An Evaluation of the Need and Early Intervention Support for Children (Aged 2-4 Years) with an Autistic Spectrum Disorder in Northern Ireland

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RESEARCH REPORT

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Acknowledgements

Executive Summary

In Northern Ireland as well as internationally the incidence of preschool children diagnosed with an Autistic Spectrum Disorder[2] (ASD) is increasing. The response to this has been variable across Education and Library Boards (ELBs) and also among Health and Social Services (HSS) Trusts.

The following aims were defined for the study by the Department of Education (NI):

1. To identify the level of need for early intervention across Northern Ireland of children under five years of age who have a confirmed diagnosis of ASD.
2. To identify means for effective and consistent provision across the five Education and Library Boards.
3. Provide a literature review of best early intervention practices to inform effective service planning.
4. Make recommendations to ensure parents of children with autism receive support tailored to individual needs and circumstances from the point of concern about the child through diagnosis and until school entry.
5. Identify indicators of best practice and policy guidance so as to guide improvements in early years education for this group of children over the next ten years. This should inform the strategic planning of the Department of Education (DofE) and the Department of Health, Social Services and Public Safety (DHSSPS).

The first section of this report provides an introduction to the project.

Section 2 presents a review of extant policy and guidance in relation to preschool children with ASD within Northern Ireland. Other than the Report of the Task Group on Autism (2002) which emanated from the Department of Education, there appear to be few comprehensive statements of policy from statutory services on children with ASD and their families.

The third section is a summary of recent literature in this area. Internationally there has been a marked increase in the number of research studies undertaken in the field of ASD in the early years. The focus has been largely on identification, assessment and diagnosis although more evaluations of interventions are appearing, especially of behavioural approaches. There is also an emerging consensus on responses that are required to meet the needs of the children and their parents' aspirations. These are detailed in two main sections: assessment and interventions.

Section 4 summarises present service provision as reported by nominated informants in the five ELBs and the eleven Community HSS Trusts. However it will not be possible to give an accurate count of the number of preschool children with ASD in Northern Ireland until there is equity in the availability of diagnostic services; with common criteria used in identifying ASD and a standard dataset maintained across the region. That said the numbers of preschool children with any form of ASD is probably in the region of 300 and those with an autistic disorder (i.e. meeting stricter diagnostic criteria) may be around 100. This equates to around 100 babies born in Northern Ireland who will later have a diagnosis of ASD.

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[2] There is growing use internationally of the term 'Autism Spectrum Disorder'. Definitions of this condition are given on pages 57 and 58.

A wealth of information was garnered about the range of services and supports that are available to preschool children and to their families. This provides a baseline against which further developments can be monitored. However there is strong impression of marked variation across Boards and Trusts which is to the obvious disadvantage of families in areas with less well-developed services.

Section 5 summarises the information collected from parents and professionals. Interviews and focus groups were held with over 100 parents.

- Parents are aware of the child's difficulties by their second birthday yet they may wait a considerable time before a diagnosis is made; in some areas up to two years. Both parents and professionals find this unacceptable and it is against best practice internationally. Moreover families require information and support during this time especially on promoting communication, play and social relationships. Around half encounter behaviour management problems.

- Health visitors and GPs are the professionals parents are most likely to contact when they suspect a problem.

- Present assessment procedures are generally well received by families.

- Community paediatricians and speech & language therapists are the two professions that families have most contact with. However in the course of a year, families may have contact with 5-6 different professionals.

- Home based interventions were welcomed by families for the support it gave parents, the information conveyed on ASD and the focus on communication.

Three themes emerged from the questionnaire responses from HSS professionals.

- The need for improved diagnostic and assessment services to reduce waiting times;

- Better support for families from when the problem is recognised.

- The need for multi-disciplinary and inter-agency working.

Early years education personnel already have an involvement with preschool children with ASD and appear willing for this to be extended. The need for training was highlighted and the success of new courses directed at preschool personnel has been noted. Likewise, support from knowledgeable professionals was also required.

Section 6 reports the findings from a consensus study into the extent of agreement on recommendations for good practice and service standards with preschool children and their families. These were derived from experiences of parents and professionals within Northern Ireland but many echo recommendations internationally. Although some of these recommendations could be incorporated into better professional practice, many require a more strategic push for them to become a reality throughout Northern Ireland alongside an increase in resources to meet the new demands.

Hence the final section of the report outlines the core elements of a strategy for taking forward the work begun by this project. The over-riding priority is to create structures and systems that will encourage partnership working while strengthening local initiatives. Fortunately in Northern Ireland there is growing expertise, experience and willingness in making this a reality. There never has been a better time to embark on developing a regional strategy for ASD in the early years.

Section 1: Introduction

In many affluent countries there has been a reported increase in the numbers of children – boys especially – being diagnosed with autistic spectrum disorders (ASD). Debate continues as to whether or not this represents a real rise in these conditions or if it results from better identification and earlier diagnosis (Fombonne, 2005). Nonetheless this means many more families are affected and they often feel at a loss to know how best to help their child.

International experience suggests that positive changes are possible with early identification followed by consistent intervention that involves the parents and provides direct teaching of essential skills with the child. However controversy continues over the particular methods that are best suited to the needs of the children and their families. Even so, there is broad agreement on the intervention strategy that is required (Jordan, 1997):

- Recognising and identifying the child's problems from an early age – 18 months onwards.

- Developing an individual education plan to address the child's particular difficulties and needs

- Training families on teaching programmes which they can use with their child at home.

- Supporting families with the extra stresses they experience.

- Encouraging the social inclusion of the child in family and community life such as preschool facilities.

In many countries - Northern Ireland included - Health, Education and Social Services have been slow to implement these elements of good practice. In part this is due to a lack of financial resources but more crucial has been a lack of necessary expertise among service staff and effective inter-agency and inter-disciplinary working. Nonetheless there is an increased commitment to improving service provision from the Department of Education (Task Group Report, 2002) and from Health and Social Services (as per the paper on autism prepared by the four HSS Boards in 2004).

This provided the backdrop for the present study. Although the Department of Education (NI) commissioned it, the study was undertaken with the full knowledge and co-operation of the Department of Health, Social Services and Public Safety (DHSSPS). A Steering Group was appointed to advise and guide the work of the project (see Appendix 1).

Project aims

The following aims were defined for the study by the Department of Education (NI):

1. To identify the level of need for early intervention across Northern Ireland of children under five years of age who have a confirmed diagnosis of ASD.

2. To identify means for effective and consistent provision across the five Education and Library Boards.

3. Provide a literature review of best early intervention practices to inform effective service planning.

4. Make recommendations to ensure parents of children with autism receive support tailored to individual needs and circumstances from the point of concern about the child through diagnosis and until entry to nursery or primary schools.

5. Identify indicators of best practice and policy guidance so as to guide improvements in early years education for this group of children over the next ten years.   This should inform the strategic planning of the Department of Education and the DHSSPS.

Sources of Information

The Figure summarises the sources of information which were accessed during the study in order to fulfil the aims.
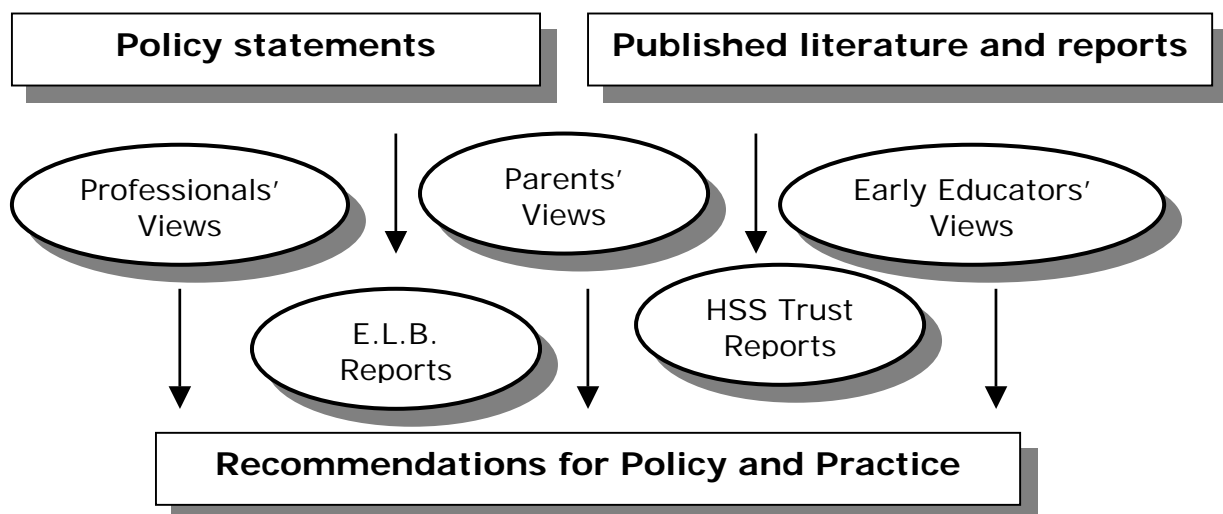
The information obtained from these different sources are summarised in the following sections.

Section 2 presents a review of policy and guidance in relation to preschool children with ASD within Northern Ireland while Section 3 is a summary of recent literature.

The fourth section summarises present service provision as reported by nominated informants in the 5 Education and Library Boards and in 11 Community HSS Trusts. Information was also obtained from questionnaires distributed to professionals and from telephone interviews and focus groups with parents.

Section 5 reports the views of various stake-holders to present provision and their recommendations for improvements.

Section 6 reports the findings from a consensus study into the extent of agreement on recommendations for good practice and service standards with preschool children and their families.

The report ends by proposing the core elements of a strategy for taking forward the work begun by this project.

Section 2: Review of Policy and Guidance

This section attempts to answer the question: "What level of strategic and operational service guidelines are in place at present for ASD in Northern Ireland and more particularly for preschool children and their families?"

Following consultation with the Steering Group, in July 2005 a letter was sent to all statutory and voluntary agencies in Northern Ireland known to have an interest in ASD in the early years (see Table 2.1).   This requested copies of any policy and guidance documents they had prepared covering ASD and preschool children in particular. (NB Please note that when the word "policy" is used it was inclusive of operational/practice/strategic documents).   Table 2.1 summarises the responses received. (NB Copies of all documents are stored with the project team.)

Table 2.1 Policy and Guidance Documents on ASD in Northern Ireland

Agency	Documents Received
1. Education	
Department of Education	Task Group on Autism Report 2002 with a chapter devoted to early intervention. ASD Guidelines for Schools 2005
Belfast ELB	Guidelines and Referral form to access ASD service ASD Service: ASD Policy Document and ASD Child Protection Policy
North East ELB	Only general policies with ASD references
South East ELB	ASD (Service Description)
Southern ELB	None available
Western ELB	None available (Special Education policies only – no reference to ASD)
2. Health and Social Services	
DHSSPS	None. Review of Mental Health and Learning Disability is pending (2005/06)
Eastern HSSB	Four Board Paper (Response to Priorities for Action DHSSPS) 2003/04
Western HSSB	WH&SSB Strategy for Autism – consultation to commence shortly
Northern HSSB	None available
Southern HSSB	1. Evaluation of New Autism Services in the SHSSB Area (Apr 2004) 2. SHSSB Strategy for Children with ASD (2005) (Nov 2005)
Armagh & Dungannon HSST	None available - Undertaking review of ASD services at present
Causeway HSST	ASD Diagnostic Service:- Operational Procedure and Service Leaflet
Craigavon & Banbridge HSST	No reply
Down Lisburn HSST	None available
Foyle HSST	No reply
Homefirst HSST	Operational Procedure Autism Assessment and Diagnostic Service – review due to take place between Jan and Mar
Newry & Mourne HSST	None available

N&W Belfast HSST	Operational Policy (ASD School Age Clinic) ASD (CDC Clinic): Social Work Remit and Referred protocol. OT Service Statement regarding ASD and Referred Policy for Children with ASD
South & East Belfast HSST	No reply
Sperrin Lakeland HSST	None available
Ulster Community &Hospital Trust	None available
3. Voluntary Organisations	
Autism Initiatives	None available - plans to develop Early Intervention programme
Autism NI (PAPA)	Service principles and guidelines e.g. - NI Diagnostic Scoping Study - Keyhole Research - Position Statements – "Therapies and Interventions" and "Assessment and Diagnosis" - Connecting with Autism (CWA)
Barnardos	No reply
Centre for Early Autism Treatment	Policy Statement provided
Eagle Project (BCM)	No reply
MENCAP	No reply
National Autistic Society (NAS)	Position Statement: Therapies and Interventions (ASD) Useful References
NI Preschool Play-groups Association	None available
PEAT	No reply
Playboard NI	No reply
Positive Futures	No reply
Sure Start	None available – general policies only

Summary of conclusions

Although the various documents contain much useful information and good practice, the following conclusions are noted:

Education Sector

There is no consistency across ELBs.

- There is an absence of ASD Policy Documents, in preference for "generic" special educational needs policies in WELB and SELB.

- The limiting of ASD Policy Documents to ASD specific services in SEELB and BELB i.e. not reflected in "Board Policy Documents".

- Although ASD is referenced in some Board Policy Documents, there is an absence of an ASD policy underpinning specific services.

This variation is surprising given the overarching status of the Report on the Task Group on Autism (DofE, 2002) which conducted a major review of Autism services and made recommendations for strategic service enhancement.

We have heard that a cross-Board Group is currently working on an early years curriculum but no details were made available to us.

Health and Social Services

- The Department of Health and Social Services and Public Safety (DHSSPS) has provided some strategic guidance through Priorities for Action Documents but these relate to specific funding proposals.   The ongoing Review of Mental Health and Learning Disability has made recommendations for the strategic development of ASD services but no Departmental response is forthcoming as yet.

- Two of the four Health and Social Services Boards are committed to producing a detailed Strategic Plan for Autism. A preliminary Paper from the four HSS Boards was agreed in 2004 but this only relates to issues within Assessment and Diagnosis of Autism.

- The Southern HSS Board are the most active and productive agency in developing ASD evidence based practice and strategic underpinning of service development. A particular focus has been on the early years and in joint working with the Southern ELB in assessment and early intervention.

- Eight of the eleven Community Health and Social Services Trusts responded to the request for information but of these only three had evidence of an ASD Policy Document and all related to specific operational/service documents (e.g. assessment and diagnostic clinics). There were no Health and Social Services Trust Strategic Documents for ASD.

Given the essential role that Health and Social Services have in the early identification of children with ASD, it is disappointing that Trusts have not addressed this issue more fully. The lack of strategic guidance from DHSSPS may be a factor although certain HSS Boards have been more proactive than others.

Voluntary Sector

Twelve voluntary agencies were contacted and three supplied policy statements or related materials. These varied in depth and quantity, with Autism NI (PAPA) having a clear focus on cross-agency policy development. The Voluntary Sector's response to this issue is disappointing except for those agencies with an obvious core commitment to Autism.

Conclusions

Other than the Report of the Task Group on Autism which emanated from DofE, there appear to be few comprehensive statements of policy in regard to children with ASD and their families.   (Fuller details of existing policies and procedures are reported in Section 3.). This means that service developments are dependent on committed professionals and parents who have to act with few extra resources at their disposal.

Section 3: Review of International literature

Introduction

The term Autism Spectrum Disorders (ASD) will be used throughout this section to refer to the group of Pervasive Developmental Disorders (PDD) as described by the International Classification of Diseases – 10th Edition (ICD-10; World Health Organisation, 1993) and The Diagnostic and Statistical Manual of Mental Disorders – 4th edition (DSM-IV; American Psychiatric Association, 1994). Although the two terms are now used almost synonymously, the term ASD would seem to be more easily understood by parents and professionals than PDD (Baird et al, 2003). Appendix 2 summarises the criteria used in DSM-IV and ICD10.

ASD is not a category within ICD-10 or DSM-IV but is used as a pragmatic 'umbrella term' to reflect the current level of knowledge and degree of certainty of the different syndromes. However it has been noted that although DSM-IV seems ideal for diagnosing 'classic' autism, it is less adequate for diagnosing less severe forms of the disorder that comprise the rest of the autistic spectrum (Skellern, 2005).

While there is as yet no suitable test for the universal screening of pre-school children for ASD, the identification of ASD can nevertheless be improved by the increased recognition of alerting signals to identify those children for whom further assessment is needed. There should also be a positive response to parental concerns at all times. Opportunities for identification are available in the home, in early educational and day care settings, in schools and during health care provision (NAS, 2003).

Literature Search Strategy

Literature databases including Allied and Complementary Medicine (AMED), British Nursing Index (BNI), Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE, PsycINFO, Web of Science, Cochrane Central Register of Controlled Trials and Cochrane Database of Systematic Reviews, and search engines such as Google Scholar, were used to access information on relevant published literature for the years 2000-2005. Search terms included: autism, autistic disorder and early intervention. The most frequently cited studies prior to 2000 were also included where appropriate.

The review covered UK and international studies which have been published, or which are ongoing, and that embraced different types of intervention including those based on Applied Behaviour Analysis and communication enhancement (TEACCH). Particular attention was paid to recent, early intervention programmes undertaken in Northern Ireland and in Great Britain.

Recommendations from previous reports were used as a baseline on which to evaluate recommendations from recent studies and critiques of earlier studies. These included:

DENI (2002*) The education of children and young people with autistic spectrum disorders: Report of the Task Group on Autism,* Belfast: Department of Education (NI)

MEDICAL RESEARCH COUNCIL (2001) Review of autism research: Epidemiology and causes.   London, MRC

NEW YORK STATE DEPARTMENT OF HEALTH EARLY INTERVENTION PROGRAM, 1999, Clinical practice guideline: report of the recommendations, autism/pervasive developmental disorders, assessment and intervention for young children http://www.health.state.ny.us/nysdoh/eip/menu.htm.

NATIONAL AUTISTIC SOCIETY (2003) National Autism Plan for Children. London: NAS.

PUBLIC HEALTH INSTITUTE OF SCOTLAND (2001) Autistic Spectrum Disorders: Needs Assessment Report. Glasgow: NHS Scotland.

SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK (2005) Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. Glasgow: NHS Scotland.

The review is arranged under themes that are particularly pertinent to early intervention. However details of screening and assessment tools for ASD are summarised in Appendix 3.

Assessment and Diagnosis of ASD

Autism affects three core areas of behavior: social skills, communication and behaviours of interest. Its first signs are usually observed by three years of age but there may be warning signs before the child is one year old and many parents will first notice problems with these areas of behaviour between 15 to18 months of age (Ozand et al, 2003). Indeed, up to 55% of autistic children already show some symptoms before one year of life and up to 88% do so before the age of two (Gray and Tonge, 2001). Moore and Goodson (2003) suggest that it is possible to make an informed clinical diagnosis of an ASD in children aged 2-3 with 100% accuracy.

There has been an increase in recognition of the early features of autism amongst primary healthcare professionals and this has led to earlier referral to paediatric and child development specialists (Baird et al, 2001).   However, most clinicians are reluctant to diagnose autism at an early age and, therefore, most children with autism are not diagnosed until close to their third birthday, when language difficulties and behavioral differences become much more apparent. Nevertheless, much of the recent research focuses on manifest behaviors or behavioural deficits seen in very young children that may be the precursors of autism (Kabot et al, 2003). Scambler et al (2001) suggest that an absence of pretend play, rather than more general types of play behaviour, might be able to predict autism.

Studies aiming at the early identification of autism have been conducted especially through home videos made before two years of age with children who were later diagnosed with strictly defined autism (Bernabei and Camaioni, 2001; Werner et al, 2000). Reports suggest that most parents identify the onset of first concerns at about 18 months of age. However, early videos taken by parents at around the first birthday may show features which discriminate the child later diagnosed as having autism from other children of the same age.

Studies have shown that a diagnosis of autism can be reliably made at between 2 and 3 years of age, although a diagnosis of the broader autistic spectrum is less reliable at this age than in older children (Charman and Baird, 2002). These and other studies have suggested that early symptoms of autism are especially related to problems with joint attention; defined as behaviours that develop before language and that involve attention. Young et al (2003) suggest that some early symptoms may be observed by parents at ages, on average, lower than two years.

Early Detection

The American Academy of Neurology/Child Neurology Society's Practice Parameter (Filipek et al., 2000) developed a stepped algorithm for the diagnosis of autism that may be useful to practitioners.

The first level is routine developmental surveillance, generally completed by paediatricians. If a child fails this first level of surveillance, then an audiological assessment is completed and autism screening performed using an autism screening instrument. If the child fails this, then a formal diagnostic evaluation should be completed to identify children at highest risk (Bryson et al, 2004).

In recent years many Community Child Health Departments in the UK have ceased to carry out routine 2-year and 3.5-year developmental surveillance checks. Instead of the universal screening of the entire population, targeted or selective screening has been introduced in many areas. There have been concerns about the possibility that this change could consequently lead to a later detection of cases of ASD, especially at the "milder end" of the spectrum.

Early detection of these children and intervention is essential, since this can lead to considerable improvement in outcome (Tebruegge et al, 2004). Early diagnosis means early intervention and this means, in most instances, an autistic child growing to adulthood, leading an independent life scale, holding a job and having a near normal lifestyle. It has been demonstrated that autism intervention gives best results if given before 5 years of age (Ozand et al, 2003).

However, very early identification may also bring negative outcomes to families. This may include disbelief, fear, anger, grief, and confusion and may result in refusal of services, searching for a different diagnosis, participation in alternative and complementary therapies procedures, and the obsessive use of multiple interventions (Domingue et al, 2000). Service providers may find appointments cancelled or services discontinued altogether as the family processes the information or chooses to disbelieve it. The process of reporting a diagnosis of ASD can be emotionally charged for both parents and professionals (Nissenbaum et al, 2002).

Early interactions with the family must establish a relationship of mutual respect and a willingness to listen and learn, to ask and answer questions, to problem-solve individualised solutions, and to seek additional resources as appropriate. No one family member or professional can be expected to have all of the answers, or the energy, to meet the child's needs (Guralnick, 2000).

Equally, parents want to be positively involved in helping their own child and do not always want to be reliant on professionals. This may be one reason why parents are interested in home-based programmes (Christie and Chandler, 2002).

Ongoing surveillance

According to Hall (2003), ASD does not meet the criteria for screening and he recommends surveillance by a parent-professional partnership and rapid response to concerns throughout the preschool years. Likewise, Tebruegge et al (2004) propose that no formal universal screening should be carried out at 2 years and 3.5 years. Instead they recommend a strategy whereby the health visitor negotiates the nature of subsequent reviews at the age of four months with the parents in the light of individual needs. This approach would rely mainly on the parents to recognise autistic features or abnormal development and subsequently seek assistance from health care professionals. Awareness training of play group and nursery staff, as suggested by the National Initiative for Autism: Screening and Assessment (NIASA), may be an important tool to overcome this problem (NAS, 2003)

Guidelines proposed by NIASA do not recommend primary screening for ASD by the use of tests applied to the whole population at specific ages based on previous reports, e.g. Baird et al. (2003). However, they endorsed the recommendation that at specific times in the pre-school years (8–12 months, 2–3 years and 3–5 years) there should be a focus on development by a health professional with the parents or carer.

Specialists sometimes err on the side of positive diagnosis of autism when they are less than certain. This tends to be used as a strategy to facilitate a child's access to funding sources which require categorical diagnoses despite the complex spectrum of clinical reality. A possible solution to this 'over-diagnosing', according to Skellern (2005), may involve objective assessment of the functional needs of the child, which is not restricted through specific disability diagnoses, i.e., an educational ascertainment model that is based on the functional impairments and hence specific needs of the child, rather than based solely on the presence of a medically definable disease/ disorder.

In a review of single-subject studies of behavior intervention for young children with autism published from 1996–2000, six studies were identified that included functional assessment procedures. Of those studies, the average percentage of behavior reduction was 94.6% (Horner et al., 2000). Campbell (2003) recommends pre-treatment functional assessment, and experimental functional assessment (EFA) in particular, as opposed to indirect or descriptive methods of functional assessment. Although methods of EFA are more time-consuming and costly than indirect methods, training practitioners to implement EFA methods is, according to Campbell (2003) worth the time and effort.

Increased prevalence

Increasing numbers of children with ASD are now diagnosed in the preschool years. This is due to several factors, including the broader conceptualisation of autism as a spectrum of disorders, the recognition that ASDs can be present in individuals across the IQ range, and the appreciation that ASD can co-occur in individuals with identifiable organic disorders such as Down syndrome and tuberous sclerosis (Charman et al, 2004).

Fombonne (2005) reviewed 37 epidemiological studies across 14 countries predominantly carried out in urban settings. He concluded that newer surveys suggest the best estimate for prevalence of all ASDs is close to 60 per 10,000 (i.e.

including those that fall short of the strict diagnostic criteria for an 'autistic disorder' and sometimes referred to as 'pervasive developmental disorders: PDDs).

In Staffordshire, England, among an identified population of 15,500 children aged 2.5 to 6.5 years (Chakrabarti and Fombonne, 2001) the prevalence rate for an 'autistic disorder' was 16.8 per 10,000 (5% confidence interval of 10.3 to 23.2 per 10,000) and 62 per 10,000 for PDDs. A later study by the same team of 10,900 children aged 4 to 7 (Chakrabarti and Fombonne, 2005) found an increased rate of 22 per 10,000 (range 14.4 to 32.2) for autistic disorders and 59 per 10,000 for PDDs.

Fombonne (2005) concluded that most of the increase is accounted for by changes in diagnostic concepts and criteria and by improved identification. Similarly in the United States, the proportion of children diagnosed with ASD in each State ranged from 6 per 10,000 to 46 per 10,000 in 2000-1 (Mandell and Palmer, 2005). Higher rates were significantly related to higher levels of educational and health spending. The authors speculate that better trained educationalists, along with better access to paediatricians and school-based health services increases the recognition of ASD in children.

Diagnostic assessment

Charman and Baird (2002) recommend that diagnostic assessment should include detailed information on developmental history, parents' descriptions of the everyday behaviour and activities of the child, direct assessment of the child's social interaction style, and formal assessment of communicative, intellectual and adaptive function.

Clinical assessments should concentrate on the identification of impairments in early non-verbal social communication behaviours that characterise children with ASD from two years of age, including social orienting, joint attention, imitation, play and reciprocal affective behaviour. Additionally, the use of standardised assessment instruments and the strict application of the DSM and ICD diagnostic criteria should be employed with caution, as an expert clinical view has been shown to be more accurate.

An important aspect of early diagnostic consultation is an open and straightforward approach to the negotiation of the diagnostic view with parents over time. It is important to nurture parents' acceptance and understanding of the diagnosis, and their ability to manage and attune to their child's needs, through ongoing follow-up consultations. Referral to appropriate local services, an understanding of the particular need for a focus on a structured environment, and the development of non-verbal communication skills are priorities.

In Northern Ireland a consultative research project into the provision of assessment and diagnostic services was undertaken with the main stake-holders, including representatives from provider Education Boards and HSS Trusts and commissioners of health and social services (Moore et al, 1999). Focus groups involving nearly 100 parents and professionals were held throughout the region 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.   The need to invest in appropriately co-ordinated, child focused, inter-professional diagnostic services had the unanimous support of respondents.   They 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) which provide access routes for diagnostic services and follow up support.

- They should aim to foster effective liaison between health and social service agencies, educational personnel and schools.

- They should encourage effective liaison between parents and professionals.

Although there was an appreciation of the need for specialist services, most respondents felt that priority should be given to enhancing existing community services.

Conclusions and Recommendations

Based on the foregoing review of research, and the various reports on ASD referenced at the outset of this Section, a number of conclusions and recommendations can be drawn[3]:

Screening

- a feasible screening methodology could be implemented by primary health care professionals who conduct regular health checks on young children, such as paediatricians, health visitors, child health nurses and general practitioners.

- parents require regular opportunities (at least at 8-12 months, 2-3 years and 4-5 years) to discuss their child's development as part of 'surveillance' to detect and respond rapidly to any developmental concerns.

- paediatricians should move from widespread developmental surveillance to a more proactive model of development screening of 'at risk' infants and young children, followed by more prompt referral to early intervention.

- screening at two years has been shown to identify many children with autism/ASD. However, strong empirical grounds exist for assuming that significant numbers are still missed (Baird and Charman, 2000), thus ongoing surveillance or monitoring of screen-negative children is essential

- assessment should be available locally, or at least within the geographical area equivalent to the local 'population unit'. It should be timely and delays should be audited.

- the age of detection/diagnosis of all developmental problems including autism/ASD as a specified disorder should be audited in each local area.

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[3] In the listings, research reports are referenced but those emerging from reports are not.

- existing screening instruments should be used only to assist in the assessment of risk, not as a basis for decision making; ultimately, the decision is a clinical one.

- it is best to use tools or instruments that specifically test for the presence of autistic spectrum disorders.

- checklists, by themselves, tend to miss many of the less usual manifestations within the autism spectrum. Diagnosis can only be clarified by experienced clinical observation, together with a detailed and systematic interview (Howlin 1998).

- the use of screening questionnaires by primary care physicians and early childhood professionals currently offers the best method for the early identification of children with autism (Gray and Tonge, 2005)

- screening tools should never be used in isolation from clinical observation and judgment (Gray and Tonge, 2005).

Developmental Surveillance

- early signs of autism could be detected during health visits as an adjunct to ongoing surveillance or monitoring of development.

- as part of routine developmental surveillance, primary care physicians should assess for the early social-communicative, play and behavioural signs of autism; these signs can be detected by questioning parents and through direct observation.

- the focus should be on the profile or pattern of behaviours, and on their relative frequency compared to what is age, or developmentally, typical.

- signs of autism should be monitored from at least 12 months of age, as some cases can be detected by 18 months and signs may be evident even earlier. Special attention should be paid to development between 18 and 24 months of age, a period during which many (but not all) cases of autism are detectable.

- there is also a small subgroup in whom initial signs of autism may not be apparent until after the second year; ongoing surveillance is essential rather than screening at a single point in time.

Diagnosis

- early diagnosis of ASD is essential to facilitate early intervention (Baird et al, 2003)

- diagnosis of autistic spectrum disorders should be as local to the child and family as possible, and all districts need to develop specialist expertise to do this.

- diagnostic assessment should be linked to intervention; the assessment process should be an integral part of that intervention (Christie and Chandler, 2002).

- diagnosis should be by history taking, focusing on the developmental story and systematically inquiring for core behaviours, and by observation in several settings.

- diagnosis must be followed up with physical help and support for parents to enable them to develop skills that they can make use of as the child grows up (Jones, 2002; Christie and Chandler, 2002)

- it is more important to identify the areas of need and provide intervention than to wait for a definitive diagnosis to be made; the child's progress and diagnosis can then reviewed on a regular basis (Wray et al, 2005).

- the main goal should be a timely referral of children at high risk for autism to specialised diagnostic or treatment services. Rather than postponing treatment until a final diagnosis is made, immediate referral to generic early intervention/developmental/speech and language services, as well as ongoing clinical monitoring for autism, is recommended.

- Partnerships between education, health and social services and with parents are essential (Moore et al, 1999).

Family Assessment

- careful consideration should always be given to parent's concerns, which are typically legitimate; they should trigger referral for a general developmental assessment (GDA) and not be deferred until the next routine surveillance check

- the views of the child should be incorporated where appropriate; an advocate should be used where necessary.

- an assessment of family functioning should be carried out to determine parents' level of understanding of their child's condition in order to offer appropriate counselling and education.

Multidisciplinary Assessment

- the screening of individuals for ASD requires a multidisciplinary team and the use of objective scales. Structured techniques should be used to assess children's social behaviour (joint attention, eye contact, facial expression, and affect) and their capacity to imitate (Gadia et al, 2004)

- reviews from the United States and the United Kingdom support the use of multidisciplinary teams (New York State Department of Health,1999; Medical Research Council, 2001) and a range of professionals (including a paediatrician or psychiatrist, a psychologist, a speech and language therapist, an occupational therapist and a social worker) should be included in the team (Wray et al, 2005).

- there should be an identified multi-disciplinary/multi-agency team of professionals with specialist skills in ASD to whom open referral, including by parents, is possible.

- programmes of ASD awareness training should be provided on a continuous basis to extend from health visitors and primary care doctors to all day care/early years staff/the early education practitioner and school/education related services; the training should include joint multi-agency and carer training.

- teams should be available to assess individuals across the age range. More than one team may operate in the same area depending on the age of the individual being assessed.

- occupational therapy and/or physiotherapy assessment should be available to identify and assess functional difficulties of children with sensory needs and

problems, motor planning difficulties and motor co-ordination disorders and self-care problems.

- a key worker should co-ordinate management of post diagnostic support, across all agencies, including the management of transitions and the sharing of detailed information. The key worker may come from any professional background depending on family preference and the defined needs of the child.

Continuing Professional Development

- professionals report concerns about their competence and lack of training as reasons for not clearly stating a diagnosis (Nissenbaum et al, 2002)

- professionals can identify ASD if they have an awareness of normal development and the specific developmental impairments identified in research studies in autism and incorporated into checklists such as CHAT.

- training should be available to all health care professionals across disciplines, particularly primary health care physicians; they should receive enough continuing education to accurately recognise the early alerting' signals of potential ASD in order to refer children to specialists in the field as soon as possible (Heidgerken et al, 2005); professionals can then discuss with parents the possibility of a problem before referral to second tier services.

- research suggests that the ways in which information is communicated matters a great deal if it is to be effective in influencing people's behaviour. Messages that communicate positive benefits rather than losses are more effective in motivating people to take action.

- efforts to change physician prescribing practices are more effective by having multiple contacts over an extended period of time (6 to 8 months) rather than only one or two contacts.

Intervention

In the UK, psychosocial treatments, rather than biological treatments, would appear to be the preferred interventions for children with ASD but there is a distinct lack of a systematic evidence base for their effectiveness (Charman et al., 2003). Sackett et al (1997) argue that decision-making should be conscientious, explicit, and make judicious use of current best evidence. An evidence base should, therefore, combine experience with various forms of research evidence to the specific problem under investigation. There exists a hierarchy of evidence going from unsystematic clinical observations to randomised clinical trials with evidence from the top of the hierarchy having a greater "scientific" impact on decision-making than lower level observations. Unfortunately, most of the evidence that supports the beneficial effects of interventions for children with ASD tends to fall at the lower end of this evidence hierarchy. Indeed, most of the studies in this area lack experimental evidence of effectiveness, are small-scale, and focus on short-term goals. There are also a number of methodological weaknesses such as incomparable samples, lack of control for other intervening variables, assurance of treatment compliance, poor quality measurement tools, and variable definitions of the cohort (Fletcher-Campbell et al, 2003; Diggle et al, 2005). Nevertheless, there are instances in which the benefit of treatment is so

clear that evidence from a lower level in the hierarchy can be used to support decisions; it may be extremely weak (such as the recollections of a more experienced colleague) but it still counts as evidence.

Established interventions for children with ASD generally draw on procedures derived from special education and behavioural psychology and, despite some practical and theoretical differences, they tend to share many common features (National Research Council, 2001).

Evidence from the research literature suggests that targeted interventions should begin as early as possible (Buschbacher and Fox, 2003). Studies clearly indicate that children who have intervention before they reach five years of age cope much better than those who receive intervention later than this. Otherwise, maladaptive patterns of behaviour and communication become firmly engraved in the child's brain. The best results are obtained if the intervention is performed before two years of age (Ozand et al, 2003).

Methodological Issues

Although research supports the effectiveness of a range of interventions for children with ASD, there is no evidence that any one approach is more successful than others. There is very little evidence that any treatment alters the core symptomatology of ASD (NAS, 2000). There are very few well-designed and adequately controlled studies in this area (National Research Council, 2001; New York State Department of Health, 1999; Rumsey et al, 2000). Due to this lack of data, the evidence base for evaluating one intervention or programme over another is extremely limited (Charman et al, 2004). For these reasons no definite recommendations can be made about individual therapies across all children.

There is also emerging evidence that some therapies previously advocated by professionals and parents, such as auditory integration therapy, are no more effective than placebo (Mudford et al, 2000; Dawson and Watling 2000), whilst others (such as Facilitated Communication) are now discouraged because of adverse side effects or other risks to the child (Dunn-Geier et al, 2000).

Scientific evidence of efficacy assumes a homogeneous population. In general, "efficacy" is the ability to produce a specifically desired effect in an intended target population whereas "effectiveness" is normally demonstrated in practice and takes account of the multiple barriers to proper administration. Since children with ASD present as a heterogeneous group it is possible that some treatments that do not have demonstrated effectiveness across the population, may, nevertheless, be highly efficacious in a small sub-set of that population. Thus, if there is some *a priori* rationale for using a specific treatment with a particular child, this should be carefully monitored. Ideally, single subject case designs should be utilised to assess efficacy and monitor side-effects (NAS, 2003).

It is unlikely that any single intervention will have the same effect on all children with ASDs. Indeed, there is a consensus in the literature that the promotion of one intervention over another is mistaken, even for one particular child, as the needs of the child will change as he or she develops (Fletcher-Campbell, 2003). A number of interventions may be required to address the full range of needs of any individual child (Jones, 2002). There is, however, good evidence that the needs of children

with ASD are highly individualistic; different children will have different needs and that they will respond differently to the same sensory stimuli (Fletcher-Campbell, 2003).

Eclectic Approaches

Generally speaking, an eclectic approach is one that does not hold rigidly to a single paradigm (such as behaviourism) but, instead, draws on a wide range of theories, ideas, techniques and methods and can encourage cross-fertilisation and, possibly, the development of new approaches. For example, psychologists may accept certain behavioural principles but will not necessarily attempt to use behaviourism to explain all aspects of human behaviour. Instead, they accept that many factors influence behaviour and so consider all perspectives in identifying, changing, explaining and determining behaviour. However, within the literature on ASD, the meaning of the term 'eclectic' is not always clear and it is not always possible to identify what theories, or models, are being used to support practice.

For example, many intervention programmes use elements and principles of Intensive Behavioural Intervention (IBI) to underpin their approaches although these tend to be at considerably less intensive levels than interventions based solely on behavioural principles (see later section). Currently, IBI has the best documented evidence for its efficacy, although the area still remains controversial (Luiselli et al, 2000; Boyd and Corley, 2001). On the other hand, few of these "eclectic" approaches have been subject to the same level of evaluation and refereed publication outcomes, which has come to characterise IBI. Eikeseth et al (2002) suggest that it is the type, rather than the intensity, of treatment that accounts for the outcomes produced by intensive behavior analytic treatment and recent studies suggest that an intensive special education programme, delivered by experts as part of normal educational provision for children with disabilities, can do just as well as traditional IBI (Prior, 2004).

Examples of the more commonly used eclectic approaches include the following.

TEACCH programmes have been reported to be effective in improving self help, social skills, and communication, reducing inappropriate behaviours, enhancing the quality of life, along with lower parental stress rates (Van Bourgondien et al, 2003). Ozonoff and Cathcart (1998) used a TEACCH-based home program intervention for young children with autism. Parents were taught how to work with their preschool autistic child in the home setting, focusing on cognitive, academic, and prevocational skills essential to later school success. The treatment group showed marked improvements to a control group although the only scores used were PEP-R. Similar results are reported by several uncontrolled studies of comprehensive centre-based programmes.   Despite this, there is a lack of robust, large, well-controlled studies evaluating its effectiveness (Francis, 2005) and the functionality of what is taught is not always apparent as superficial training has led to the literal copying of procedures rather than the application of principles to individuals and contexts (Jordan, 2001).

Likewise, **PECS** has spread rapidly across the UK (Magiati and Howlin, 2003) but, again, there are few published studies into its effectiveness and there are limitations to the evidence that is available, e.g., lack of controls, and comparison with other communication systems. PECS is usually implemented in settings in which a number

of different approaches are being used so it may be difficult to study its benefits in isolation. Additionally, there is no evidence that it is effective outside the home or school (Jones, 2004).

The **Child's Talk** research project describes a multi-disciplinary team approach to providing autism specific assessments and communication intervention and focuses on underlying skills in establishing joint attention, intentionality and understanding meaning conveyed in social signals and language (Aldred, 2002). The approach uses naturalistic models of intervention which follow the child's lead in parent-child interaction and interpret the child's behavioural responses as meaningful signals of intent. Significant improvement in communication, reciprocal-social interaction and expressive language skills were found in the treatment group compared with the control group. Results suggest that the behavioural symptoms of ASD can be improved and positive social communication skills promoted with highly specialised intervention. Results also support the benefit of early intervention; younger children made the most significant increase in socialisation, communication and language skills and that this was associated with a decrease in behavioural symptoms. So, whatever the child's cognitive abilities, repairing the bi-directional communication break down between parent and child facilitates the development of the critical underpinnings for effective interaction and communication. Siller and Sigman (2002) found that the more that parents synchronised their behaviour with that of their young children with ASD during play, the more their language developed. There is strong empirical support for the efficacy of functional communication training to replace problem behaviors (National Research Council, 2001) and for the effectiveness of a range of approaches for enhancing the communication skills of children with ASD along a continuum from behavioural to developmental (Woods and Wetherby, 2003).

More Than Words (The Hanen Programme for Parents of Children with Autism Spectrum Disorder), is an intensive training programme for parents of preschool children with ASD and is designed on the premise that parents are their children's best teachers. It is an eclectic approach that emphasises the blending of aspects from both behavioural and naturalistic child-centred programmes. It incorporates current best practice guidelines and the strategies used are empirically and theoretically grounded in recent research on parent-child interaction. A number of studies have documented its efficacy but with varying levels of evidence. However, a recent study by Baxendale and Hesketh (2003) compared the Hanen Parent Programme (HPP) in terms of its effectiveness and suitability for an inner city UK population with clinic-based direct intervention. They found no statistically significant differences in child language scores between the two therapy groups. Moreover, the HPP was twice as intensive (in terms of therapist time) and this has resource implications

Joint attention training Dawson et al (2004) suggest that it is possible to facilitate the development of joint attention in children with autism by increasing their motivation to attend to social stimuli and triadic communicative exchanges. Integrating joint attention training into existing interventions may be important for children with autism. In addition, training parents in these techniques may help to maintain joint attention skills outside of the treatment setting (Whalen and Schreibman, 2003). Earlier studies have shown success by applying strategies in a

more systematic fashion to elicit a joint focus in play routines through the use of rich affect, mutual imitation and drama (Rogers, 2000; Sherrat, 2002).

In a similar vein, Bernard-Opitz et al (2004) compared traditional behavioural approaches and natural play interventions for young children with autism. They found that behavioural and play approaches affect behaviour in different ways and that autistic symptomatology of young children may be amenable to treatment.   For example, Yang (2003) suggests that Integrated Play Groups (IPGs) can create a cultural environment with the potential to enhance socialisation and imagination in children with ASD. Early play intervention would appear to be very important in the development these children but it has to be embedded within a broader treatment programme. If play skills acquired in the course of an intervention are not supported and broadened after the initial programme is completed, they may be lost (Van Beckerlaer-Onnes, 2003).

Evaluation of Interventions

Eikeseth et al (2002) found that children who received behaviorally based intervention made more progress than children who received a more eclectic approach.   More recently, Howard et al (2005) found that Intensive Behavioural Treatment (IBT) was "considerably" more efficacious than eclectic interventions such as PECS and TEACCH-type activities. Indeed, they suggest that such eclectic treatments flatten, or decrease, rather than increase the slopes of the developmental trajectories of most children and that such children are likely to lose more ground to their typically developing peers the longer they remain in such intervention programmes. There is a serious lack of sound scientific data on the efficacy of these eclectic methods (NAS, 2003) and many studies fail to fulfil even the most basic research criteria (New York State Department of Health, 1999; Charman et al, 2003; Kasari, 2002). Studies have typically used small sample sizes and have had inadequate controls. Many of them have used outcome measures that focus on cognition rather than social interaction and communication.

However Aldred, Green and Adams (2004) did undertake a pilot randomized control trial of a new theoretically-based, social communication intervention that targeted parental communication in a randomised design against routine care alone. The active treatment group showed significant improvement compared with controls on the total score, and particularly on the reciprocal social interaction score of the primary outcome measure – Autism Diagnostic Observation Schedule (ADOS). There were also improvements on secondary measures of expressive language, communicative initiation and parent–child interaction. The authors concluded that a Randomised Treatment Trial design of this kind is feasible and acceptable to patients.

Francis (2005) evaluated other commonly used interventions and found that, while some do have empirical support, there is no clear evidence favouring one approach over the others. Nevertheless, it seems clear that early intervention is essential (Christie and Chandler, 2002); early experiences play a critical role in shaping brain architecture as well as brain function and treatment that is intensive, long in duration, and delivered directly to children (rather than just to their caregivers) produces better outcomes than treatment without those elements (Howard et al, 2005).

The intensity of intervention necessary to provide optimal outcomes is as yet undetermined for preschool children who are at risk for ASD, but it is clear that the more time spent in active, positive engagement, the better the outcomes (National Research Council, 2001). Based on the limited research available, it cannot be presumed that current early intervention practice of 1 to 2 hours per week of special instruction or related services is adequate (Woods and Wetherby, 2003).

Early Intensive Behaviour Analytic Intervention (EIBI)

Although behavioural methodology has been evolving and new techniques have been introduced, applied behaviour analysis (ABA), and discrete trial learning, still remain the core feature of behavioural intervention in autism. Although some professionals and parents involved with children with autism use the term ABA to describe a singular method of systematic instruction, it is important to note that ABA offers a wide array of interventions and approaches to behavior change. It is an essentially pragmatic science that provides data on the effect of an intervention on the behaviour of an individual or individuals (Buschbacher and Fox, 2003). It consists of the use of scientific methodology to understand behaviour and how it can be changed. Early Intensive Behaviour Intervention (EIBI) is generally understood to be the use of applied behaviour analysis techniques to provide intensive treatment. Intensity of treatment refers not only to the number of hours provided (typically between 20 and 40 hours per week), but also the design and implementation of treatment programmes. However, with the literature on EIBI, there is a lack of operational definition of terms such as 'ABA', 'eclectic', and 'intensive'.

Recent studies have documented the efficacy of EIBI (e.g., Eikeseth et al, 2002; Green et al, 2002; Bryson et al, 2003). Additionally, parents show high satisfaction and reduced stress over the course of treatment in comparison to parents whose children did not receive EIBI (Smith et al., 2000). However, a major issue is that in none of these intervention studies was the ABA treatment compared to another form of intervention (Hohmann, & Shear, 2002).

Although all published studies of EIBI demonstrated that many children made substantial gains, outcomes varied within and across studies. The numbers of intensively treated children who achieved normal or near-normal functioning, more modest improvements, and relatively small improvements varied from study to study. There were also methodological differences across studies: some were quasi-experimental while others used true experimental designs, and few assigned participants to groups randomly (Kasari, 2002).

More recently, however, Sallows and Graupner (2005) demonstrated that the UCLA early intensive behavioral treatment program could be implemented in a clinical setting outside a university, with a similar sample, and that the earlier findings by the UCLA group regarding favorable outcome could in large part be replicated without aversives. However, Reed et al (2005) compared ABA, Special Nursery Placements, Portage and PACTS[4] programmes on a variety of aspects of children's abilities. They examined community-based, rather than clinic-based, interventions in an attempt to isolate some of the contributing factors of successful interventions. There

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[4] Parents and Children Together – Family-based literacy, language and numeracy programme. Details at: www.literacytrust.org.uk

was no evidence of overall recovery from autism; the Autism Quotient did not dramatically improve in any of the children. This contradicts earlier findings by Lovaas (1987) of almost 50% rates of recovery. Results suggest that both ABA and Special Nursery Placements are more effective than the Portage or PACTS.

As an aggregate, published studies offer compelling evidence that many children with autism who receive EIBI make substantial gains. However, EIBI can last upwards of four hours a day and this can place major strain on families. Recent research suggests that the number of treatment hours do not correlate with outcomes (Gabriels et al, 2001) and that there has been an over-estimation of the minimum number of hours required per week (Luiselli et al, 2000).

Parental Involvement

Many parents of children with ASD chose to become more involved in interventions, with some taking on the role of therapist to some degree, either by implementing suggestions on an informal basis from medical and educational professionals working with their child on an informal basis, or by using a more intensive, full-time intervention within the home. This shift reflects the recognition that parent involvement can help the child to maintain and generalise developmental gains made though intervention, as well as increasing the availability and intensity of intervention (Williams and Wishart, 2003).

Smith et al (2000) suggest that parents are not at risk of significantly increased stress through involvement in home-based intensive intervention programmes. However, (Hastings, 2004) suggests that parents of children with ASDs are more likely to experience serious psychological distress than parents of children with other developmental disabilities. Furthermore, if they adopt escape-avoidance strategies to cope with the stresses of raising children with autism, they are likely to report more stress and mental health problems. In contrast, those using positive reframing strategies report less stress (Dunn et al., 2001; Hastings and Johnson, 2001). The level of psychological distress is associated with factors such as the severity of behavioural disturbance shown by the child with ASD, the gender and age of the parent, levels of social support received by the parent, psychological characteristics of the parent such as perceived self-efficacy, locus of control and coping styles (Dunn et al., 2001; Hastings and Brown, 2002). However, Hastings & Johnson (2001) found that a high level of belief in the efficacy of the intervention was associated with lower levels of parent stress, regardless of the severity of the child's autism. However, families might be at risk if they begin to have serious doubts about the programme with which they are involved. The age of child at the onset of intervention and programme duration were also associated with stress levels, the latter finding indicating that family effects do not necessarily remain static over the course of an intervention.

Some parent training programmes (such as EIBI) may be too intensive in terms of the amount of information given over a short period of time. Other programmes focus only on deficits and difficulties and this does not inspire hope (Jones, 2002). Williams and Wishart (2003) suggest that pressures on the parents' time is a frequent drawback, and increased happiness in families still using the intervention a year after training is common when the child does not have intellectual disabilities in addition to ASD and when few financial difficulties were caused by running the programme.

Parent training programmes need to fit in with a family's lifestyle, values and beliefs so that teaching can occur in natural settings and family stress is not increased. A range of options is necessary within a geographical area to suit the particular needs of individual families, e.g., workshops, home-based programmes, and literature on ASDs. Professionals need to discuss options with parents, and to negotiate and agree on needs and actions. Parents should be provided with optimistic information on the implications of ASD and effective strategies. This information should be research-based but should also be accessible by parents with limited literacy skills. Practical support for families in understanding and managing their child is essential. Consideration needs to be given as to what follows when the programme ends, so that parents continue to feel supported. This is made easier when those running the training are part of local services and can have a continuing role (Jones, 2002). Interventions must be tailored to the individual needs of children and families (McConkey and Truedale, 2004)

There is a need for specific, ongoing, post-diagnostic support and counselling for parents. Support programmes need to target family and relationship variables as well as ASD children and their behaviours, in order to sustain the family unit and improve quality of life for parents and caregivers as well as those children. Some parent group programmes focus on enhancing carer awareness and teaching communication strategies, although no systematic evaluations have been published (Aldred et al, 2004). Apart from the training in the various techniques of an intervention, there are also comprehensive packages for educating parents, such as the Frameworks for Communication Project (Chandler et al, 2002); the NAS EarlyBird programme for parents of preschool children (Shields, 2001) and the Keyhole Project (PAPA, 2003).

Examples of Programmes

The Frameworks for Communication Project evaluated a model of service delivery that makes an explicit link between diagnosis and intervention and which seems to fit well with current legislative priorities in the UK. These include parent partnership, interagency collaboration and early intervention. This avoids the situation where families are brought into conflict with local agencies over issues of principle (e.g., how a specific method fits with inclusive models of education) and practice (typically with regard to arrangements for funding). Chandler et al (2002) found that all children in the project made substantial progress in social interaction and expressive communication, including gestural and verbal communication.

The EarlyBird (EB) programme provides a good model of practice for service delivery to the pre-school child with autism and his or her family. It incorporates theoretical models based on TEACCH and PECS. It emphasises partnership with parents. Engwall and MacPherson (2003) found that stress levels in parents with children with ASD who were involved in an EB programme were significantly reduced and they felt more in control and empowered. Parents acquired relevant knowledge, skills and coping strategies and had a better understanding of how autism affected their child's behaviour and communication. They also came to terms more readily with their child's diagnosis.

Keyhole Early Intervention Programme This home-based programme was developed in Northern Ireland by PAPA in conjunction with speech and language therapists and early childhood educators. It consists of a series of visits by an early intervention therapist to the child's home during which careful assessments are made of the child and an individual programme of activities is drawn up in association with parents to further the child's communication, play and social interactions.   A pre-post evaluation with 36 families identified significant gains in these areas with some impact on the mother's well-being (McConkey et al, 2003, 2004).   The Keyhole project also developed a training course and materials for use with staff in playgroups and preschools (Crawford et al, 2004) which is now being delivered regionally through the NI Preschool Playgroup Association. The project also developed and evaluated ACCESS Workshops as parent training. PAPA now offers these throughout Northern Ireland.

Cultural Issues

Whilst services for children with ASD may be needs-led, they may, nevertheless, fail to recognise the cultural values that underpin the definition, or even recognition, of those needs (Jordan, 2001). Current provision for children with ASD in the UK has traditionally been based on values that are derived from a variety of cultural contexts, notably from the USA (e.g., ABA and TEACCH). Such culturally-rooted practices may not transfer easily to UK culture. Nevertheless, according to Schopler and Mesibov (2000), the development of services for children with ASD in several countries has been influenced by the TEACCH philosophy and it has been successfully adapted to suit particular education/health service models and to complement cultural characteristics such as family perceptions of disability and special needs.

However, there would also appear to be a lack of awareness of cultural issues and of the ways that these affect children with autism and their families. There is little information regarding how multicultural families adapt to raising a child with autism but it is likely that such children will have more difficulty with the academic and behavioural customs of school culture than do children from the dominant culture. Consequently, ethnic diversity may affect the services available for children with ASD from multicultural backgrounds and they are more likely to be challenged on at least four dimensions rather than the traditional three: communication, social skills, behavioral repertoires, and *culture* (Taylor Dyches, 2004).

Complementary and Alternative Medicine (CAM) Therapies

Professionals are often called on to make decisions or give advice regarding the variety of interventions available for young children with ASDs. These may include auditory integration therapy (AIT), sensory integration therapy (SIT), facilitated communication (FC) and dietary interventions . However, there is no broad consensus, and very little research undertaken, regarding these treatments. Generally, they not been accepted by clinicians or researchers as legitimate methods of alleviating the core features of ASD (Dawson and Watling, 2000; Sinha et al, 2004; Baranek, 2002). Furthermore, they can be time-consuming and expensive.

Nevertheless, anecdotal reports of improvement or cure have ensured their continuation, and many parents continue to be interested in using them. Of the four

approaches mentioned above, only the use of SIT, at least as a complementary intervention, and certain dietary interventions, would seem to have some justification. SIT may be effective with those children who are over- or under-responsive to various environmental stimuli. Gluten and/or casein free diet may reduce some autistic traits (Millward et al, 2004).

According to Smith and Antolovich (2000), some parents of children with ASD sense both the practical limitations of the existing empirically validated interventions and their "shallowness" of effect with respect to the core features of ASD. This may explain their continued interest in, and use of, alternative invalidated treatments; they may be more interested in improving their child's quality of life rather than simply reducing symptom severity (Bodfish, 2004). Consequently, research on established treatments should include the potential concomitant use of CAM therapies as more definitive evidence is needed to inform parents', carers' and practitioners' decision making. Healthcare professionals should, furthermore, be supportive of families who wish to use CAM therapies, while cautioning them against those that may have a detrimental effect on the child's health, and the cost involved in pursuing these treatments. Parents who wish to explore specific CAM therapies for their child should do so with the support and knowledge of their named senior clinician from the base service and their named key worker (NAS, 2003).

Training

It is important to enhance knowledge about ASD and of the intervention strategies that are effective in those who are going to be working with children with ASD. There should be training for carers (parents and others) following identification of the child's needs. The ACCESS workshops developed as part of the Keyhole Project are a good example of this. In addition parental access to shared training with professionals in the field should lead to a common understanding of needs and interventions (NAS, 2003).

The emphasis should be on practical strategies rather than theoretical knowledge (Crawford et al, 2003) although theoretical understanding is, of course, essential. It is important that staff are competent in a range of interventions that are underpinned by research evidence supporting their effectiveness and that are internationally recognised (McConkey and Truesdale, 2004). They need to have a repertoire of relevant knowledge and skills (Fletcher-Campbell, 2004).

Crawford et al (2003) suggest that courses could be tutored by people with complementary expertise and that a network of tutors could be identified within each region to facilitate this. Alternatively, a training resource pack could be made available to guide tutors through the course content and methods although training workshops would also be needed to familiarise new tutors with the course materials. Additionally, as more preschool personnel gain expertise in working with children with ASD, they could become tutors and advisors. The success in Northern Ireland of the Keyhole training for preschool personnel is an example of the viability of these approaches.

Research

More qualitative research is needed and future studies should focus on which intervention gains can be predicted by characteristics of the child such as intellectual ability and language skills and which can be attributed to environmental variables such as family involvement, sibling and peer relationships, resources and parental beliefs and values (Schuler, 2001). Furthermore, professionals who are working with children with ASD should be encouraged to conduct research on interventions themselves; outreach teams, educational psychologists, and others should be collecting and analysing data on the effects of interventions with support from academics and researchers (Jones, 2002). They need to maintain careful records of strategies and tools used in order to assess the child's progress and the impact on the family (McConkey and Truesdale, 2004).

Prognosis

While there is good evidence supporting the short- to medium-term benefits of early intervention, it may not be impacting ASD at a deep enough level to produce the kind of socially valid outcomes that are being tracked in studies of adult outcomes in ASD (Bodfish, 2004). Outcome studies in autism suggest that the disabling features and cognitive style are life long and that IQ, particularly verbal IQ, is a powerful predictor of future ability to undertake a job and live independently. A recent study of adult outcomes for children with autism showed that only 22% achieved a "very good" or "good" outcome while the majority (58%) were rated as having "poor" (46%) or "very poor" (12%) outcomes (Howlin, 2004).

Conclusions and Recommendations

In the absence of definitive evidence for the effectiveness of intervention strategies for pre-school children with ASD, professional judgment is needed but this must be based on the best available evidence. This evidence should come from a variety of reputable sources and steps should be taken to ensure consensus, where possible, across a wide range of professionals. For example, the report of the National Research Council (2001) provides sound guidelines. In addition, there are other sources that can be used to decide on which interventions to use: current theories and social and cultural values; previous experience with other children; knowledge of a particular child; and individual responses to previous interventions (Jones, 2002). Shea (2004) reports that there is consensus in the professional literature that a variety of educational and therapeutic techniques can help children with ASD at all levels of functioning to develop skills, interests and relationships.

Based on recent research literature[5], there would appear to be agreement that:

- no evidence exists to show that one approach is more successful than others (Fletcher-Campbell, 2003; Diggle et al, 2005).

- if there is some *a priori* rationale for using a specific treatment with a particular child, this should be carefully monitored to confirm their applicability.

- effective interventions are those that start early and are properly focused for both child and family (Lord, 2000; Pratt et al., 2001).

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[5] In the listings, research reports are referenced but those emerging from reports are not.

- intervention provided before age 3½ has a greater impact than that after age 5 (Harris & Handleman, 2000).

- intervention should be clearly structured, routine, and use a visual approach (Fletcher-Campbell, 2003; Buschbacher and Fox, 2003)

- intervention must take account of the characteristic behavioural patterns of children with autism, showing an understanding of what may underlie those behaviours (Buschbacher and Fox, 2003)

- intervention must be intensive (National Research Council, 2001; New York State Department of Health, 1999; Pratt et al., 2001).

- parent education and involvement should be included in early intervention and preschool programmes (National Research Council, 2001; Pratt et al., 2001); parents are "experts" on their own child (Christie and Chandler, 2002)

- there should be training for carers (parents and others) following identification of the child's needs; access to shared training with professionals in the field should lead to a common understanding of needs and interventions.

- specialist professional training in ASD for staff involved in the identification of ASD should take place both during qualification and post qualification. In particular an acknowledgement and understanding of the breadth of the autistic spectrum needs to be achieved.

- nominated individuals should have developed their practice, knowledge and awareness of ASD to such a level that they can provide appropriate training and consultancy to colleagues during training and post qualification.

- all parents and professionals involved in child health and development should understand how to access training and consultancy within their locality.

- the use of parents as co-therapists provides an economical method of increasing the number of hours a child receives treatment in a constant and consistent way.

- the use of parents as co-therapists empowers parents and makes them feel in control of their child; this results in a better parenting style and the avoidance of distress and disappointment (Diggle et al, 2005).

- professionals should discuss options with parents, and negotiate and agree on needs and actions (Jones, 2002).

- parents should be provided with optimistic information on the implications of ASD and effective strategies; this information should be research-based but should also be accessible by parents with limited literary skills (Jones, 2002)

- consideration needs to be given as to what follows when the programme ends, so that parents continue to feel supported (Jones, 2002)

- practical support for families in understanding and managing their child is essential and this is made easier when those running the training are part of local services and can have a continuing role (Jones, 2002).

- a comprehensive approach is favoured with individualised treatment goals and programmes, which involve the parents and other individuals working with the person with ASD in a reciprocal and coordinated manner.

- programmes should not be intense when the parental stress is high, as the latter will counteract the effectiveness of the programme. Programmes could be offered along with some form of initial parental training/counselling (Reed et al, 2005).

- focus on the development of specific skills and on increasing social communication and understanding (Buschbacher and Fox, 2003); studies have demonstrated that a variety of teaching methods effectively increase social skills (e.g., direct instruction, peer tutoring, video-modeling, social stories/games, scripted self-management) and that such methods are effective in preschool children with autism (Rogers, 2000).

- integrating joint attention training into existing interventions may be important for children with autism. In addition, training parents in these techniques may help to maintain joint attention skills outside of the treatment setting (Whalen and Schreibman, 2003)

- instruction should be systematic with individualised goals and objectives based on the principles of applied behavior analysis (ABA); language should be clear and unambiguous (Fletcher-Campbell, 2003)

- a professional–family partnership may facilitate the family's implementation of strategies used in a therapy setting to home and the community, thereby increasing the likelihood of the child generalising skills across his or her environments (Diggle et al, 2005; Buschbacher and Fox, 2003)

- integration with peers should be promoted: preschool children with ASD, should be included in programmes and activities in which other preschool children participate (Buschbacher and Fox, 2003)

- cultural differences should be recognised and acknowledged; there should be a commitment to meeting the needs of families from all cultural backgrounds, recognising the profound impact that cultural differences may exert for families with a child with an ASD (NAS, 2003).

References

Appendix 4: gives details of all the articles referenced in this section.

Conclusions

Internationally there has been a marked increase in the number of research studies undertaken in the field of autistic spectrum disorders in the early years. The focus has been largely on identification, assessment and diagnosis although more evaluations of interventions are appearing, especially of behavioural approaches. There is also an emerging consensus on responses that are required to meet the needs of these children and the aspirations of their parents.

Section 4: Service Provision in Northern Ireland

The Chief Executive Officers of the five Education and Library Boards (ELBs) and of the 11 Community HSS Trusts were asked to nominate an official who would act as contact person for the project. This individual was sent a standard pro forma – with slight modification for the two different bodies - that had been developed specifically for the project in consultation with the Steering Group. They were asked to complete this in consultation with their colleagues. In the case of HSS Trusts they were reminded that this may need to be done across different Programmes of Care. Replies were received from all ELBs and from all eleven Community HSS Trusts.

The information obtained is summarised in this paper but a full transcript of the data and comments made by the respondents is available on request[6].

Numbers of children aged 2-4 years with ASD

A priority aim for the project was to obtain an indication of the numbers of children in Northern Ireland with either a confirmed or suspected diagnosis who were known to either HSS trusts and to Education and Library Boards.

Database held by agencies

Each agency was asked if they maintained a database of all children with a confirmed diagnosis of ASD. Four of the five ELBs and eight of the 11 Trusts stated that they did. In the main this contained information about the child; date of birth and date of diagnosis. All ELBs but not all Trusts recorded who made the diagnosis and postcode of the child's home. Information on associated learning disabilities, services received and services required was less commonly held. Other information recorded by a few agencies were the referring agency and if a statement of SEN had been issued. Only two of the HSS Trusts and one of the ELBs stated that the dataset was shared with other agencies (in this instance the information came from HSS Trust to the ELB).

Numbers of children

Agencies were asked to provide the numbers of preschool children on 1 Sept 2005 whose date of birth fell on or after 2 July 2001 (NB This date signifies children who will be eligible to attend school from 1st September, 2005. Children born on or after this date are considered to be 'preschool' children.)

The reported figures are summarised in Table 4.1 below but a number of cautions need to be entered.

Informants were asked to provide an estimate of numbers if they did not have an accurate listing of children. This is indicated in the Table by 'e' before the number. Named data on individuals could not be accessed so there is likely to be an element of double-counting in the replies received from Education and HSS.

In order to enable comparisons across the different boards and trusts the total figures have been expressed as a ratio to the child population (3-4 years) in the 2001 national census. This was chosen because persons under three years are unlikely to

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have a diagnosis of ASD. However this may account for the inflated figures in certain Boards and Trusts if two year olds are counted in their returns for children with ASD.

Table 4.1 : The numbers of children known to ELBS and HSS Trusts

NB: e – estimate provided by informants or to indicate a derived estimate ;
na – data not supplied by respondents; NR – no reply received.

ELB	Con-firmed	Sus-pected	Total	Rate per 10,000*	HSS Trust	Con-firmed	Sus-pected	Total	Rate per 10,000*
Belfast	10	10	20	30.1	N.W.Belfast	na	14	e14	e37.3
					S.E. Belfast	21	e 10	e 31	e69.9
South East	e 70	e 50	e 120	e117.6 (e78.4)~	Ulster CHT	e 10	3	e13	e36.5
					Down Lisburn	e 24	e 53	e77	e156.0 (e104.0)~
Southern	16	na	16	e15.7	Craig. & Ban.	na	na	na	na
					Newry & M.	1	2	3	9.9
					Armagh & D.	na	20+	20+	e66.2
North East	e 11	e 40	e 51	e 47.9	Homefirst	e 8	30	38	e42.9
					Causeway	3	na	e3	e11.1
Western	6	na	6	e7.1	Foyle	5	16	21	42.0
					Sperrin Lake.	na	na	na	na
Total	**e113**	**e100**	**e213**	**e 44.4**	**Total**	**e73**	**e148**	**e220 e275+**	**e57.0+**

* The rate is calculated on the numbers of 3 and 4 year olds in the population of the Board or Trust.
+ Increased to account for the missing data from three HSS trusts.
~ prevalence recalculated for 2,3 and 4 year olds.

As the Table shows there is wide variation across the five ELBs in the number of children identified and suspected as having an ASD (range in prevalence rates from 7.1 to 117.6 per 10,000). A wider range exists among the HSS Trusts (9.9 to 156.0). Given this variation, the summated figures for Northern Ireland as a whole can only be taken to reflect the numbers of children identified rather than the 'true' population. The figures suggest a total of around 250 preschool children; of whom around half have a confirmed diagnosis.

Another approach is to apply the prevalence rates found in other studies to the population in Northern Ireland.   When the rates reported by Chakrabarti and Fombonne (2005) for Staffordshire are applied to the NI population of 3 and 4 year olds (i.e. 48,000 using 2003 mid-years estimate), the likely numbers of preschoolers with an ASD would be as follows:

Pervasive Developmental Disorder: 281 (5% confidence: range 217 –345)

Autistic Disorder: 106 (5% confidence: range 68 – 157)

Comparison of these figures with the reported data from Northern Ireland would suggest that certain Boards and Trusts may be over-inclusive in their definition of children with ASD and/or in their estimates of children with these conditions. (NB The elevated rates are still apparent when the prevalence rates are recalculated for children aged 2 to 4 years – see Table 4.1). Of course it could be that the prevalence of ASD is higher in this part of Northern Ireland but this would then serve to reinforce the finding of a wide variation across Boards and Trusts.

It seems more likely that a combination of the availability of diagnostic services and the criteria used by them, primarily determine the numbers of children identified with an ASD.

Conclusions

It is not possible to give an accurate count of the number of preschool children with ASD in Northern Ireland until there is equity in the availability of diagnostic services; with common criteria used in identifying ASD and a standard dataset is maintained across the region. That said the numbers of preschool children with any form of ASD is probably in the region of 300 and those with an autistic disorder (i.e. meeting stricter diagnostic criteria) may be around 100.

Referral Process

Most HSS Trusts reported that health visitors, GPs and Speech & Language therapist made referrals. Other groups who referred included educational psychologists, community medical staff, occupational therapists and social workers. One Trust also mentioned as sources for some referrals, CAMHS and Surestart; another trust named teachers and two Trusts mentioned parents making referrals.

In HSS Trusts, referrals were either made to a community paediatrician or the multi-disciplinary assessment team. The most commonly given reason for referral was communication problems and delayed development.

In ELBs, referrals tended to come from community paediatricians and allied health professionals but in addition from nursery schools and special schools. In three Boards the children referred appear to be seen by educational psychologists or specialist teachers in ASD in conjunction with health colleagues. In two Boards this appears to be done solely by educational personnel. Educational psychologists are involved in all Boards.

One ELB reported that parents can self-refer for assessment as did one HSS Trust. All other agencies replied that they could not, although some noted that they may self-refer to other services as a prelude to being seen for specialist assessment.

HSS Informants were asked the length of time a preschool child might wait to be assessed and diagnosed. In four Trusts the average length was 6 months; in three Trusts it was 9 up to 12 months and in one Trust it was between 3 and 6 months. However the range across all Trusts was reported to be 1 to 24 months; with three Trusts reporting a maximum of 8/9 months; two of 12 months; four of up to 18 months and one up to 24 months. However parental report suggest that these estimates may be under-estimates and waiting times seem longer to them (see p.43).

Improvements

Recommendations for improvements to the referral process included the following.

- More detailed information needs to be provided by the person making the referral; perhaps by completing a pro forma.

- Improved awareness of the referral procedures and process; referral criteria made clear; use of standardised procedure.

- Better health and education collaboration in referral process; maybe one-stop shop for all queries about ASD.

Assessment and Diagnosis

Seven of the eleven HSS Trusts reported that they provided a specialist assessment clinic which was multi-disciplinary in nature. However in all HSS Trusts community paediatricians were involved in making a diagnosis. Other professionals involved were speech & language therapists and consultant clinical psychologists with one Trust mentioning occupational therapy.

The teams involved in the seven specialist clinics all involved a paediatrician and speech & language therapist and most had psychologists (clinical or educational) also. In some clinics, early intervention therapists, teachers or OTs were involved. In two trusts, one session per month is held, whereas in others it is four, six , eight or 20 sessions.   The number of children seen per month ranges from one to eight. Families typically attend for one session although a second and third session are also held in some clinics with additional consultations with individual professional taking place outside of the clinics.

Children are usually seen in order by date of referral. Exceptions may be the presence of another child with ASD in the family, possibility of breakdown in educational placement or specific difficulties.

While on the waiting list, families may be offered information about ASD if parents request it (3 trusts); ongoing support from health visitors (1 Trust); the child may attend group SLT and OT sessions (2 Trusts); benefit from SLT outreach to playgroups and nurseries (1 Trust). One Trust encourages phone contact with early intervention staff.

Two trusts have plans to decrease waiting times by increasing the number of clinic sessions held (from 1 to 2; and from 1 to 4 sessions) and two further trusts are in negotiations to do this.   One trust commented on the filtering out of inappropriate referrals and another has plans to introduce workshops for parents in conjunction with the ELB. One Trust plans to provide further training for community paediatricians and is bidding to increase the numbers of SLTs, OTs to augment the assessment teams.

In ELBs it is educational psychologists who are involved in making assessments but in one Board, staff from the peripatetic preschool service are also involved. Educational personnel work alongside HSS colleagues.

Informants suggested that the average age at which children received a confirmed diagnosis was between 36 and 42 months with 30 months being the minimum age.

Improvements

Informants were asked to note the improvements needed in the availability of personnel to undertake assessments and to make a diagnosis.

- Reduction in waiting times is essential.

- More personnel with expertise in ASD.

- Resources required for more assessment sessions; especially if an accurate diagnosis is to be given.

- Multi-disciplinary teams are a necessity with an involvement from Education and Health personnel. Some trusts have difficulty accessing medical and psychological input.

- Intervention personnel/services need to be linked with assessments to provide continuity.

- More consistency in assessments across HSS Trusts

Role of Child Development Clinics

Informants were asked their views as to the extent they felt community child assessment and development clinics can assess and diagnose children with ASD, rather than having specialist clinics? The prevailing view was both types of clinics are required.

- Community clinics could undertake assessments and diagnosis of ASD provided the staff had experience and skills in relation to both ASD and multi-disciplinary working; and of working alongside colleagues from Education. Extra resources would need to be provided to clinics to cover the extra time needed with these children along with better facilities.

- Specialist clinics would still be required; to assess children with more complex needs; to enable specialist expertise to be better used and to provide more time for a thorough and robust assessment.   One Trust alluded to the legalities that also surround making a diagnosis and felt that this was therefore best done by a specialist team.   However another Trust noted that assessments need to be done in different environments, such as observing the child with their peers, and not just in clinics.

Specialist services available

Informants were asked to list the services they provided exclusively for preschool children with ASD or those with suspected ASD.

Eight trusts reported having a specialised early intervention services; three in EHSSB area; three in SHSSB and two in WHSSB. In addition some trusts offered specialist therapy services, preschool teachers and playgroups, and social worker support. Details on the number of children using these services was generally not provided neither were the numbers of children on the waiting lists.

In addition Trusts worked with a wide range of voluntary agencies (especially in the Belfast area) although the particular ones varied from one Trust to another. These included Barnardos, PAPA, Belfast Central Mission, NI Music Therapy, LEAP, PEAT,

CEAT, Spectrum Centre and Mencap, as well as services provided by ELBs and other HSS services.   Information on numbers using these services was generally not provided.

All ELBs reported providing some form of support service which included home interventions, support to playgroups, preschool and nurseries and an advisory service provided by preschool teacher linked with a special school.   The numbers reported to use a specialist service ranged from 8 to 65 in three Boards with the numbers on waiting lists reported as 2,8 and 25.   These services were usually not linked with HSS provision.   However the ELBs did report on other educational services used by preschool children with ASD.   In three Boards it was the preschool home teaching service; in two Boards a voluntary organisation provided preschool services and in one board mention was made of specific preschool facilities and in another board of behavioural support team.

Improvements to services
The ELB respondents noted the need for:

- More teachers in peripatetic, early intervention and ASD support services
- More teaching support assistants in early education facilities.
- A strategic plan to further inter-agency and multi-disciplinary working.
- Further training of all preschool staff and families.

The HSS Trust respondents noted the need for:

- Increased SLT therapists
- Increase in occupational therapy, clinical psychology, community paediatricians and social work.
- Increase in early intervention therapists (Also two trusts noted that current EI therapy was provided from short-term funding.)
- Better access to educational psychology.
- Better co-ordination both within health services and between health and education services to avoid duplication and provide seamless service. Not clear to parents how to access services.

Specific Interventions for ASD

A section of the pro forma enquired if the Board or Trust personnel trained and supported families in specified intervention approaches. The numbers reporting each type of intervention are noted below.

TEACCH: In one ELB parents can attend a 3-day TEACCH training. Two further Boards mentioned supporting parents in using these approaches in home or centres. Six HSS Trusts also mentioned using TEACCH.

ABA: Three ELBs provide support to families and it was mentioned by three HSS Trusts. A further Trust listed behaviour modification.

PECS: One ELB provided training for parents and one other mentioned that this is used by support teachers. Four HSS Trusts reporting using this.

Hanen: One ELB mentioned parents would have support and eight HSS Trusts provided support.

Other approaches used: Staff in one ELB and in one HSS Trust (same area) also use Greenspan-Floor time and Portage, another ELB and HSS Trust (different areas) provides training on sensory issues and one ELB offers training in interactive play and one HSS trust mentioned Social Skills Groups during holiday periods.

Comments on specific interventions
Respondents recognised the need to provide a variety of intervention approaches as these should be tailored to meet the needs of the child and/or a 'combined skills' or 'holistic' approach should be used.

Some ELBs felt there was too much emphasis on ABA from a small group of vocal parents and that more needed to be learnt about how all the various interventions worked in practice – strengths and weaknesses. One HSS Trusts attempts to maintain a reliable research base on interventions and audits regularly their use within their services. Other Trusts called for further evaluations as they felt the evidence-base was lacking at present.

Improvements
Respondents highlighted the need for staff/parent training in specific interventions through accredited courses. This would require extra resources. Also one Trust noted increased number of professionals would be required to cover a wider range of interventions, ie. Autism intervention workers, SLTs, clinical psychology. This Trust went on to note that health visitors might be available to support families once intervention programmes had been established. One trust felt there should be regional guidance on the various interventions and their value in supporting families. Another trust commented on the need for life-long family training especially at points of transition.

Training and Support for Parents

Respondents reported a range of courses they made available to parents although it was not always apparent whether or not they were attended by parents with pre-school children.

The courses provided through four of the five ELBs included:

- Understanding Autism (2 day course)
- PECS
- Interactive play sessions
- Sensory integration/sensory issues.

Seven HSS Trusts provided training courses and others referred parents to training provided by PAPA or Barnardos. These included:

- Introduction to ASD,
- TEACCH,
- Hanen,

- Use of visual strategies.
- ACCESS workshops provided by PAPA
- Time for you (Caring for carers)
- Behaviour Management

The main aims of this training were reported as giving parents a basic understanding of ASD, impact on families; skills in managing core elements of ASD at home; an opportunity for parents to meet one another and relevant professionals, and to have information on support services and advice on evidence-based interventions. Parent courses were generally seen as a vital part of intervention. Good attendances by parents were generally reported.

Improvements
Among the improvements noted were:

- Joint funding and delivery of courses by education and health.
- Availability of staff to deliver courses effectively
- Availability across centres at the same time;
- Short courses rather than whole day courses suit parents better; also keep informal with discussion of family issues.
- Range of courses required to cover different interventions
- Funding to cover costs of courses

Staff Training

Respondents provided information on courses on ASD provided for staff involved with preschool children in the past 12 months and also in the past three years. A three-tier approach appeared to be used.

All ELBs provided 'general' training for nursery school assistants and teachers. The following one or two-day courses were named:

- ASD general training including structured teaching/ understanding autism/visual strategies;
- Managing behaviour
- Structured teacher training
- ASD support training in special needs
- ASD cluster group training
- Overview of strategies for intervention.

A range of courses were specifically mentioned for teachers, either in special schools, nurseries or peripatetic and support services.

- ProfExel ASD awareness training (online)
- Profexel ABA training
- TEACCH

- PECS
- ICON-ICAN
- Masters in ASD at Queen's University, Belfast.

Two Boards noted courses for educational psychologists (NB These staff were also included in courses for teachers):

- University of Birmingham ADS course for Ed Psychs.
- IABA/ABA Trinity College, Dublin
- Asperger's course
- North-South Conference on Autism
- Sensory issues in ASD

HSS Trusts

The training courses organised by HSS Trusts tended to be for early years personnel, range of HSS staff, doctors and CDC staff. Mostly these were half day or one day courses but could be up to 5 days. These included courses on:

- Awareness training,
- Making a diagnosis,
- TEACCH.
- ICON/ICAN
- Keyhole early intervention

Three trusts mentioned courses for Health visitors and another two Trusts ran courses for doctors.   Other groups of staff reported to have taken part in training were: social workers, playgroup workers, Surestart early years workers, residential child care, children with disability team members and hospital staff.

Four of the eight Trusts provided the training in association with ELBs.   The special interest group that meets bi-annually in PAPA was mentioned by one Trust as a 'haven for training and support'.

Improvements
The following improvements were highlighted by the various respondents.

- Finance to fund training; e.g. fees for externally provided training, range of different training required.
- Staff to deliver training
- Planned programme of training needed for continuous professional development for staff in this area.
- Targeting the training to the needs of specific groups of staff
- Health and Education working more closely.

Several respondents cited staff training as an essential part of their work and one they wanted to develop. They also recognised that much had been achieved.

Priorities for service developments if further resources became available.

The ELB informants focussed on the need to expand the ASD service for the preschool age group with increased numbers of teachers and support assistants. They noted the success of this to date and felt that it could provide prompt support in home/playgroup/ nursery setting and allow for increased parental contact.

Other proposals were:

- Opening specialist ASD nursery units

- Increased training for parents and preschool staff, and skilling of teachers/advisors to supply the service which is currently being provided by outside agencies.

- Continued extension of mainstream provision to include more autism specific learning support classes, development of autism advisory and intervention services –increase in staff for early years.

- Better collaborative working with other services in early years.

HSS Trust informants tended to focus more on increases in the numbers of early intervention therapists but also in OT, SLT, Social work, clinical psychology and paediatrics.

Others mentioned.

- Increase in assessment and diagnostic clinics

- One person to coordinate all ASD provision in Trust who is not attached to any one directorate or budget.

- Increased access to play provision, family support and day care.

- Active intervention of behaviour difficulties when first identified.

- Empowering families with basic skills to cope better.

Possible solutions/improvements that could be made with minimal extra resources or within existing resources

Although respondents stressed the need for additional resources - having noted that often developments to date had been funded from existing resources – they did foresee a number of areas in which improvements could be made at little additional cost. These included:

- Development of more training packages.

- Better communication and coordination of initiatives within and across agencies; use of individual education plans to support integrated working.

- Inter-service working groups to identify and disseminate best practice.

- Improved links with voluntary sector; having directory of services available.

- Using community development strategies to support children with ASD in mainstream settings.

- Isolate specialist team members from CDC work.

- Provision of clerical support to specialist teams.

- Joint research projects using clinical information that has been gathered.

- Improved IT provision (e.g. email).

Partnership working between HSS and ELBs.

Some informants noted that this was well developed in their area and others stressed the importance of maintaining or developing links, especially in assessment and diagnosis. One ELB and HSS trust were working together on a strategy to reduce waiting lists.   One HSS Trust has set up an ASD advisory group from Trust and voluntary/community groups and also an ASD Steering Group with reps from Trust and ELB. The WHSSB has set up a number of planning Groups on ASD on which Trusts and Education participate.

However several informants noted the following:

- There is duplication in provision and gaps that are unfilled by both ELBs and HSS Trusts.

- The skills of specialists across and within teams needs to be monitored to avoid duplication and gaps.

- One multidisciplinary team for each area would be easier for families.

- Joint working is required at all levels – planning and coordination, as well as at individual level.

- Regular meetings are required to discuss issues and this requires time from personnel involved.

Conclusions

A wealth of information has been garnered about the range of services and supports that are available to preschool children and to their families. This provides a baseline against which further developments can be monitored. However there is strong impression of marked variation across Boards and Trusts which is to the obvious disadvantage of families in areas with less well-developed services.

Section 5: Experiences and Views of Parents and Professionals

In addition to the views of informants in the Boards and Trust, information was obtained on the views and experiences of parents, and of professionals in HSS trusts and early childhood educators.

Parents

Three sources of information were available about the experiences and views of parents in Northern Ireland who had a child aged 5 years and under with an ASD.

In the past three years, over 100 parents had been interviewed at home as part of research and development projects undertaken by the University of Ulster in association with PAPA and other agencies: Down Lisburn HSS Trust, S&E Belfast Trust, SHSSB and WHSSB (fuller details are given in Appendix 5).   These interviews covered difficulties experienced by families, their views in relation to assessment and diagnostic services and to various early interventions.   This data was supplemented by focus groups convened by PAPA in the WHSSB area as parents from this area were under-represented.

Community paediatricians in 11 community HSS trusts were asked to circulate a letter to all parents on their waiting lists for assessment with a suspected ASD inviting them to contact a named person at the University of Ulster if they were willing to take part in a telephone interview. An unknown number of letters were sent but 12 parents were interviewed.

The main findings across all these three sample are summarised in the body of the report but fuller details are contained in the reports noted in Appendix 5.

Identifying that there was a problem

• Nine out of 10 parents were aware of the child's difficulties before they were two years of age. (Of 104 families who had a preschool child with a diagnosed ASD, 32% were aware of the child's difficulties before 12 months of age; 35% between 12-17 months; 22% between 18 to 23 months and 11% 24 months or later.).

• The main indicators that alerted the parents to a problem were delayed speech; the child's unusual behaviours; their lack of interaction and suspicion of hearing difficulties.

• In the majority of families it was the mother who first spotted the problem; although in a number of instance both parents noticed it or the father or a grandmother.   However in around one in three families it was a person outside the family who suggested to the parents there might be a problem; most commonly a health visitor. Other professionals named included speech and language therapists, community medical officers and preschool teachers.

• Eight out of ten families contacted their health visitor and four out of ten their GP for advice.

• Some families recounted how these professionals had not listened to them to when they had first voiced their concerns.

Waiting for assessments

- Many parents were frustrated and angry with the length of time it took for assessments to be made and a diagnosis to be given.

- information that parents would have liked available when they suspected a problem was about ASD, the assessment process, charities and support services available.   They would have liked to have had the name of a contact person they could contact with expertise in ASD.

- While waiting for assessments a few parents obtained information from organisations such as PAPA or PEAT, or from professionals such as speech and language therapists or health visitors. However some had no information available to them.

- The majority hoped to obtain a firm diagnosis from the assessment with appropriate provision following. Some families complained about the length of the statementing process.

Assessments

- Various professionals were named by parents as having assessed their child. The most commonly mentioned were community paediatricians (89%) followed by speech and language therapists (60%). Hearing assessments were mentioned by over one-third of parents. Other professionals mentioned - but by less than one-third of parents - were occupational therapists and physiotherapists.   Preschool teachers and educational psychologists were mentioned by less than one in ten parents.

- On the whole parents attending specialist assessment clinics (N=45) found the assessment process helpful; most felt there had been time for their questions to be answered; the process had been explained to them, a thorough assessment had been done and they were satisfied with the conclusions reached.   The aspects that more parents were less happy with – although a majority were nonetheless happy – included not being sure of the next step and having a clear picture of the child's strengths and weaknesses.   Few parents had any suggestions for improvements. Five parents commented unfavourably on the length and intensity of the assessments and the settings they were done in. Three commented on the lack of support and information offered following the assessment.

Difficulties reported by parents

- According to parental ratings on the Vineland Adaptive Behaviour Scales, the children's development ranged from those who were markedly delayed to those whose scores were close to the range for their age group. However most children did show developmental delays; especially in the communication, socialisation and daily living skills domains.

- Over three-quarters of parents reported that their child had problems with language, with play and relating to other people.   Other problems mentioned by more than half the families were the child's unusual interest in toys or objects and problems with adapting to change.

- Around half the families reported behaviour management difficulties such as hyperactivity, aggression and sleep problems.

- Three quarters of parents felt that they did not have the necessary skills to deal with the child's problems.

- Parents described a variety of impacts the child had on their family. The most commonly mentioned were social limitations on the family; the continual strain they experienced; constant supervision that was required and the other children in the family losing out.

Services and supports

- Speech & language therapy was the most commonly mentioned service received by families whose child had a confirmed diagnosis of ASD in the previous 12 months (around 90% of families mentioned this).   Health visitors were the next most frequently mentioned (75%) and around two-thirds of parents reported contacts with community doctors, GPs and educational psychologists.   Fewer than half the families had contact with social workers or other therapists and most would have liked more contact.   On average, parents reported contacts with 5-6 different professionals in the past year although this may have been limited to one consultation. Parents felt a post-code lottery operated in who received services.

- In general, parents mostly reported that these contacts were helpful. Comments about unhelpfulness tended to reflect a lack of follow-up by the professional, lack of time spent by professionals in giving explanations to parents, pessimistic attitude to the child, lack of knowledge about autism and insufficient contact.

- The children attended a range of early education facilities including nursery school, primary schools, playgroups, crèches and parent-toddler groups. Most expressed satisfaction with their choice.

- The gaps in provision noted by a minority of families were for more speech & language therapy; parent education/support groups; and specialised placement for children with ASD in preschools and in schools.

- The majority of parents aspired for their child to attend a mainstream school with learning support available. The most commonly given reasons were that it was in their neighbourhood, and that the siblings attended. Around one in five parents were considering a special school placement.

- Around four in ten of the families surveyed were in contact with parents whose children had similar problems. Informal support came mainly from their families; around two-thirds mentioned this. Around one in four families had no sources of informal support.

Home-based intervention

Information was available from 49 families who had taken part in a home-based early intervention programme (Keyhole and Rainbow Box project).

- The children showed significant improvements in their developmental scores from the Vineland Scales notably in communication and socialisation. Parents rated their

child as having fewer problems with play, language and relating to other people. Independent assessments of the child pre and post the intervention also identified significant improvements.

- All but two families found the intervention helpful and would recommend it to others.

- The main reasons given for its helpfulness was that it provided them with support, gave information about ASD and provided the child with a means of communication.

- The most commonly expressed improvements were for the programme to have more visits; to continue for longer; and for the visitor to spend longer time with the child.

- The two forms of continuing help most commonly mentioned when the programme ended was for a named contact person/key-worker and for continuing speech and language therapy.

Conclusions

- Parents are aware of the child's difficulties by two years of age yet they may wait a considerable time before a diagnosis is made. Families require information and support during this time. Most require information on promoting communication, play and social relationships. Around half encounter behaviour management problems.

- Health visitors and GPs are the professionals they are most likely to contact when they suspect a problem.

- Present assessment procedures are generally well received by families.

- Community paediatricians and speech & language therapists are the two professions that families have most contact with. However in the course of a year, families may have contact with 5-6 different professionals.

- Home based interventions were welcomed by families for the support it gave parents, the information conveyed on ASD and the focus on communication.

Professionals' Views

As part of the study, pro formas were mailed to community paeditricians and managers of the following professions within the 11 community HSS trusts – speech & language therapy, health visiting and occupational therapy. In addition hospital-based paediatricians and child and adolescent psychiatrists were also contacted. Replies were received from 25 respondents (9 speech and language therapists, 7 community paediatricians, 4 health visitors, 4 occupational therapists and 1 child and adolescent psychiatrist).

In addition the views of 35 HSS professionals (20 health visitors; 6 SLTs, 4 Community paediatricians, 5 others) to early intervention services for preschool children with ASD in WHSSB had been obtained in another study (McConkey, Truesdale-Kennedy and Barr, 2005) and for 30 professionals in the SHSSB area (McConkey and Truesdale, 2004).

Specialist assessment clinics

The main advantage of having specialist clinics were seen to be for assessment and confirmation of diagnosis, the availability of a multi-disciplinary team of professionals with appropriate skills and knowledge; the availability of advice and support to parents.

The most frequently reported improvements were for more clinics to be held to decrease waiting times; better inter-disciplinary communication; and more resources for staffing. Other suggestions included better pre-clinic contacts; better follow-up; and more awareness of the service.

Although some professionals felt that community assessment and development clinics could assess these children, it would require extra resources for this to happen and still more complex cases would require a specialist assessment.

Service developments

• Personnel in community clinics required training in skills and knowledge related to ASD and in multi-disciplinary approaches. Also mentioned were better links with local and regional support groups.

• Professionals wanted to have more time allocated to work with the children and for a named person/key-worker system to operate.

• The main unmet service needs they perceived were:

- Inadequate access to diagnostic services

- Poor information giving and support to families

- Lack of follow-up and early intervention

- Lack of suitable educational provision for children with ASD

- Lack of child-minding, short break services and summer schemes for families.

Priorities

The main priorities for service developments were:

- Support for families, notably in early intervention.

- Multi-disciplinary working

- Joint working between Health and Education.

- Reduce waiting times for assessment.

Improved working between education, health and social services could come from:

- More multi-disciplinary working

- Joint training

- Better communication

- Joint meetings

- Better integrated service.

Conclusions

The two dominant themes in professionals' responses were:

- Improved diagnostic and assessment services to reduce waiting times;

- Better support for families from when the problem is recognised.

They also stressed the need for multi-disciplinary and inter-agency working.

Views of early years educators

Although information was not specifically sought from early year's educators for this study, this information had been obtained in various projects in the EHSSB area (56 staff in playgroups and 68 participants in an ASD training course: McConkey et al, 2003) and from 40 early years educators in the WHSSB (including playgroup leaders and teachers: McConkey et al, 2005).

Experiences

- The majority of respondents reported having had a child with ASD within their facility in the past five years (range 1 to 35 children).

- Around half, reported receiving advice and support from:
    - Visiting teacher/adviser
    - Speech and Language therapist
    - Psychologist

- Half the respondents reported they would be willing to have a child with ASD in the future with nearly all the remainder stating they would consider if asked. The main reasons cited for accepting a child were:
    - the appropriate resources and support are available;
    - all children should be included and have the right to an education;
    - more aware having been on training courses;

- The reasons given for having to refuse a placement:
    - the lack of specially trained staff.
    - availability of staff and overall staff-child ratio.
    - lack of support to staff
    - if the child was physically aggressive towards another pupil or staff.

Needs

- The main support requirements they had were:
    - Visits/outreach support from professionals
    - Training
    - Special needs assistant/support workers

- The main training needs were:

- Techniques and strategies for assisting children with ASD in groups or classes.
- Knowledge about ASD
- Supporting parents
- Managing behaviour
- Promoting communication.

Impact of training

NIPPA in association with PAPA have developed a six-session module on ASD. Staff who have taken this module reported:

- A greater understanding of autism
- Using structured teaching approaches with the child in group or class;
- More use of visual communication with children.
- More confidence in working with the children.

Conclusions

Early years personnel already have an involvement with preschool children with ASD and appear willing for this to be extended. The need for training has been highlighted and the success of new courses directed at preschool personnel has been noted.

Likewise, support from knowledgeable professionals is also required.

Section 6: Consensus study on recommendations

In the preceding three sections a range of recommendations and standards for good practice were identified in service provision to preschool children with ASD and to their parents. The final stage of the information gathering consisted of a postal survey in which volunteer participants agreed to rate a series of recommendations that had been culled from the response to questionnaires allied with literature reviews and policy statements.

Respondents were asked to indicate their agreement on a five-point scale ranging from strongly agree, agree, neutral, disagree and strongly disagree. In additions, the recommendations had been grouped into four sections (see below) and within each section they were asked to identify two priority recommendations. In summary, the main aim was to identify the recommendations and service standards that commanded widespread support.

In all 16 people responded, which was a disappointing response as over 30 questionnaires had been posted. Replies came from speech and language therapists, educational psychologists, paediatricians, clinical psychologists, senior education officer, an occupational therapist and health visitors. Hence a range of professionals were represented.

Listed below are the recommendations with which no one disagreed and at least one respondent identified as a priority. In italics are recommendations with which no one disagreed but also no one identified as a priority. The recommendations listed first are those on which agreements were highest.

(NB Details of recommendations on which some respondents disagreed can be supplied on request but they were few in number.)

Theme 1:Strategy

Education, health and social services, must make an integrated response to the needs of these children *and* of their families. This will be manifest in joint training for staff, joint working in assessments, and joint delivery of a range of intervention approaches.

Voluntary and community services, such as Sure Start and playgroups have a major contribution to make in supporting preschool children and their families. Statutory services must seek partnerships with them.

A small number of staff within and across a number of specific professional groups should have particular expertise in this area so that they can provide consultancy and training to other staff groups, and to whom specific families can be referred who experience more complex needs. These professionals should work across areas that equate more to ELB Board areas than to the present HSS Trust areas.

Children and family should be able to access appropriate help and guidance from services without having a diagnosis.

A co-ordinator of preschool services for children with ASD will be nominated from existing staff in either ELB or HSS Trusts. They will form a main point of contact for families and act as a service 'spokesperson'.

Preschool children with ASD should be able to access mainstream early childhood facilities in their locality. This includes child-minding, crèches and summer schemes

Theme 2: Assessment

A multi-disciplinary assessment is recommended consisting of community paediatricians, speech and language therapists and psychologists (likely educational psychologists). Other professionals may also be involved as required, e.g. social workers and OTs.

Services within a defined geographical area should hold a common dataset on all children assessed as having an ASD so that numbers and characteristics of the children can be summated across Northern Ireland and monitored over time.

An accurate assessment of the needs of the child along with a defined, individual plan to meet those needs is more important that a diagnostic label.

Specialist assessment clinics should be available within each HSS Trust and in larger geographical areas, preferably in more than one location.

Professionals in Northern Ireland should be encouraged to use a common set of assessment tools. This will assist in sharing of information across and within agencies and professions.

Parents on a waiting list for specialist assessment should be notified that the referral has been made; given updates on when an appointment is likely to be made and provided with suitable information to guide them on ways of helping the child and coping with concerns.

Children with developmental delays and suspected ASD should be assessed as early as is possible and no later than the child's third birthday.

The waiting time to be seen for assessment should not exceed four months from initial referral.

ASD comprises a range of disorders that are not always easy to diagnose. Moreover it can co-exist with other developmental difficulties and impairments. The allocation of a definitive diagnosis may not be possible.

Theme 3: Intervention

Personnel working in early intervention services must be able to implement practical strategies for minimising the child's difficulties and coach parents in their use.

Service audits and reviews should be undertaken regularly. The views of parents should be central to this. The findings should be made widely known and adjustments made as required.

Home-based Support should be available. A trained and experienced professional visits the family at home on a regular basis for a defined period of time. The main focus is often on managing the child but parental support may also be necessary.

Home teaching services provided by Education and home-based HSS services needed to co-ordinate their inputs to families to avoid unhelpful duplication and demarcation of functions.

Data should be kept to enable the outcomes of interventions to be monitored. Services should develop a common set of outcome indicators. These should be open to independent scrutiny.

ASD is essentially a disorder of communication and socialisation. Hence it is vital that interventions which focus on these aspects are widely promoted and used within all services, notably PECs, TEACCH and Hanen.

Group-based Support should be available: A group of parents who have children of similar age meet regularly for a number of sessions. The primary focus is on parent needs.

Any plan that is drawn up must also take account of the family needs and circumstances.

Personnel working in early intervention services must be able to answer parents' questions about autism and its impact on their child in particular.

Personnel working in early intervention services must be able to assist parents to cope with the stresses they may personally experience.

Certain children may also benefit from other approaches, such as ABA and staff with expertise should be available to implement these as required.

Theme 4: Training

People working in primary health care – GPs, health visitors – and in early childhood education, such as playgroups – should have a greater awareness of the signs of ASD and ways of coping with the children's difficulties.

Parents and other family members should be provided with accessible information about ASD and ways of coping with the children's difficulties. This should be available in a variety of formats – print, DVDs, Internet and through telephone advice lines.

Three levels of training courses should be available: *Level 3: Specialist training.* To provide a more in-depth study based on both theory and practice of the topic. Ideally the training would be multi-professional and tutored by persons with recognised expertise in the field. This training would be university-accredited; preferably as postgraduate level. It may be provided on a UK or all-Ireland basis.

Level 1: Awareness training courses for community staff and families; round 6 –12 hours or 2 working days - (this would also cover certain elements in NVQs). These should be available locally either face-to-face or by electronic means

Level 2: Foundation training in ASD with particular reference to assessment and specialist techniques. This could consist of a range of shorter training courses would amount to the equivalent of 15–20 working days. These could be provided on a Northern Ireland basis.

Child-minders, personnel working in crèches and on summer schemes also need to be made aware of these children's needs and supported to provide places in their services.

Professional staff in a wide range of settings can act as distributors of information and provide families with contact addresses where they can seek further help locally.

Conclusions

The consensus study provided indicative data of the main priorities for service improvements and developments. These were derived from experiences of parents and professionals within Northern Ireland but many echo recommendations internationally.

Although some of these recommendations could be incorporated into better professional practice, many require a more strategic push for them to become a reality throughout Northern Ireland alongside an increase in resources to meet the new demands.

Hence the final section of the report deals with how strategic planning might be advanced.

Section 7: Strategic Planning

The justification for strategic planning with respect to early intervention in autistic spectrum disorders can be summarised as follows.

- In recent years the numbers of children being identified with ASD has increased significantly in most affluent countries including the UK and Ireland.   As yet the identification is not uniform across all areas of Northern Ireland but as this happens, the numbers will continue to rise.   In time the numbers may level off (or even drop if the birth rate continues to decline) but they will still represent a sizeable number of children with particular needs (currently estimated at 6 per 1,000).

- The Children Order (NI) (1995) requires HSS Trusts to take reasonable steps to identify 'children in need' in their area; to assess the needs of such children and to make an integrated response in meeting their needs.   Likewise the Education (NI) Order (1996) places a duty on Education and Library Boards to identify and assess children who they think have, or will have, special education needs.   It would seem sensible that these duties are undertaken in strategic and planned ways by these bodies or their successors.

- There is plenty of evidence that present service provision in Northern Ireland to these children and their families is very uneven. Informants from ELBs and HSS trusts have provided the data; professional staff have made strong representations for change and families are increasingly aware of the variation in availability of services. This inequity is impossible to justify (although excuses can be given) and must be rectified. Strategic planning is one means for achieving this.

- As in other areas of health and education, the expanding knowledge base regarding the diagnosis and interventions of ASDs necessitates an increase in resources in order to meet family and society expectations. If this is done on an 'ad hoc' basis, which mostly has been the case thus far, then inequities are likely to arise. It often generates confrontations as scarce resources are fought over. Again a more strategic approach would allow for businesses cases to be produced and incremental increases in spending to be budgeted.

- Ultimately the failure to plan strategically often stems from a lack of priority given to an issue.   In modern society this often comes from politicians and from the media.   Both groups are taking an increased interest in ASD as evidenced by the All-Party Parliamentary Group on Autism at Westminster and the Autism Ambassadors within the NI Assembly. Indeed a formal launch of the 'Politics for Autism Report' is planned for early 2006 at Westminster and in the Welsh and Northern Ireland Assemblies. Also there are increasing numbers of newspaper and television reports and programmes relating to autism. A Strategic Plan can also help to inform and mobilise support from these two groups.

Towards developing a strategic plan for Northern Ireland

Following discussion with the Project Steering Group, a number of proposals were formulated to assist in developing co-ordinated, multi-agency strategic plans for ASD

in the early years. The central driver of the process is seen to be an inter-departmental group between DofE and DHSSPS but this must be complemented by actions at a more local level.

Figure 7.1: Proposed framework for strategic planning
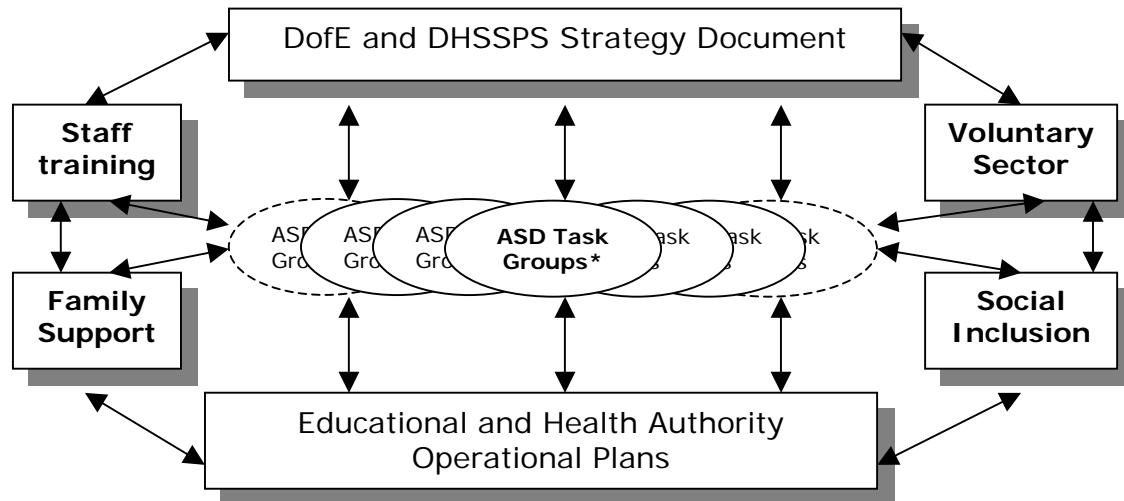
* One per existing ELB areas or each new district council area.

Policy

DofE and DHSSPS should produce a joint strategy on assessment and intervention with preschool children with ASD and support for their families. However this 'early years' strategy should cover the age range 0 to 8 years so as to include the children's school placement up to the end of Key Stage 1 and the identification of those with Asperger's Syndrome.

This strategy document would identify policy and good practice on topics such as:

- establishing a shared database on children identified as having an ASD which could also be used to monitor and track service provision and interventions;

- procedures for early identification and referral among primary healthcare staff;

- information and support for parents whose children have suspected ASD;

- multi-disciplinary, multi-agency assessments;

- the role of specialist clinics;

- post-diagnosis intervention and support services in preschool, nursery and Key Stage 1.

Already a good start has been made with an Inter-Education and Library Board Group set up on ASD and two HSS Boards are currently working on a strategy on ASD with their corresponding ELB.

Furthermore the Inter-Departmental Group for Special Educational Needs (SEN IDG) could provide an overall context for this work. For example, the Steering Group formed for this project might be reconstituted as a subgroup of the SEN IDG to take forward this work on a time-limited basis. This exercise would be especially

appropriate given the new departmental roles envisaged in the Review of Public Administration and the increased emphasis on 'joined-up government'.

An external agency/consultant could be commissioned to facilitate this exercise.

Given the extent of agreement on the way forward reported in this study, this work could be completed by mid-2006. It is important that it is completed speedily as it will help to drive forward the subsequent steps in the process.

ASD service provision

The operations of the policy would be the responsibility of the two new bodies envisaged in the Review of Public Administration; namely the Education Authority and the Health Authority. Although details are unclear as yet, both bodies potentially provide a means of ensuring more equitable service delivery across Northern Ireland. This might also be a time to explore the possibility of ring-fenced, joint funding of specific services, such as those provided to children with special needs.

Based on estimated numbers presented earlier in the report, throughout Northern Ireland there would be around 900 children aged 0-8 years with some form of ASD; around 130 in any one of the seven new district council areas; with around 20 children joining this grouping each year and a similar number leaving.

However it is important that due cognisance is taken of local needs and existing service provision. To this end, during 2006 joint ASD Task Groups could be formed in each of the seven proposed District Council areas or as an interim measure in the existing five ELB areas. They would provide a 'blue-print' for the development of joint assessment and diagnostic services; the provision of early intervention services; parent and family support and staff training initiatives. This process should help to ensure that existing good practices are maintained as well as addressing specific short-comings. The preparation of business cases would be a priority in obtaining funding.

Nominations to the five/seven local ASD Task groups would be sought from ELBs, HSS Boards and Trusts, primary care commissioning groups and the voluntary sector. A convenor would be appointed/agreed for each Group. The convenors would meet to share information and hopefully evolve a common approach to their planning. Until such times as the two authorities are established, the convenors group might 'report' to the SEN IDG and they could be co-opted members of it.

This stage of the process could be completed by Spring 2007 so that local plans would be submitted to the two new authorities thereby enabling a co-ordinated plan to be developed for Northern Ireland as a whole. This should be 'rolled out' in the financial years 2007/08 onwards.

Staff training

A priority within both the strategic and operational planning described above is the development of an integrated, regional training strategy for staff working in education, health, social services and in the voluntary and community sectors. However it is crucial that training is made available at a locality level as well as regionally.

A three-tier training plan needs to be developed:

1) Increasing the competence of 'mainstream' services to assist these children and their families (especially GPs, health visitors and early years education);

2) Equipping professionals such as therapists and teachers with the basic skills to assess and plan interventions to assist these children and their families;

3) Developing specialist and trans-disciplinary expertise among different professionals.

Existing systems have inhibited the development of an integrated, regional strategy but the proposed new authorities provide an opportunity for doing so, especially if strong links are formed between them and the existing and potential training providers in the voluntary, statutory, further and higher education sectors. In particular the DHSSPS have supported the development of PAPA as a lead training agency in ASD within Northern Ireland.

Hence there is a strong foundation on which to build a regional training strategy given the training expertise presently to hand within Northern Ireland and the variety of means for accrediting training that are available. The new Education authority could take the lead in this work given the explicit responsibilities it will have for staff development and training. This would help to clarify the training function of the proposed Cross-Border Centre for Autism in Middleton, Co Armagh.

This element of the strategic plan could be implemented from 2007 onwards.

Voluntary Sector

Parent Groups and voluntary organisations with an interest in ASD have made a major contribution to the development of services thus far. This needs to continue and this sector should be seen as partners with statutory services.

Their engagement in strategic and operational planning should help in co-ordinating their lobbying among local politicians, the media and the wider public to make them more aware of the needs of these children and their families. Particular emphasis should be placed on success stories and on sharing resources and expertise across the sector and with other agencies.

This sector has a vital role to play in supporting families.

Supporting families

Families with concerns about their child's development, and those who have received a diagnosis, should have easy access to information and support preferably through a 'one-stop' facility. This is best delivered at a local level but might be better co-ordinated regionally especially in the preparation of information resources. In the longer term this type of service might be integrated with information services for families in general.

The proposed ASD Task groups should give particular consideration to the issue of supporting families. This must be seen as an essential element of the work of all staff and not made the responsibility of any one professional group. Nonetheless there is merit in the concept of each family having a named or key-worker who can act as the main point of contact.

Opportunities must be created to train and empower parents and other family members.   Certain training courses provided for professionals might be open to parents, or adapted for them, as already happens in certain areas of Northern Ireland.

Siblings of children affected by ASD deserve special attention. Opportunities should be provided for their needs to be met. This is probably best done by voluntary or community agencies within the context of sport and leisure pursuits.

Social Inclusion

Another strand in planning and service delivery needs to focus on the children themselves and their age peers who arguably have been overlooked in this report. The aim would be to promote the child's social inclusion within their local community and nurture positive attitudes towards children who are different.   Priority should be given to developing and sustaining options for supporting children with ASD in mainstream settings. This is in accord with parents' wishes and the accumulating expertise in making such a strategy successful. However this will not suit all children but when specialist placements are used, determined efforts must be made to promote contacts with their age peers.

Conclusions

This section has outlined the critical elements of the strategic plan for ASD in the early years. The basic presumption is that this is best achieved through partnership working.   However the present reality is that many different and diverse agencies and groups exist, each with a valid and valuable contribution to make. Some will want to do continue working in their own way or in their own locality; taking little account of another's efforts.   Hence the over-riding priority is to create structures and systems that will encourage partnership working while strengthening local initiatives.   Fortunately in Northern Ireland there is growing expertise, experience and willingness in making this a reality. There never has been a better time to embark on developing a regional strategy for ASD in the early years.

Appendix 1: Members of the Steering Group

Appendix 2: Definitions of ASD

Appendix 3: Screening and Assessment Tools

Appendix 4: References to Literature

Appendix 5: Information obtained from parents

Appendix 1: Members of the Steering Group

John Hunter (Chairperson), ETI, DE
Irene Murphy, Special Ed Branch, DE
Patricia Wyers, Statistics and Research Branch, DE
Nuala McArdle, DHSSPS
Clare Mangan, SELB
Carole Adair, SELB
Kate Doherty, SEELB
Joanne Atkinson, SEELB
Gillian Gamble, NEELB
Clare Bailey, Homefirst HSS Trust
Heather Crawford, Down Lisburn HSS Trust
Helen Beckett, NICCY

In attendance:

Arlene Cassidy, PAPA: NI Autism Charity
Greg Kelly, University of Ulster
Roy McConkey, University of Ulster

Appendix 2: Definitions of ASD

Diagnostic criteria for "Autistic Disorder" (DSM-IV, 1994):

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

> a) marked impairment in the use of multiple nonverbal behaviours, such as eye-to- eye gaze, facial expression, body postures, and gestures to regulate social interaction

> b) failure to develop peer relationships appropriate to developmental level

> c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

> d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:

> a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

> b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

> c) stereotyped and repetitive use of language or idiosyncratic language

> d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities as manifested by at least one of the following:

> a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

> b) apparently inflexible adherence to specific, nonfunctional routines or rituals

> c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)

> d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

Diagnostic criteria for "Autism Disorder" (ICD-10; WHO 1992)

At least 8 of the 16 specified items must be fulfilled:

a) Qualitative impairments in reciprocal social interaction, as manifested by at least three of the following five:

1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction

2) failure to develop peer relationships

3) rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness

4) lack of shared enjoyment in terms of vicarious pleasure in other peoples' happiness and/or spontaneous seeking to share their own enjoyment through joint involvement with others

5) lack of socio-emotional reciprocity.

b) Qualitative impairments in communication:

1) lack of social usage of whatever language skills are present

2) impairment in make-believe and social imitative play

3) poor synchrony and lack of reciprocity in conversational interchange

4) poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes

5) lack of emotional response to other peoples' verbal and non-verbal overtures

6) impaired use of variations in cadence or emphasis to reflect communicative modulation

7) lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

c) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by ate least two of the following six:

1) encompassing preoccupation with stereotyped and restricted patterns of interest

2) specific attachments to unusual objects

3) apparently compulsive adherence to specific, non-functional routines or rituals

4) stereotyped and repetitive motor mannerisms

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5) preoccupations with part-objects or non-functional elements of play material

6) distress over changes in small, non-functional details of the environment.

d) Developmental abnormalities must have been present in the first three years for the diagnosis to be made.

Appendix 3: Screening and assessment tools

Although several instruments have been designed to assess autism in young children, it is recommended that no single autism assessment instrument be used as the sole basis for diagnosing autism. This Appendix briefly describes the various tools that are reported in the literature.

Autism Behaviour Checklist (ABC; Krug, et al, 1979) is one of the oldest of the autism checklists. Its demonstrated specificity and sensitivity is relatively low and it is considered of limited usefulness (NY State Department of Health Early Intervention Program, 1999). It is not a diagnostic instrument but has been described by de Bildt et al (2005) as the only available standardized, internationally applied instrument for autistic symptomatology, suitable for screening a large population.

The Autism Diagnostic Interview- Revised (ADI; Lord et al, 1994) is an investigator-based parent interview. It is tied to current diagnostic criteria and has excellent reliability and validity, good sensitivity and specificity, and it is now considered a necessary component of a diagnostic evaluation (Tidmarsh and Volkmar, 2003). It does require extensive time and training to administer and may be most useful as part of a more in-depth assessment in children for whom screening tests suggest a fairly high level of concern for autism (New York State Department of Health Early Intervention Program, 1999). For children under 4 years the coding uses current symptoms only. When administered at initial ascertainment as part of diagnostic screening, using the standard diagnostic algorithm threshold score for autism of 21 for nonverbal children and 22 for verbal children, it has been found to be valid in diagnosing autism in preschool children (Lord et al, 1993).

Autism Diagnostic Observation Schedule (ADOS; Lord et al, 2000) is a semi-structured assessment of play, interaction, and social communication. Although it can be used as part of a multidisciplinary intake assessment, it is standardised on the basis of extensive training of clinicians before it can be administered, which limits its practicality (New York State Department of Health Early Intervention Program, 1999). Although not initially designed as an outcome measure, it is a sensitive, standardised measure of current functioning and test-retest reliability is adequate (Aldred et al, 2004). As a companion to the ADI-R, the Autism Diagnostic Observation Schedule-Generic (ADOS-G) has good reliability for determining children in the autism spectrum (Tidmarsh and Volkmar, 2003).

Childhood Autism Rating Scale (CARS; Schopler et al, 1988) is a useful instrument for children ages two and over that can distinguish children with ASD from children with other developmental disorders, as well as distinguish amongst levels of severity within the autism range. It is imprecise in its descriptive ability but has good reliability and validity although these are in need of updating, even when used by raters who are relatively naïve to autistic spectrum disorders. It is constructed to be immediately useable with minimum training by professionals from a wide variety of disciplines. Saemundsen et al, (2003) indicate that the CARS represents a broader diagnostic concept of autism than the ADI-R and it tends to capture a more global impression of the child (Tidmarsh and Volkmar, 2003).

Checklist for Autism in Infants and Toddlers *(*CHAT; Baron-Cohen et al, 1992) was developed to identify children at risk of autism at 18 months of age. It has been

designed to be used by general practitioners or health visitors at a child's 18 month checkup. It has been shown to be able to distinguish between children with autism, developmental delay, and normal children (Baron Cohen et al, 1996), and autism and other developmental delays (Scambler et al, 2001). It is the most well known screening test for identifying possible ASD in very young children. However, it may incorrectly identify autism in children with severe developmental delays who otherwise are not autistic, and may miss some children whose early symptoms are mild and nonspecific and whose symptoms have not yet emerged (New York State Department of Health Early Intervention Program, 1999). There is not yet sufficient validity data on the CHAT to support its use as a second-level screen for ASD in two year old children (Wetherby et al, 2004)**.**

Conners' Rating Scale (CRS-R; Conners, 1997) assesses children aged 3 to 17 for behavioural problems, hyperactivity and attention-deficit disorder. There are two versions of the CRS-R; the *Parent Rating Scale* (completed by the parents or caregivers of the child), and the *Teacher Rating Scale* (completed by the teacher/tutor responsible for administering or supervising the intervention). Although not used primarily for autism *per se*, this tool has been identified as important in the assessment of the effects of interventions for autism on behavioural difficulties (Handen et al, 2000) and it provides a compliment to those measured by the Vineland Adaptive Behaviour Scales (VABS).

Children's Social Behaviour Questionnaire (CSBQ; Luteijn et al, 1998) is a parent questionnaire that aims to measure problems in subtle social skills in children with milder forms of PDD. Although it was originally developed for, and investigated in, children with normal intelligence, its psychometric qualities with respect to test–retest reliability, inter-rater reliability and internal reliability of the scales, and convergent validity were reported to be good. As the instrument is simple and short, it is a relatively easy way to measure specific social skills. It not only has specific value as a measure of subtle social skills to identify PDD, but also can differentiate between levels of intellectual disability (de Bildt et al, 2005).

Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP; Wetherby and Prizant, 1998, 2002) is a standardised tool designed for screening and evaluation of communication and symbolic abilities of children between 12 and 24 months of age. It seems well suited for early identification of very young children with ASD because it measures prelinguistic skills that have been identified as deficits in preschoolers with ASD and should be evident in younger children. One of the components of the CSBS DP is the Infant-Toddler Checklist. Wetherby et al (2004) found that the Checklist was an effective tool for identifying children with ASD as having a communication delay in a first-level screening. Unlike the CHAT or M-CHAT, the Infant-Toddler Checklist is not designed to screen specifically for ASD, but rather, is designed as a first-level screen for children with a broad array of communication delays. Wetherby et al (2004) suggest that children with ASD are likely to have low scores on the Social composite of the Checklist and this pattern could be used to indicate the need to conduct an autism-specific screen, such as the CHAT or M-CHAT.

Developmental Behaviour Checklist – Primary Carer Version (DBC; Einfield and Tonge, 2002) is a 96 item parent, or carer, completed checklist designed to measure

behavioural and emotional disturbance in children and adolescents with intellectual disability. Although it is designed for children ands adolescents aged 4–18 years, Gray and Tonge (2005) suggest that it is a potentially useful screening tool for autism in children aged 18–48 months with developmental delay. A DBC Early Screen is planned to assist early childhood primary care professionals with the identification of developmentally delayed young children who may benefit from a referral to a specialist autism assessment service.

Diagnostic Interview for Social and Communication Disorders (DISCO: Leekam et al, 2000) is an interviewer-based schedule for use with parents and carers. It has excellent inter-rater and test–retest reliability, and is highly valid for assigning diagnoses (including common co-morbidity diagnoses) in the autism spectrum. It includes a range of items intended to detect milder forms of autism spectrum disorders. In addition, the DISCO has a developmental perspective and is specifically intended for use throughout the person's lifespan (Wing et al, 2002).

However, for use in diagnosis, algorithm items for ICD childhood autism should not be applied in isolation but instead the qualitative and developmental nature of behaviour should be taken into account by reference to other areas of the DISCO. Currently, this may be achieved by the interviewer combining clinical judgement with the use of algorithm items. In contrast, the algorithm for autistic spectrum disorder which incorporates information from other DISCO items and emphasises the quality of behaviour appropriate to both age and level of ability, can be used by clinicians in its present form. A major advantage of the DISCO is that it facilitates the systematic recording of details of different aspects of development, allowing it to be used to investigate the problems and needs of individual children even if they do not fit neatly into a defined sub-group (Billstedt et al, 2005).

Gilliam Asperger's Disorder Scale (GADS; Gilliam, 2001) is designed to evaluate children with unique behavioral problems who may have Asperger's disorder. Both validity and reliability have been supported.

Gilliam Autism Rating Scale (GARS; Gilliam, 1995) comprises four subtests, eachdescribing behaviours symptomatic of autism. It is appropriate for persons aged 3 to 22 years, and is designed for use by teachers, parents, and professionals. It has strong psychometric characteristics confirmed through studies of test reliability and validity although South et al (2002) have raised some concerns about its use in a diagnostic setting.

M-CHAT (Robins et al, 2001) is a modified version of the CHAT. It has been used to screen children at their 18 month well-baby checkup (18–25 months of age) and a high-risk children in receipt of early intervention services (aged 18–30 months) (Robins et al, 2001). However, there is no sufficient validity data on the M-CHAT to support its use as a second-level screen for ASD in the second year of life (Wetherby et al, 2004).

Pervasive Developmental Disorder Screening Test II (PDDST-II*;* Siegel, 2004) is a screening test designed for administration in different settings where there are concerns about possible ASD. Sensitivity and specificity are adequate, with the exception of low specificity for the developmental care setting.

Psychoeducational Profile-Revised (PEP-R; Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) provides a developmental approach to the assessment of children with ASD. It is an inventory of behaviours and skills designed to identify uneven and idiosyncratic learning patterns. The test is most appropriately used with children functioning at or below the preschool range and within the chronological age range of six months to seven years. The PEP-R provides information on developmental functioning in imitation, perception, fine motor, gross motor, eye-hand integration, cognitive performance, and cognitive verbal areas. It also identifies degrees of behavioural abnormality in relating and affect (cooperation and human interest), play and interest in materials, sensory responses, and language. Independent reviews have identified areas of concern about the PEP-R. Mirenda (1995) stated that the PEP-R is psychometrically weak in the areas of validity, reliability data, and has a small normative sample. Tindall (1995) cited difficulty in administration, weak construct validity, and generally poor scientific evidence supporting its usefulness. More recently, however, Steereman et al (1997) concluded that the PEP-R is a good tool for assessing children with ASD with adequate reliability and validity and Shek et al (2005) demonstrated that its psychometric properties are stable across cultures and that related findings support the cross-cultural reliability of the tool.

Social Communication Questionnaire (SCQ, previously the Autism Spectrum Questionnaire or ASQ; Rutter et al., 2003) is built on the structure of the Autism Diagnostic Interview and was developed to differentiate PDD from non-PDD children in a clinical sample. It may not be a good screening tool for use at a population level as it does not differentiate Asperger Syndrome from other autism spectrum conditions, nor differentiate between different 'points' on the autism spectrum. The data for its sensitivity and specificity are limited and its capacity to differentiate young children under 4 years of age with autism from those with developmental delay has not been established (NAS, 2003).

Screening Tool for Autism Two-Year-Olds (STAT; Stone et al, 2000) is an interactional assessment of children aged 24–35 months. It is an empirically derived measure designed for use by professionals involved in early identification and intervention and differs from the CHAT in that it was developed as a second-stage screening instrument to differentiate children with autism from children with other developmental disorders (Stone et al, 2000). Although it has a high sensitivity and specificity in populations of children with autism or non-autistic spectrum disorders, it is less accurate at distinguishing children with autism from those with pervasive developmental disorder not otherwise specified (PDDNOS). It is intended to be used in a population of children already identified as having developmental problems and its value is limited by its apparent lack of specificity in a more mixed population. However, if it is used as a screening test, rather than for definitive diagnoses, this need not be a serious problem (Zwaigenbaum, 2005).

Vineland Adaptive Behaviour Scales (VABS; Sparrow et al. 1984) is an internationally well known interview for parents, measuring the adaptive functioning of a child. It is widely used in autism research and may be useful in detecting autism, yet seems to have limited value in detecting PDDNOS (de Bildt, 2005).

Appendix 4: References to the literature

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Appendix 5: Information obtained from parents

Home-based interviews have been conducted with the families of 104 children who had a confirmed diagnosis of ASD in Northern Ireland (see below).

For most families (N=85; 82%) the mother was the primary carer, 9 (9%) reported that it was both parents, 5 carers (5%) reported that the father was the main carer with one (1%) family reporting that the grandmother was the main carer. (Four families did not provide information).

In all, 71 (68%) families reported having a wage earner in the household, compared to 28 (27%) who did not. This was not answered for five families (5%).

The age of the main carer was mostly between the ages of 30 to 39 (N=61; 59%), with 28 (27%) carers under the age of 30 and 11 (11%) carers between the ages of 40 and 49. Four cares did not report their age.

As with the age of the main carers the spouses were mainly aged between 30 and 39 (N=55; 53%), with 16 (15%) spouses reported to be between the ages of 40 and 49, 13 (13%) under the age of 30 and 4 (4%) spouses between the ages of 50 and 59. Six (6%) spouses did not report their age. For 10 (10%) carers this question was not applicable.

Most (N=41; 39%) main carers were reported to have O'Levels/G.C.S.E's, 33 (32%) had higher education and 12 (12%) had A-Levels. Thirteen (13%) main carers reported to have left school at 15. The remaining 5 carers did not report their educational background.

Parents were asked if they owned their own home, 75 (72%) stated that they did while 24 (23%) reported that they did not. Five families did not provide this information. For those persons who reported that they did not own their own home 13 (13%) lived in council accommodation, 6 (6%) lived with their parents and 5 (5%) carers lived in privately rented accommodation.

In regard to ethnicity 99 (95%) carers were white with 1 carer stating that they were "other". Data was missing for 4 carers.

Of the 104 children, 91% (N=95) were male and 9% (N=9) were female. The children were aged between 2 and 5 years; four-fifths were aged 3 to 4 years. Thirteen (13%) of the families reported that they had other children with similar problems.

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