagnosis is made. Frith and Soares (1993) found that 76 percent of parents had received a diagnosis by the time the child was 5 years old. However a more recent study by Howlin and Moore (1997) involving nearly 1300 members of the National Autistic Society,

reported that only 53 percent of their children had been diagnosed by this age. Moreover, there were wide regional variations in diagnosis; families in Scotland, Cumbria and Belfast were more likely to receive later diagnosis than their peers in the rest of the United Kingdom.

Christie (1998) in pressing for an earlier diagnosis of these disorders argued that *'to deny parents access to that diagnosis is to deny them a complete understanding of their child's needs and to restrict their access to information and support'* (p.8). Fraser and Levine (1995) reported that a majority of parents felt relief on confirmation of a diagnosis and they urged professionals to refer parents to appropriate resources.

Nonetheless, the difficulties in arriving at a diagnosis are well documented. Shea and Mesibov (1985) reported that classical cases of autism are greatly outnumbered by cases with mixed, impure and partial characteristics. Happe (1994) noted that it is easier to recognise individuals at the mid-point of the spectrum rather than those at the lower end where the child's level of functioning is so poor that social, communicative and imaginative functioning is in line with general developmental functioning. At the upper end of the spectrum, people may have developed coping strategies that disguise their real problems.

Screening and diagnostic tools for use with children under three years are still in the development stage (Votanis et al, 1994). Also reservations have been expressed about the efficacy of primary care services being able to reliably detect

such children given the low numbers they are likely to have in their case loads (Peter, 1993).

The value of multidisciplinary working in making a diagnosis is also well attested in the literature, particularly paediatrics, psychology, psychiatry and speech and language therapy (Ellis, 1994). However existing systems often do not allow for this; split as they are between education and health services; with the latter further located in hospital and community settings. Parents often complain of the lack of co-ordination and communication among these agencies and professionals (Stallard and Lenton, 1992; Beresford, 1995).

It was against this background that the present study was instigated by PAPA (Parents and Professionals and Autism); the main parent support group in N. Ireland. The aim was to identify the current range of diagnostic facilities provided for people with autistic spectrum disorders in N. Ireland and to develop proposals for more effective and responsive diagnostic and assessment services. Support was obtained from the DHSS (NI); the four Health and Social Service Boards as well as a number of provider Health and Social Service Trusts.

The study aimed to document the experiences of the main stake-holders (parents and professionals) and to synthesise these and their suggestions for improvements into a set of principles and recommendations which would command widespread support. The data collection and methods were essentially qualitative and consultative. N. Ireland's size (1.5 million) made this a feasible

endeavour. Both the process used and results obtained could prove relevant to other regions in Britain and Ireland.

Method

The research took place in two main stages. The first stage aimed to identify the key attributes of diagnostic and assessment services for children with autistic spectrum disorders and to map the nature of existing services in N. Ireland. The improvements that service providers perceived as being needed were also documented at this stage.

Stage 1: Five components were included.

1. A review of the literature identified experience in UK and North America; primarily based around parental reports.
2. Four focus groups were held throughout N. Ireland with 34 parents who were members of PAPA. This provided an opportunity to hear parental experiences of existing diagnostic services and their suggestions for improvements. It would also confirm or qualify issues that had arisen from the literature.
3. Written questionnaires were sent to nominated persons in each Health and Social Services Board (purchasers of services); the five Education and Library Boards (responsible for statementing and meeting children's special educational needs) and eleven Health and Social Services Trusts who provide services to families and children. The questionnaire was designed to obtain a written account of the current diagnostic services in their geographical area and in particular the generic and specialist provision for the diagnosis of

autistic spectrum disorders. Replies were received from 15 of the 21 agencies approached (72%).

4. A second written questionnaire was sent to 100 professionals throughout N. Ireland who were thought to have an involvement (directly or indirectly) in the provision of diagnostic services for people with autistic spectrum disorders. They were drawn from health, social and educational services. The questions covered the assessment tools and procedures used, inter-disciplinary working, communication with parents, follow-up activities and implications for the training of professional staff. Replies were received from 44 persons (44% response) including community medical officers and paediatricians (N=8); teachers (N=8); health visitors and community learning disability nurses (N=8); occupational therapists and speech and language therapists (N=8) clinical psychologists (N=5) and consultant psychiatrists (N=3). It is likely that these respondents had more involvement with diagnostic services than did non-respondents.
5. Information was obtained from visits or through questionnaires of specialist diagnostic services for this client group in seven N. Irish locations and one in London.

From this information, the research team, assisted by the project steering group identified the principles that should underpin the provision of any diagnostic and assessment service as well as generating models for how these would be delivered in N. Ireland. The second stage consisted of a validating these conclusions.

Stage 2: The validation was performed in two ways.

1. Four consultation/information sessions were held throughout N. Ireland with 24 invited parents and 34 professionals drawn from health (doctors, nurses and therapist N=18), education (psychologists, school principals and teachers: N=13) and social services (Assistant Director of Children's Services and social workers: N=3). Each meeting was chaired by a member of the Steering group and small group discussions were used to explore the key issues for improving diagnostic services.
2. A written summary of the principles and proposals emerging from Stage 1 and the above consultations was then sent to the 67 respondents to previous questionnaires for their confirmation and comments. This group included professionals involved in service planning and delivery education as well as those working directly in diagnostic services. Replies were received from 69% of respondents.

Fuller details of the methodologies used are provided in Moore et al (1999).

Results

Four themes dominated in the data obtained from this study.

Perceptions of present diagnostic provision.

Overall in N. Ireland there are great variations in the services provided to families.

In some localities, quite sophisticated and specialist diagnostic services are available for autistic spectrum disorders while in other localities diagnostic

services in general are poorly developed.

In particular, many respondents reported that one of the key problems they had experienced was the lack of information about diagnosis and referral routes. Some parents, health visitors and general practitioners, for example stated that they had witnessed confusion amongst professionals about who was involved in, and responsible for the formulation and delivery of the diagnostic and assessment process. Others noted that this lack of information extended to confusion about the provision of follow-up support services. Indeed the failure to provide adequate follow-up after diagnosis was a major area of concern.

Parents also felt that many professionals appeared to be reluctant to take responsibility for making a diagnosis and this was evident too in comments from professionals. For example some stated that providing a diagnosis in the absence of inter-professional support was “a traumatic experience” . A number of general practitioners, health visitors and speech and language therapists expressed a lack of confidence in their attempts to formulate a differential diagnosis.

One of the main reasons given for the lack of experience in the diagnosis of more complex conditions (and presenting symptoms) was the lack of exposure to diagnostic techniques during initial professional training. In order to compensate for this, many professionals noted that they had to train themselves to become more aware of the process and to familiarise themselves with the assessment

tools required to inform a diagnosis. However when asked to describe the instruments used in the diagnostic process, 40 different developmental assessments and psychometric tests were noted by 44 respondents. This included ten different scales relating to autism, the most popular of which was the Childhood Autism Rating Scale (Scholper, Reichler & Renner, 1988) but even this was only used by six of the 44 respondents.

Another key issue reported by each group of respondents was the lack of a co-ordinated multi-professional approach to diagnosis. Parents advised that they had received conflicting advice from different professionals. For instance:

“Our entire diagnostic procedure was very traumatic and often despairing due to the lack of communication and support from the Child Development Centre and their inability to diagnose his condition and provide adequate therapy, intervention and support.”

However other parents noted that the quality of their diagnostic experience had been enhanced through attendance at co-ordinated child development and specialist assessment clinics in the Province.

Diagnosis for my son was made by a senior Clinical Medical Officer, a Behavioural psychologist and a Speech and Language Therapist when he was four and half years old. (It) involved a day-long series of tests and detailed information from myself and my husband. We were invited to a ‘feedback’ with the above people present and were asked what we thought was wrong with our son and then we were told he had autism. We were glad that P. had a diagnosis.

Evidence was also provided with regard to a number of significant referrals that had been made to consultant psychiatrists in learning disability. Such referrals related to adolescents and adults with Autistic Spectrum Disorder who had not been appropriately screened or diagnosed for the condition in childhood.

Finally, the importance of sharing the outcome of the diagnosis with members of the inter-professional care/education team was emphasised. Several professionals (e.g. health visitors and family doctors) advised that they were not always informed of the outcome of a diagnosis thus leaving the onus with parents to advise others of the outcome. Both parents and professionals agreed that detailed, written reports should be provided and disseminated.

In sum, the need to invest in appropriately co-ordinated, child focused, inter-professional diagnostic services had the unanimous support of respondents.

More specifically respondents recommended that such services:

- Should be provided locally and integrated as core components of community based paediatric services in each Community HSS Trust.
- They would be enhanced through the provision of responsive pre-school services (with an involvement from educational psychologists) and provide access routes for diagnostic services and follow up support.
- They should aim to foster effective liaison between health and social service agencies and schools.
- They should encourage effective liaison between parents and professionals.

The nature of home-based support – post diagnosis.

The majority of professionals and parents felt that diagnosis should not be 'set in concrete' but should be regarded as a dynamic process leading to further reassessment. However it was not uncommon for diagnosis to be provided 'in a vacuum', with no structured advice and follow-up support.

By far the greatest difficulty reported was the overall lack of provision of responsive therapeutic intervention programmes for these children. The perceived stress that this caused parents and professionals (some of whom were often reported to be singularly attempting to co-ordinate services) was further compounded by inter-professional conflict that had been witnessed between some diagnosticians as to favoured approaches.

On a more positive note, parents and professionals reported that excellent care packages have been provided in some areas of the Province. This was particularly evident where the support of a pre-school teacher was available, supported by co-ordinated specialist care and therapeutic responses from health and social care professionals.

Parents and professionals agreed that resultant care plans should be formulated jointly following discussion and negotiation with all key stake holders (thus reducing any perceived bias of uni-agency or professional ownership).

Respondents also advised on the need to allocate named key workers to co-

ordinate care for individuals presenting with complex needs. They suggested that such plans could be extended to form life plans to assist in planning for the transition from childhood through adolescence to adulthood.

Finally, it was acknowledged that child development centres had an important role to play in the provision of longer-term support for children.

Staff skills and competence in Autistic Spectrum Disorders

All respondents emphasised the need for training to enhance competence in the assessment and diagnostic process for both parents and professionals. In particular, primary care staff (such as health visitors, general practitioners, nursery and primary teachers) need awareness training in early detection and referral routes. Such training should be particularly helpful in raising awareness of conditions that may later lead to a confirmed diagnosis.

Information leaflets should also be provided and disseminated through primary care staff outlining how to obtain support, access provision and identify the key issues involved in the diagnostic process.

There was general support for the principle that training is central to the delivery of effective assessment and diagnostic services for this client group and their families. Hence a key feature of any specialist resource should be a commitment to share their skills and expertise in a systematic and regular way with local practitioners. Moreover, inter-professional training should be provided on a

shared learning basis between the health, social and education sectors. The importance of learning and training alongside families was also identified as a prerequisite to effective skill acquisition.

The nature and role of specialised diagnostic services

Throughout Britain and Ireland, various specialised diagnostic services have been established for this client group and a number of parent and professional respondents were enthusiastic about them. However respondents saw these as the third level of a continuum of assessment services:

Level 1: Generic screening, assessment, diagnostic and treatment services provided for children within the context of paediatric child development centres in community settings..

Level 2: Generic services provided for children and adults with atypical presentations. This would include genetic clinics, disability teams and child psychiatric services.

Level 3: Specialist services focusing explicitly on the provision of diagnostic assessment and follow-up treatment for people with suspected but difficult to diagnose Autistic Spectrum Disorders.

Each of the three categories of diagnostic services have a part in the provision of a co-ordinated and responsive diagnostic service. The respondents in this study

felt that the aim should be to enhance confidence and competence within all three categories but that specific emphasis and focus needs to be placed on child development centres and primary health care teams. Local services, provided by educational, health and social service staff, have obvious advantages in fostering close links with individuals and their carers and they are the most viable means of providing ongoing follow-up support.

However the effectiveness of generic services at Levels 1 and 2 would be enhanced through the provision of advice and training and for this, third level services specialising in autistic spectrum disorder are needed. In particular, the service(s) would provide:

- a body of expertise and specialist knowledge in autism for Northern Ireland;
- a second opinion in difficult to diagnose cases
- a treatment plan for difficult to manage cases
- specialist access for education and training of parents and professionals as an outreach activity.

However greater clarity needs to be introduced within the present system to ensure that specialist services complement rather than replace the provision that needs to be made at Levels 1 and 2.

Some respondents were concerned that the resource implications of providing specialist services in a relatively small geographical area will militate against their realisation as will the lack of any immediately identified agency to take

responsibility for its provision. Nonetheless 90% of our respondents supported the need for some form of specialist service within N. Ireland.

One possible way forward was the creation of a 'virtual' multi-disciplinary service made up of specialists in autistic spectrum disorders drawn from Level 2 services throughout N. Ireland. They would be seconded part-time from their employing agencies to fulfill the designated functions of the service as well as receiving further specialist training in this area. This model would reinforce the necessary linkages among the three levels while providing for a cascade of specialist training to parents and professionals at a local level.

All these recommendations were brought together into a set of ten principles which our respondents endorsed as underpinning the development of diagnostic and support services for people with autistic spectrum disorders. These are listed in the Appendix.

Discussion

This study has focused on the needs of a particular subgroup of children and identified various ways in which their needs and those of their families could be better met. Care was taken to ensure that these proposals had the support of all the main stake-holders although no claim could be made as to the representativeness of their views nor was any attempt made to assess the efficiency or effectiveness of existing services.

However the proposals which emerged from the study cannot stand alone from the wider services that are available provided for children and families. It was beyond the scope of this research to determine if the outcomes would be as applicable to children presenting with other developmental disabilities such as cerebral palsy and ADHD. Yet it is likely that the principles formulated for this client group would have wider applicability and that some of the suggested improvements to diagnostic services could be equally applicable (Beresford, 1995).

If that were so, then the debate becomes one as to how specialisms can best operate within generic child and family services. Failure to address this issue, runs the risk that the particular skills and expertise required to identify and intervene with specific disorders will not be nurtured. This debate is central to the evolution of 'best value' services and to a large extent revolves around the training and development of staff. This will necessitate change at both initial and post-qualifying training to better equip professionals to take on both generic and specialist roles (Leathard, 1994).

A related issue is how best to nurture new advances in specialist areas through research and the evaluation of innovative practices. This too was beyond the remit of the present project and it is debatable whether a region as small as N. Ireland could sustain viable research and development programmes in a range of specialisms. The favoured solution of creating national and international networks of research-practitioners has yet to become a reality although the advent

of new communications technology, such as tele-medicine, does offer hope in this regard.

Finally, an emphasis on assessment and diagnosis must not detract from the ongoing provision of appropriate and effective interventions to ameliorate the disabling effects of these disorders and to support families in their caring role. Therein lies arguably the greatest challenge to our existing educational, health and social services. This will require significant training (and retraining) of personnel and creative reconfiguring of service systems.

(3,568 words)

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Appendix 1:

Proposed Principles for the Development of Diagnostic and Support Services for People with Autistic Spectrum Disorders.

1. Individuals who are diagnosed with an Autistic Spectrum Disorder need to be valued as Individuals first and all services must aim to address their general needs as well as their specialist needs.
2. Individuals have the right to access a range of suitably qualified staff close to their home. The goal of services is to enable individuals and their families/carers to lead a life that is as normal and inclusive as possible and as such should aim to minimise their social exclusion and disability.
3. Local professionals and carers working with all individuals who have Autistic Spectrum Disorders should have access to appropriate specialist training and education.
4. Families should remain fully involved in the planning and delivery of both diagnostic and treatment services. In so doing they have the right to receive a confirmed diagnosis of Autistic Spectrum Disorder if/when it is made. Diagnosis should be combined with the provision of co-ordinated multi-agency support for families as part of an ongoing life-stage process, and not as 'an end in itself'.
5. The diagnosis of Autistic Spectrum Disorder and its associated support process should commence as early in the individual's life as possible to sustain the families' adaptation to the outcome of the diagnosis and to maximise and enhance the child's developmental potential.
6. A detailed multi-disciplinary assessment of the individual person with Autistic Spectrum Disorder and his/her family should accompany the diagnosis. Assessments should be systematically and regularly reviewed and updated. Service deficiencies should be identified. A comprehensive inter-professional assessment (and accompanying treatment programme) should be ongoing and formally reviewed and updated at various stages throughout the person's life.

7. Collaboration among and between the statutory and non-statutory services should (where appropriate) be integral to the development of diagnostic and support services. It should reflect a partnership based on the principle of mutual respect and be responsive to the diverse needs of service users.
8. The diagnosis of Autistic Spectrum Disorder presents considerable challenges to professionals. As Autistic Spectrum Disorder is a relatively new diagnostic category there remains much work to be undertaken to complete our understanding of the concept. Arrangements for the diagnosis of Autistic Spectrum Disorder, and effective planning of provision must ensure that structures are in place to involve various professionals in service delivery and needs assessment.
9. All therapeutic interventions for people with Autistic Spectrum Disorder (and their carers) should be based on the principle of evidence-based practice and systematic enquiry. As such, mechanisms need to be co-ordinated and implemented to share and disseminate advances in new knowledge to all carers and professionals.
10. All treatment services for people with Autistic Spectrum Disorder and their carers should be systematically evaluated. Local generic and specialist services should monitor outcomes and the effectiveness of service delivery through inter-professional audit and quality assurance procedures.