

# **INDEPENDENT REVIEW OF AUTISM SERVICES**

**Chaired by Lord Maginnis of Drumglass**

**6 May 2008**

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# **The Lord Maginnis of Drumglass**

## **FOREWORD**

Health Minister Michael McGimpsey MLA announced an Independent Review of Autism Services in September 2007. He wanted advice and a properly structured plan on how best to improve provision for those with Autism Spectrum Disorder (ASD), and for their families.

When I was asked to Chair the Review I determined that it was not the role of a highly skilled and experienced Team to evaluate or adjudicate between clinical methodologies but, rather, that it should devise a “Pathway” for early identification, early assessment & diagnosis, and early intervention for those coming on to the autistic spectrum. Thereafter, transitional stages in the lives of those with ASD required consideration. We have researched, consulted widely and, I believe, produced a Report that can assist the Minister to create a cohesive, coordinated and effective provision that is sensitive to the needs of those with Autism and of their families.

I wish to thank the members of the Review Team who have, generously and selflessly, contributed their time and their skill – in spite of the competing pressures they all face. Their commitment and dedication was exemplary.

The entire Review Team is grateful to all those who contributed to the process by providing evidence based on their expertise and experiences.

I believe that the Team, insofar as we have considered all aspects of Autism Services, has identified how the various interventions and services can best be co-ordinated to reduce waiting lists, and help individuals, carers and families find the quality of service and advice they deserve.

I must emphasise that implementation of the Team’s recommendations will depend on greater levels of co-ordination across the different Government Departments than is currently the case. Health and Social Care staff and others in

the voluntary and community sectors who have, heretofore, struggled to overcome so many difficulties, will hopefully, find our structured proposals helpful and rewarding.

**KEN MAGINNIS**

## **REVIEW TEAM MEMBERS**

**Chairman:** Lord Maginnis of Drumglass

**Members:** Dr Stephen Bergin  
Heather Crawford  
Professor Michael Fitzgerald  
Dr Sandi Hutton  
Professor Rita Jordan  
Dr Joan McGuinness

## **THANKS**

The Review Team would like to thank the following for their contribution to the review.

All Parents, Carers and families of individuals on the Autism Spectrum who assisted the Review Team in many ways

The Aspergers Network

Autism NI (PAPA)

Dr Michael McBride, Chief Medical Officer, N.I.

Martin Bradley, Chief Nursing Officer, N.I.

Linda Brown, Deputy Secretary, DHSSPS

Dr M Keenan, University of Ulster

John Cole, Chief Executive, Health Estates, DHSSPS

Sir Reg Empey, Minister for Employment and Learning, NI

Mary Harney TD, Minister of Health Rol

Catriona Ruane, Minister of Education, N.I.

Brian Cowan TD, Minister of Finance, Rol

General Teaching Council for Northern Ireland

An Taoiseach Bertie Ahern TD

Angela MacLeod, Lecturer in Autism, University of Birmingham

Angela McLernon Nursing officer, DHSSPS

St. Mary's Marino Teacher Training College, Dublin

St. Pat's Drumcondra Teacher Training College, Dublin

Chairman, Director and staff at Middletown Centre for Autism

National Autism Society

Northern Ireland Music Therapy Trust

Patricia Lewsley, Commissioner for Children and Young People, NI

PEAT

Police Service of Northern Ireland

Management of the Northern Ireland Prison Service

Education Faculty, Queens University

Principal and staff from St Mary's Teaching College, Belfast

Stranmillis University College, Belfast

St. Mary's University College, Belfast

Wraparound, SHSSB

Specialists from Health & Social Care Trusts

Specialists from Health & Social Services Boards

## **INTRODUCTION**

This report sets out a Framework for the development of Autism Spectrum Disorder (ASD) Services, which the Independent Review of Autism Services believes should be established within Health and Social Care Services (HSC) in N. Ireland over the next 3-5 years. The Review Team recognises the lack of ASD services across N. Ireland, particularly services for older adolescents and adults. Therefore, the need to develop specialist ASD services forms the main focus of the Review report, together with the need to create more co-ordination and cohesion across the broad range of services provided.

While the potential costs associated with developing comprehensive lifetime ASD services would be considerable, we propose that significant progress can be made towards the development of more comprehensive services through better use of existing resources and improved inter-departmental cooperation.

After discussions with several Government Departments, Health and Social Services Boards, Health and Social Care Trusts, and others, the Review Team noted that the unmet health and special care needs linked to ASD have to be seen in the context of a series of competing financial pressures. This makes it essential that we form a clear picture of how we can set out those needs in order of priority, plus a realistic, pragmatic approach to what we can hope to put in place by 2013.

We have set out our proposals for ASD services for children, adolescents and adults in that context. We propose a 'Framework' which provides a blueprint to guide the future planning and development of diagnostic, assessment and treatment/support services within Health and Social Services in N. Ireland. We also propose that the future delivery of these services should be based on a regional ASD Network, which provides services across the 5 Health and Social Care Trusts, linked into other key agencies and sectors, including relevant services delivered from other NI Departments.

The Framework is summarised below. This outlines a Health & Social Care (HSC) service structure which can support a child, adolescent or adult, and their families,

from initial presentation, through assessment within generic services followed by ASD-specific specialist and support services.

The Review Team also recommends that additional resources should be put in place urgently. These should be sufficient to clear the undiagnosed cases totalling 600/700 over the next 18 months – without further cases being added to the existing backlog.

***ASD Service provision Framework***

<b>A</b>	<b>PRE-DIAGNOSIS : CASE FINDING</b>
<b>B</b>	<b>ASSESSMENT &amp; DIAGNOSIS SERVICES</b>
b.1	• <i>Local - Generic services</i>
b.2	• <i>Area - ASD specific specialist services</i>
b.3	• <i>Regional - complex cases</i>
<b>C</b>	<b>INTERVENTION &amp; TREATMENT/SUPPORT SERVICES</b>
c.1	• <i>Early intervention services</i>
c.2	• <i>Specialist ASD teams</i>
c.3	• <i>Continuing care &amp; support services</i>
<p><b>REGIONAL NETWORK</b> – <i>local specialist ASD teams, i.e. ‘b2’ above, work together within a regional ‘consortium’ arrangement, ie. ‘b3’</i></p>	

Key recommendations from the Review Team include additional services, with the services & systems of individual Trusts linked together to achieve a more effective system of service delivery. This should operate on a regional basis to pool resources & expertise. Similarly, there is a need for structured co-operation between NI Departments. The Review Team is grateful to representatives from several of those Departments who have already started to take forward a range of these complementary issues on a co-ordinated effective, and value for money basis.

## **EXECUTIVE SUMMARY**

The Independent Review Team have outlined a series of key recommendations linked to various services which can be improved. These are not listed in order of priority:-

- Reducing the shortfall in existing ASD Service provision and an estimate of the resources required. (Page 60)
- Increased screening services for early years children, involving Health Visitors and others. (Page 33)
- The need for consistent statistical information on the numbers of people affected by ASD and the services they receive. (Pages 35, 66)
- The value of autism awareness training for those in regular contact with people whose lives are affected by ASD. (Page 31)
- Autism awareness training as part of teacher training courses. (Page 30)
- Improved access to information and advice; (Page 72)  
With integrated treatment and advice centres.
- Increased levels of co-ordination between Departments and Agencies to promote a more comprehensive service for people affected by ASD and the consideration of legislation for this purpose. (Page 20, 36, 55)
- Revised care pathways to provide clearer, more consistent access to services for people of all ages in all parts of NI. (Page 24 )
- The importance of links to a range of service providers in other sectors. (Throughout the Review)

## WHAT ARE AUTISTIM SPECTRUM DISORDERS?

Although biologically based, and currently defined by a medical classification, there is increasing recognition that Autistic Spectrum Disorders have social and educational dimensions that affect the social integration of those identified, and their families. The needs arising from ASD are extremely varied. ASD can result in a devastating and life-long disability that disrupts all aspects of life and all stages of development, although even the most severe conditions are eased with appropriate and timely education and care. On the other hand, ASD may just represent differences in typical development and ways of understanding the world, which are not disabilities as such, but may become so if those differences are not understood and accommodated in the services in which the child, and later the adult, is involved.

The autism spectrum is generally taken to include the three diagnostic categories of *autism*, *Asperger syndrome* and *atypical autism*. There are considerable individual differences in ASD, but common features across the spectrum are difficulties in three areas of development (not particular behaviours) known as the “triad of impairments”. These are difficulties in social and emotional understanding, all aspects of communication, and flexibility in thinking and behaviour. It is likely that there will be additional problems, which are not universally found in ASD, but may be a common accompaniment. These include sensory processing problems, specific language problems, general learning difficulties, dyslexia, dyspraxia, epilepsy and, in adolescence and adulthood, anxiety states and depression.

ASD may therefore be accompanied by a range of other disorders including language disability and severe learning difficulties, or they may be present in an individual with exceptional language ability, high academic skills and/ or particular abilities or talents. The severity of the autism can range from mild to severe - the dimension of autism severity is independent of the dimension of intellectual ability. People can have profound learning difficulties with mild autism (making the autism difficult to distinguish) or conversely be very bright with very severe autism (when the label is likely to be Asperger syndrome). Some professionals confuse the severity of the child’s needs with the severity of their autism, describing the child with mild autism and severe learning difficulties as having ‘severe autism’. That is

misleading when it comes to understanding the child and how best to support him or her. It is clear that individuals with ASD may present to any service, and will need understanding and support from all the professionals they encounter if they are to meet their potential, and not develop the secondary consequences of ASD which are often the most crippling.

It is not realistic to expect that all professionals will become 'experts' in ASD, nor is that necessary. What is needed is enough awareness of ASD among primary care teams and front line professionals (and especially among early educationalists) for them to recognise when further investigation and help is needed. They do not need to know everything, but they need to know enough to recognise what they don't know, and most importantly they need to know where to go to get further help and support for the individual. Therefore, there is a need for accessible 'experts' in each professional team to inform and support colleagues and there is a need for clear pathways to care that are understood by everyone involved.

Just as many different professional groups may be involved in first recognising that a child may have an ASD, or be the person to whom parents turn when they are first concerned, so many different professionals will have a role to play in diagnosis, treatment and care. Children with autism may behave very differently in different contexts, so it is important to observe the child in different settings, and to obtain different professional perspectives, to get a true picture for accurate diagnosis. This is especially true when the child is young, with a short developmental history, and where other conditions (such as sensory disorders) may mimic some of the 'autistic' symptoms. There will also be many different professionals who will have a role in treatment and care, to cover all the needs of this multi-faceted condition.

In services for adolescents and adults, two distinct groups of individuals must be provided for :-

- Those individuals diagnosed in early childhood, perhaps with more symptoms and associated difficulties, who have been managed with an autism-sensitive approach since early childhood; and

- Those individuals presenting to services for the first time in adolescence or adulthood.

A number of individuals will present to services for the first time in adulthood, when there is a loss of the protective supportive factors of childhood and adolescence, alongside increased responsibilities and relative lack of structure. Similarly, the ASD may come to light when the individual develops associated mental health difficulties, such as anxiety, depression, obsessive compulsive disorder, or psychotic illnesses.

It should be noted that whilst ASD is a specific form of developmental disorder, there are other developmental disorders such as Attention Deficit Disorder (ADD), Attention-deficit hyperactivity disorder (ADHD), language disorder or dyspraxia, some of which may occur at the same time. The breadth of issues that may arise, across the whole range of age and ability, means that the individual may need to draw on any of a range of services and specialities, and treatment will require a flexible approach from multi-agency/multi-disciplinary services.

## SCIENTIFIC EVIDENCE

*Additional supporting information is provided in Appendix 1*

### **When is support most needed?**

When faced with a condition that disrupts typical social and emotional bonding with parents, and keeps a child from the social interactions with peers that are known to be important to later social and developmental skills, there is a clear case for intervention, not just from the point of diagnosis, but from the point of reasonable suspicion, as suggested in most reviews (e.g. NIASA, 2003). Best practice guidelines suggest there should be specialist education and support available to parents and to children with ASD as early as possible. *Attempts to include children with ASD in mainstream services without specialist support being available, are not recommended.* The mildest cases might manage in such situations, but the greater risk is that the child will be frightened and turn away from learning and that staff will feel less able to manage such children in the future.

Research and expert advice have shown that periods of transition are particularly difficult for children with ASD and their families and lead to the greatest problems for placement. There are crucial times of transition.

- *From diagnosis to intervention:* Unless families are offered support and practical intervention for the child with an ASD from the point of diagnosis or ideally, from the point of reasonable suspicion, they are very vulnerable to claims made by independent, or commercial organisations advertising interventions, for example, on the Internet. Some of these interventions may be valuable, but the problem is that this is not an informed choice, and often is not based on the child's individual needs. Parents often report that the interventions they started at this time were adhered to, even when they did not seem to be working, because they felt loyalty to the first organisation to offer support and help and to put them in touch with other parents. It has also been shown that one way of coping with the stress of diagnosis is for parents to go into battle on behalf of their child, so it is important that families are offered help before parents become embattled.

- *Home based and early years intervention to school:* As seen above, the providers of home-based or early years interventions may be the first organization to support parents and offer treatment to the child. If the child has done well under this intervention (and most interventions will have a beneficial effect in the beginning, regardless of their long-term merits), then it is understandable that parents will wish to continue the same kind of intervention at school, especially if the trusted trainers in that intervention convince parents that this is the only approach, and that benefits will be lost if the child switches to any other intervention. Or parents may believe, not without some foundation, that the best school for their child is a specialist one, confusing the need for *specialist education* with the need for a *specialist (autism-specific) school*. Alternatively, parents may want a mainstream school, but without necessarily taking account of how *specialist education* is to be provided within that setting. Special schools are often resisted by parents, who need to be assured that staff are able to provide the *specialist education* their child requires, if that is the case. The parents may be making valid choices, with some justifications, but also without being aware of all the implications. There is a role for a parental guide to ensure the best options for the child and family, without polarizing attitudes.

## **DIFFICULT TRANSITIONS**

- *The difficulties moving from primary to secondary school:* This transition is the one that leads to the most difficulties for the child and parental distress and dispute with authorities, with potential implications for health and social care staff. There are many reasons for this. One is a lack of suitable *specialist provision* at the secondary stage (especially units and resource bases in mainstream schools). The second is the different nature of primary and secondary schools. The child may have coped within a smaller mainstream primary school with a teacher who knows them, but may be lost in a more complex and crowded secondary school. More teachers are involved in teaching the child, so there are more chances of encountering ignorance about ASD and an inability, or unwillingness, to adapt to the child. This can add to the child's anxieties and lead to both mental health problems,

and reactions such as '*school phobia*'. These problems can be reduced if teachers and classroom assistants are given appropriate, specialised training.

- *From school to adult life / post school provision:* However inadequate the provision during the school years, the gulf between the relatively structured time at school and life after school presents another enormous hurdle in the life of people with ASD. Where the young person is academically able enough to attend mainstream further education or higher education, they will find that these steps bring less structure but greater expectations of independence. Support is legally available in universities to enable better access for disabled students, but this does not ensure that all the necessary support services will have adequate knowledge or experience of ASD, or provide effective support. Colleges of further education may find it even harder to provide adequate support, and especially to provide the appropriate needs assessment on which those resources depend. If the person with ASD also has a learning disability, they may find some adult provision, but again it may be harder to find staff who are experienced enough to prevent problems. The group without general learning disability, but not sufficiently able to live independently, will find it hardest to source adequate support. There may be little for them unless (or until) they develop a mental health problem. Parents and young people with ASD themselves, should expect their secondary education provider to prepare pupils with ASD adequately for transition into adulthood. Again, specialist training for teachers will help make this transition easier to follow for all those involved.
- *Adulthood – other transitions:* Problems are most likely to occur with the general increase or change in responsibilities that come with adult life. Associated mental health problems are also much more common than in the general population. The Review recommends specialised training for staff in a range of key posts who may be able to interact with adults with ASD in a more appropriate way as a result.

## **'24 HOUR' CURRICULUM AND RESIDENTIAL PLACEMENT**

Because of the special needs of individuals with ASD, some aspects of their programme need to take place throughout the day, evening and weekend; making sense of the world, communication training, self help skills, regulation of sleep, activity levels, food intake, emotion understanding, leisure activities, developing friendships, and many more. Managing anxiety and preventing challenging behaviour are also aspects of learning and teaching, which extend beyond the school day. It is important that most of this teaching takes place where the skill or behaviour will need to be displayed. For some children and young people it may be sufficient for the school to work with parents (and providers of short-term breaks) to ensure this '24-hour curriculum'. For others, the level of expertise or intensity required would make that an impossible burden for the parents, and the child may need access to an extended day, or even residential provision. It is important, however, to ensure that the extra provision is resourced (especially with appropriate expertise) to carry out the 24-hour curriculum.

This is different from arguments for extended days or residential provision that depend, not on the child's needs, but on the need for respite for the family. These social needs will affect the child's development, so they are important, but they are not the same as making the case for the extra learning and teaching needed by some children and young people.

A gradual introduction into the workplace may also be needed. This may involve the need to help a person to become familiar with a work environment as part of a carefully structured, transitional process. Links to what was familiar in the past cannot be broken easily; nor can new links be established quickly.

## **SERVICE DEVELOPMENT**

Any new, effective model of ASD service provision needs to be based on clear evidence.

The evidence base for particular interventions, provided in Appendix 1, shows that there is no clear evidence that any single intervention will be the best, or most appropriate in all situations. There is, however, increasing evidence of the benefits

of a number of therapeutic interventions provided at an early stage, ideally from around the second year of life, i.e. at the point of first significant suspicion of need.

Receipt of the appropriate interventions and supports can improve individual well-being and family life and, over the longer term, help minimise the general level of disability associated with ASD. This could reduce the need for costly statutory care in later life. This underlines the need for effective detection and diagnostic processes and the need for enough skilled practitioners across the Health and Social Care Service, and also within the Education and Voluntary sectors.

Diagnosis and Assessment - In working towards establishing a more evidence-based model of care, it is necessary that diagnostic and treatment processes should be more ASD specific, and should include multi-disciplinary input from specialist practitioners from all the relevant agencies. A basic requirement is to establish services capable of detecting those who may have ASD at an early stage, preferably before the child's third birthday. Such cases should have access to responsive services capable of specialist assessment and diagnosis, and the provision of therapies, care and support from the point of earliest identification (before a full diagnosis), and before difficulties become entrenched and secondary problems arise.

While there has been some 'baseline' progress over recent years towards the development of ASD-specific diagnostic services in Northern Ireland for children, the same cannot be said of services for older adolescents and, in particular, those presenting for the first time in adulthood. The Review has identified a significant gap in terms of services for adults, not only within the HSC sector, but across a range of statutory service providers. It is recommended that this unsatisfactory situation should be changed as soon as possible.

Intervention and Support Services - Both before and after diagnosis, it is of considerable benefit to provide families with support and training to help them understand their child with ASD and to learn specific skills and expertise to help deal with their child's behavioural and communication problems. (For example the Keyhole Early Intervention Project.) Many parents provided with ASD-informed

skills soon become more self-sufficient in dealing with many day-to-day problems and issues.

Beyond the development of basic ASD-specific knowledge and skills within families, there is a need to establish specialist services which can provide a range of ASD-specific structured cognitive and behavioural interventions, interventions to improve interactive developmental communication skills and develop an awareness of responsiveness to sensory stimuli. Each area of development is important and should be provided in ways which encourage the transfer of skills. Teams of skilled practitioners are required, with expertise and experience of ASD-specific therapeutic interventions to develop and support effective approaches with all key practitioners, including parents. Some direct work with children will also be necessary for assessment and monitoring of progress. This should provide the necessary care required by children and families more quickly, and in a way that links up with existing services and pathways for referral.

Older adolescents/adults also need easy access to both specialised and general support services, to help them deal with the transition into adulthood and to maintain their independence. There is a need to develop 'treatment and intervention' services for this age group and an equally important need to establish support services to help people live their lives as independently as possible. There is also a need for services to help people with employment, further education, housing, social security and general daily living.

*The Review has noted that there are marked deficiencies and inequalities in the service provision across NI in terms of required ASD-specific diagnosis and treatment services.*

## **SERVICE PLANNING**

A number of national level and other key documents highlight the problems of uncoordinated and poorly managed ASD services and refer to the difficult experiences of children and individuals with ASD, and their families, as a result.

ASD service provision and planning cuts across different teams within Children's Services in Trusts, including child and family services, children's learning disability teams and also child and adolescent mental health services. The potential range of services for older adolescents and adults with ASD also cuts across a range of teams and directorates. This requires effective planning and coordination within Trusts. If these services are not coordinated, it is more likely that strategic and operational planning will be inadequate and service delivery to the individual child and family level will be less effective.

National level documents emphasise the need for ASD services to be underpinned by strong policy, planning and service delivery leads. Such input should cut across all HSC structures and include policy and commissioning, as well as health and social care services.

The Review recommends that responsibility for ASD policy, planning and service delivery be identified clearly across HSC structures as follows:

DHSSPS – to help ensure effective regional planning and coordination, a senior person responsible for ASD services within DHSSPS should be identified. DHSSPS should explore the need to establish a regional ASD Planning & Priorities group which would include appropriate cross-Departmental input with the Department of Education, plus wider HSC representation. This could also include family, carer and voluntary sector input. The group, could evaluate and monitor progress towards ensuring that service structures and ASD service provision develop as recommended by this Review.

Commissioning – local *strategic* planning & coordination is important to ensure effective ASD services. Although the future Health and Social Service structures are not yet in place, a robust commissioning process will be required to provide more detailed service design and planning, monitoring of actual service delivery, and performance management of ASD teams/structures on a day to day basis across the HSC. Health and Social Care Service commissioning provides an effective vehicle to oversee the planning and subsequent performance review of any new teams and ASD services that are developed as a result of this Review.

Ideally, the future commissioning process should include ways to provide families and carers with a voice within service planning and monitoring. In addition, the role and input of Education and Library Boards<sup>1</sup>, together with the voluntary and community sector should be included. It may help to establish locally based, area wide, ASD multi-agency planning groups within each Trust area to develop multi-agency *strategic* planning, implement DHSSPS priorities, develop local action plans and carry out service monitoring. These planning groups should have a direct link to the Children's Services Planning processes within each Trust area. This will ensure that the needs of children and young people with ASD are included within the wider strategic planning process for children with disabilities in areas such as early years, transitions and respite services. These groups should include input which covers health, education, employment or other relevant services. At this level the main themes should be service delivery, practical implementation and co-ordination.

HSC Trusts – Children and others with ASD have unique needs requiring a diversity of service inputs. The package of care they need will require cross-directorate input within Trusts with input required from a number of Programmes of Care. Where cross-directorate planning is insufficient, the consequences will be felt by the individual and their family.

In keeping with national level guidance, the Review recommends that a lead Director responsible for *coordinating* ASD services should be identified on a consistent basis within each of the five NI Trusts. These Directors should assume responsibility for ensuring effective *operational planning and service coordination* between directorates/sub-directorates, and therefore across Programmes of Care within Trusts. For day-to-day service planning and management, Directors should identify a lead individual who reports directly to them, to act as overall 'ASD service coordinator' within each Trust. This role would help to ensure that the various strands of service provision within Trusts communicate with both statutory and non-statutory services. This role would also promote continuity and make key transitions for children/adolescents and adults easier. The Review recommends that service models should allow overlapping age ranges and use less specific categories to

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<sup>1</sup> The Five Education and Library Boards are to be replaced by the Education and Skills Authority in 2009.

avoid unnecessarily abrupt cut-off points. This would allow cases to be considered on the basis of individual need.

While individual Directors would assume the lead *service coordination role*, other directorates would need to contribute towards meeting the wider service needs of an individual, child or family . The Review recommends a cross directorate, multi-disciplinary service provision, with an operational planning model for each Trust. Appropriate operational policies and procedures will be required - including policies and procedures covering the input of other agencies. The development of *child health information systems* to allow wider care planning within each Trust area should also be considered.

The Director and Trust ASD coordinator should work to an overall regional plan to improve policy, planning and service delivery. In the same way, the lead ASD coordinators from across the five Trusts should work towards creating the proposed regional ASD Service Delivery Network and associated Care Pathway.

The Directors and Trust ASD Coordinators should establish and lead a multi-disciplinary *ASD operational planning* group, based on Trust staff, also to include input and representation from Education, Voluntary and Community and private sectors, and families and carers. After these processes have become established, the Director could consider whether a planning group is still necessary, or whether this can be devolved to local meetings.

## **REGIONAL ASD SERVICE NETWORK**

The need for the HSC service structure to support the individual journey from initial presentation, assessment (for example, within child and family services) and *ASD-specific* specialist treatment services has been considered by the Review within the following Framework:-

## ASD Service provision Framework

	<b>Service Tier</b>	<b>Role / Function</b>
<b>A</b>	<b>pre-diagnosis : Case Finding Services</b>	- Existing community based services, e.g. primary care, health visiting – key issue: improving <b>early recognition</b> & case finding skills
<b>B</b>	<b>- ASSESSMENT &amp; DIAGNOSIS SERVICES</b>	
<b>b.1</b>	<b>Local Generic services</b>	- Existing services within Trust childcare, mental health and disability directorates involved in initial <b>diagnosis / assessment</b> process
<b>b.2</b>	<b>Area specialist ASD services</b>	- Need for specialist ASD diagnostic services, i.e. not widely available at present – proposed need to establish <b>area wide specialist teams</b> within each Trust
<b>b.3</b>	<b>Regional complex cases</b>	- New specialist teams working together within proposed <b>Network arrangement</b> : teams will offer advice and support in respect of particularly complex cases
<b>C</b>	<b>- INTERVENTION &amp; TREATMENT/SUPPORT SERVICES</b>	
<b>c.1</b>	<b>Early intervention services</b>	- <b>Early intervention</b> services
<b>c.2</b>	<b>Specialist ASD teams</b>	- Specialist ASD <b>treatment and care</b> services
<b>c.3</b>	<b>Continuing care &amp; support services</b>	- Provision of general childcare and support
<b>REGIONAL NETWORK</b> – it is proposed that local specialist ASD teams, i.e. ‘b2’ above, will join together within a regional ‘consortium’ arrangement to pool resources & expertise, ie. as per identified at ‘b3’		

There is a need for a more evidence-based and structured service development approach. The Review recommends that the specialist teams within Trusts should link together to form a regional ASD Network arrangement. This Network should include services for children, adolescents and adults.

The ASD Service Network should become the overall hub for ASD services within the region and should, for example, promote the development of a shared understanding of ASD diagnostic/treatment issues and approaches across child,

adolescent and adult services. The regional ASD Network should help with local implementation of key national level guidance (e.g. NICE/SIGN) and also the DHSSPS Regional Service Frameworks (DHSSPS, 2007). Where required, the Network should identify routes to more specialist services outside N Ireland. DHSSPS set out the six main functions of Networks (DHSSPS, 2007):

- Assist the development of essential, best practice standards and service specifications.
- Agree patient pathways across organisations to support the delivery of standards
- Measure, monitor and audit the implementation of standards, including the development of key quality indicators together with minimum data sets.
- To advise on commissioning and provide a source of expertise.
- To ensure a patient and public involvement focus in all aspects of service provision.
- Support and assist in the development of an effective workforce to deliver patient pathways and standards.

The ASD Network should also contact the wider children's services planning processes within Trusts to ensure that issues linked to ASD are considered within that strategic planning framework.

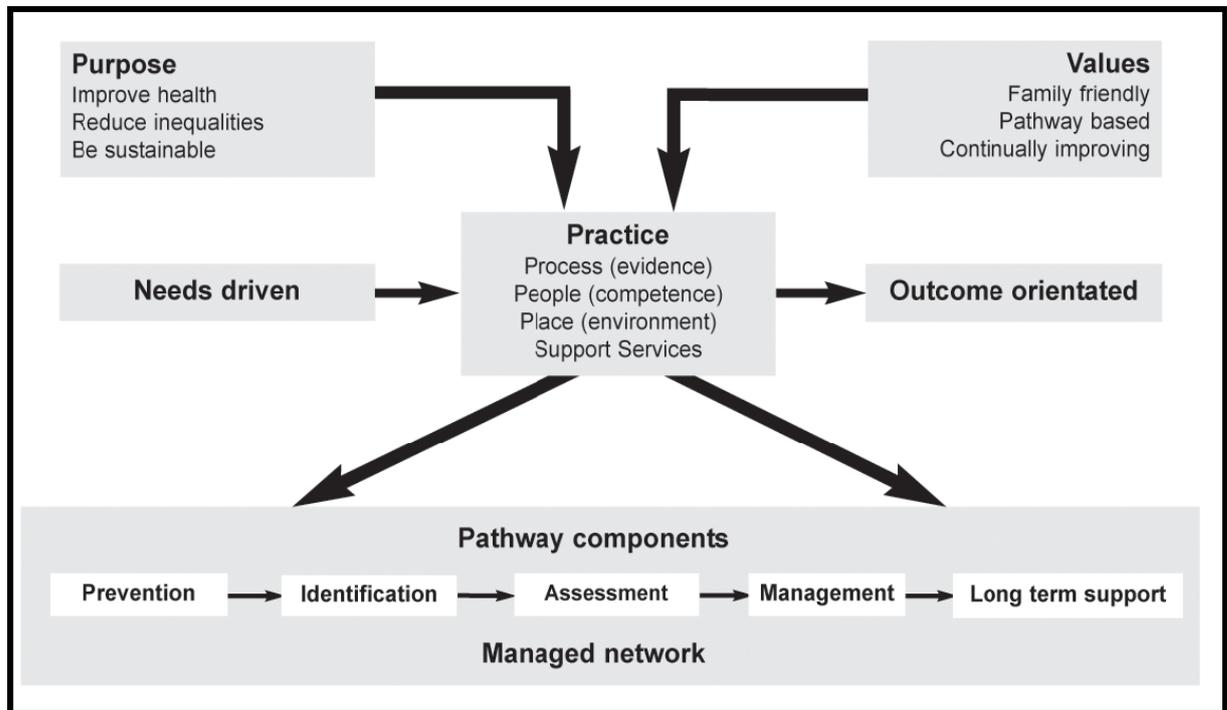
All service elements within the HSC should work together within this proposed regional Network arrangement on a Northern Ireland wide basis. The Network should identify partnership approaches that will integrate systems across traditional statutory boundaries. While mainly based on statutory HSC services, the Network should also welcome input from other key stakeholders, i.e., Education and Library Boards, families, carers, Voluntary and Community and private sector groups and other statutory partners including the Northern Ireland Housing Executive.

To help with meetings of the Network, the Review recommends consideration of technologies including telephone and/or video based conferencing services, to enable parent and family representatives to provide their input.

The precise role and function of the proposed Network should be developed in detail by service commissioners and Trusts within the HSC.

The Network should include senior representatives from child, adolescent and adult service sectors. Those within the ASD Network will need to consider the day to day outcomes. While there may be exceptions, the aim should be to develop integrated, rather than separate age-specific approaches. Some age-specific issues may need to be dealt with separately.

An example of good practice in the development of the Network, is set out in 'Modelling the Future', Royal College of Paediatrics and Child Health (Sept 2007). This considers the development of effective and modern childcare services within Network approaches. – The following diagram explains the potential components of service design and delivery.



Reprinted from: Modelling the Future, Royal College of Paediatrics and Child Health,  
Sept 2007

The Review also wishes to refer to the Scottish Autism Service Network currently in development as a way of sharing and developing ideas ([www.scottishautismnetwork.org.uk](http://www.scottishautismnetwork.org.uk)).

## **CARE PATHWAY**

The Review recommends that a key product for the ASD Network should be a regional ASD Care Pathway that should include child, adolescent and adult settings and services. This should set out the proposed journey for the child, family, or individual, covering initial contact within primary/community care, formal diagnosis/assessment, and the potential support and intervention provided by more specialist ASD services including both statutory and non statutory inputs.

The Review recommends that the Care Pathway should reflect regional agreement for referral criteria, minimum inputs for diagnosis/assessment together with treatment/support inputs. The Care Pathway development process should cover child, adolescent and adult services and settings.

For children's services, the Pathway should include reference to the regional single assessment model, i.e. UNOCINI - *understanding the needs of children in Northern Ireland* (still in development). The process is likely to emerge in due course and will be rolled out as the assessment model to be used in all initial referrals and transfers within children's services. It would therefore be necessary to ensure that appropriate processes are in place to connect the broader UNOCINI 'children in need' pathway and the specific ASD care pathway.

Given the growing importance of performance management and the need to demonstrate 'value for money', the Review recommends that the Care Pathway should incorporate a range of appropriate performance management standards and service quality indicators. In addition, the Care Pathway should include reference to the need for service practice to reflect person-centred planning, risk assessment, governance, communication with parents and also transition planning.

## **SERVICE DELIVERY MODEL**

It is proposed that within the regional ASD Network approach, future service delivery should be considered within a tiered approach to reflect the general Care Pathway

and 'child/family journey' from initial contact with primary/community care (e.g. early diagnostic suspicion) and then into more specialist services. This is set out in the following diagram:

⇒ **Initial referral from Community / other Services**

↓↓

⇒ **Local generic services** (existing range of services within Trusts)

↓↓

⇒ **Area specialist services** (area wide Trust service)

↓↓

⇒ **Regional** (complex cases considered within Network)

The proposed regional Network will have to include a range of key issues and themes which in turn would be reflected in the Care Pathway:

Primary/Community services: The key development needs highlighted by Health Visitors, and social workers included the availability of up to date advice and information for those involved in these services:-

- early detection: potential tools to identify early evidence of ASD, e.g. M-CHAT or other case finding tools
- referral criteria: this could be provided through a standard form of regional referral
- referral pathway: to define the route to local service access points in each Trust: (e.g. community paediatric and other services)
- performance management: anticipated regional waiting time targets

The issue of case detection among older adolescents and adults requires particular attention. While knowledge and awareness of childcare related ASD issues has increased among primary care and community practitioners over recent years, the same cannot be said for older adolescent and adult related ASD knowledge. Both staff and specialists have noted the knowledge and skills shortage across HSC

practitioners for older adolescent and adult related ASD issues. The Group recommends the establishment of additional programmes, and initiatives to raise awareness of ASD among HSC practitioners. Where appropriate, these programmes should reserve a proportion of their content to highlight key older adolescent and adult related ASD issues.

Trust based services: these services reflect the existing front line diagnostic/assessment and therapy/intervention services within broader Trust childcare services. Such services include community Paediatric teams (including AHP services), children's Disability teams and Child/Adolescent Mental Health services. Trust based Mental Health and Learning Disability directorates are needed for adults. The Network will need to develop ASD diagnostic and intervention skills and knowledge among key Trust staff –these include:

- diagnostic/assessment - to develop the content of the broader diagnostic and also treatment planning processes.
- parental/sibling assessment of need –, the needs of parents and siblings should also be considered within the wider 'family' assessment.
- early intervention: to provide parents with initial advice and potential service input
- protocol for structured liaison with educational services
- referral pathway: defined routes to area wide specialist ASD services
- transition, for older adolescents and adults with ASD, including supported living, vocational and employment related issues.

Area wide specialist ASD teams: There is a shortage of specialist ASD resources at present within Trusts across N. Ireland, particularly for older adolescents and adults. Network development issues will include the need to define and establish:

- diagnosis/assessment: the structure and content of the *specialist* diagnostic/assessment process
- early intervention: ASD specific, early therapeutic intervention and support services

- specialist therapeutic inputs: including evidence based structured therapeutic inputs and support services
- voluntary and community and private sector inputs – working in partnership with voluntary sector or private sector partners to sub-contract services including regional training initiatives and support services

In the past, only limited local investment has been made available to develop ASD-specific services in N. Ireland. With negligible levels of new investment being put forward, services have often been established within existing resources, or only where professionals have developed a particular interest in ASD. The development of specialist ASD services is one of the key recommendations of this Review.

The Review considers that the current level of ASD services falls well short of what is necessary for children, older adolescents and adults. Proposals for the development of these services are included in this report.

(a) ASD Diagnostic/Assessment services: it is proposed that **all children** identified with a potential diagnosis of ASD, upon reasonable suspicion that ASD may be present, should automatically pass into specialist ASD services. Where possible, services should ensure that a confirmed diagnosis of ASD is achieved by the child's third birthday. This 'early years target', is not appropriate in respect of Asperger Syndrome where speech development may mask needs and a confirmed diagnosis is not likely until later (often after 5 years).

(b) Early Intervention Services: parents and families should receive support at an early stage (i.e. within 4 weeks of initial diagnostic suspicion) to develop skills and knowledge to help them understand, manage and support their child.

(c) Structured Communication, Cognitive and Behavioural Intervention Services (SCCBI), *to enable the development of key developmental skills and understanding, and to include awareness of the potential effect of any sensory processing problems on functioning*. Services are required to provide children, families and carers with specialist psychological and learning management strategies.

The "Network" approach recommended in this Review should not be confused with a 'regional service' model. The Review is not proposing that a single regional team or

service be established. However, while services will be based in local Trust settings, the regional Network arrangement should allow for a situation where pressures which arise within any area can be eased by the overall resource, working across Northern Ireland. This should be developed by the proposed ASD Network arrangement evolving into a more proactive Regional Managed Care Network.

### **INVOLVEMENT OF OTHER SECTORS**

The Review recognises the important contribution made by groups from other sectors – including Voluntary and Community sector groups with a focus on ASD. These groups have a wealth of knowledge and skills and can establish a connection with families and carers. The private sector can also provide experience and expertise. The Review recommends that efforts should be made to include other sectors within the Network arrangement. A range of options should be considered, including local knowledge and whether these groups could be commissioned to help statutory services with parental support and development, or employee training programmes highlighting ASD across other sectors and agencies or to provide service delivery options including therapeutic care and support.

### **ASD TRAINING AND DEVELOPMENT STRATEGY**

The Review recommends that the ASD Network should provide the forum needed to develop a wider ASD training and development plan. This should help improve the knowledge and skills of service practitioners across the region, particularly in terms of meeting any knowledge and skills shortages for older adolescent and adult ASD issues. For example, the development of key skills necessary for practitioners within Trusts and primary care settings, or to the more specialist knowledge and skills. This training strategy could be recommended for training needs within other sectors, i.e. Education, or Voluntary and Community sectors, employment, or training within other agencies.

## **CASE FINDING SERVICES**

### *Early Detection –raising awareness.*

There is a clear need for early detection, earlier diagnosis and assessment, then earlier prescription and provision of the appropriate therapeutic or support services. Case detection at an early age is the key objective. There will, however still be individual cases not coming to light until much later. Therefore there needs to be appropriate 'case detection' systems in place, not only in children's services, but also within older adolescent and adult services.

General practitioners and Health Visitors, given their regular planned and unscheduled contact with children and families over the general pre-school years, have a vital role in achieving the earliest possible detection.

While parents are often the first to suspect that some anomaly is present, other practitioners, including speech and language therapists, social services, early year's services and the Education sector, also have an essential role to fulfil in the early detection of ASD.

### *ASD training and development strategy*

It is essential that those who are in contact with children, have sufficient baseline knowledge and skills be alert to the potential presence of some form of developmental anomaly or early indication of ASD. This also applies to those working in adult services, particularly mental health or learning disability care. The Review Team recommends that a regional training strategy should be developed for parents and practitioners – This should identify, agree and implement an ongoing programme of awareness and education, to include both HSC & non HSC practitioners/sectors. The content of one programme could be tiered according to the specific practitioner group requirements and therefore range from general awareness to more advanced initiatives for more specialist practitioners.

It is proposed that these programmes should be taken forward within the proposed regional ASD Network and could be undertaken in partnership with the Education and Library Boards and Voluntary and Private Sectors. This would require (i) an agreed/defined programme content, (ii) identification of key target groups, including

professionals, parents & siblings (iii) setting out the regional procedures and associated timescales (iv) a performance management systems to monitor the output and outcomes of the project. These training and development programmes should also be developed and modified for those working with older adolescents adults.

These programmes are likely to be challenging at first, and may be best delivered within local Trust settings. A consistent training and development specification may be needed across all trusts setting out the requirements of the service and anticipated timescales together with the costs.

The service could either be delivered through a Trust led process or could be contracted out, for example to the Voluntary or private other sector or through partnership arrangement across agencies and sectors.

This wider practitioner and parental education and awareness raising process may require additional resources to complete all the associated work. The Review Team recommends that any funding, which could be non-recurrent, or project based over a defined period of time, should be identified. The Review Team proposes that a 'training coordinator' post should be established within each Trust area, a total of 5 posts for an initial period of 3 years to improve the training and development.

Beyond this period, and assuming that the key objectives have been achieved, it may be possible to set in place a lower level programme which provides top up training for practitioners and maintains the process of general parental education. ASD training should then be mainstreamed within the annual training plans of Trusts.

While not a specific focus for the Review team, it is proposed that ASD awareness training should become a key element of teacher training courses within our Universities and Colleges. The Review Team is grateful to St Mary's and Stranmillis teaching colleges who, following discussions with us, have taken an early initiative forward, on autism specific training for trainee teachers, with the approval of, and funding from the Department of Education and Learning (DEL).

Given the potential 'diagnostic and treatment' practitioner resource that the Review Team is recommending should be put in place within Trusts (with the necessary funding), it is also recommended that a proportion of specialist ASD practitioners job-plans should include 'protected time' to undertake training initiatives with other non specialist practitioners, and with parents. This should include general liaison duties with professional staff, including reviews of the clinical management issues of individual cases.

#### *Autism Awareness Training*

The Review Team would recommend autism awareness training for staff in a range of jobs and roles which bring them into contact with people affected by autism. This would include staff in social security and housing. The Review Team met with representatives from the Prison Service who welcomed this idea and with representatives of the Police Service who indicated a difficulty in adding to an already overstretched training programme. The Review Team recommends that PSNI should reconsider the option of ASD Awareness Training. The training options set out above offer a range of sources for suitable training.

#### *Care Pathway – referral criteria and pathways*

Together with practitioners developing their ASD-specific skills and competencies linked to day to day practices, a greater knowledge of referral criteria and local access points to more specialist services across Health and Social Care Trusts and into other Department and agencies, is needed. Specialist ASD teams within Trusts should help to promote this approach, and the interdepartmental co-operation which it will require to operate effectively.

The Review Team recommends that agreed local referral criteria and pathways for children, adolescents and adults should be set out as part of the overall regional Care Pathway to be developed within the proposed regional ASD Network. These should be in line with the regional UNOCINI process currently being rolled out across N. Ireland.

These regional ASD Care Pathways should include children's services, and also outline the referral arrangements and local access points into more specialist services for older adolescents and adults.

*Early detection - Case finding tools*

To promote the detection of ASD at an earlier stage the proposed regional Network should consider the need for new case finding tools such as the more recent version of M-CHAT.

At present none of the existing Autism-specific case finding tools would fulfil the formal criteria set down by the UK National Screening Committee. Agreed criteria are in place between the various UK Departments of Health and those criteria must be fulfilled before any tool, or process can be recommended as a national level screening process.

Despite their limitations these tools have a role within general case finding at the *individual child and family* level. Ideally, Health Visitors, GPs, Paediatricians, and AHPs should be familiar with them as a way of identifying potential ASD symptoms. The Autism Education & Research Centre from the University of Birmingham developed a resource for the Education section of NHS Scotland which includes information for primary health practitioners on how to recognise ASD. The website has free access and it is available at [www.nes.scot.nhs.uk/asd](http://www.nes.scot.nhs.uk/asd). There are also useful videos on the Autism Speaks USA website.

The issue of screening in school-aged children is more positive, given the apparent value of CAST (Scott et al., 2002; Williams et al., 2005; Williams et al., 2006). Williams and Brayne (2006) and Williams, (2008) provide a review of screening for children with ASD.<sup>2</sup>

Some have suggested that CAST could also be used for the adult population, where it is even more difficult to find an effective screen, but this has not yet been attempted. Instead, there is the Autism Spectrum Questionnaire, which has recently been shown to be a reliable guide to higher functioning autism or Asperger syndrome in adults. CARS can be used for the full autism spectrum and again has good reliability figures, although it may miss more subtle forms of ASD. The only test developed specifically to detect autism in those with additional severe learning disability (mental retardation) is that developed by Kraijer and colleagues: Pervasive Developmental Disorder in Mental Retardation Scale: PDD-MRS.

## HEALTH VISITING

Given the key role of Health Visitors, particularly in case finding in the early years, the Review Team considered whether part of their role as set out within Hall 4, should be re-examined. Health Visitors carry out several key roles and are one of the few practitioners to see a child throughout the early stages of development until immunisation with the MMR/Pneumococcal vaccine at 15 months. There is then limited contact until pre-school vaccines become due at around 3-4 years. Detection of ASD is considered to be feasible from around 18 months onwards. The 15 month

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<sup>2</sup> Scott, F.J., Baron-Cohen, S., Bolton, P. & Brayne, C. (2002) The CAST (Childhood Asperger Syndrome Test) Preliminary development of a UK screen for mainstream primary aged children. *Autism: the International Journal of Research & Teaching*, 6, 9-13.

Williams, J., Scott, F., Stott, C., Allison, C., Bolton, P., Baron-Cohen, S et al. (2005) the CAST (Childhood Asperger Syndrome Test): Test accuracy *Autism: the International Journal of Research & Teaching*, 9, 45-68.

Williams, J & Brayne, C. (2006) Screening for Autistic Spectrum Disorders: what is the evidence? *Autism: the International Journal of Research & Teaching*, 10, 11-35.

Williams, J., Allison, C., Scott, F., Stott, C., Bolton, P., Baron-Cohen et al., (2006) The Childhood Asperger Test (CAST): Test re-test reliability *Autism: the International Journal of Research & Teaching*, 10, 415-427.

Williams, J (2008) *Screening for autism spectrum disorders in primary school-aged children* In E. McGregor, M. Nunez, K. Cebula & J. C. Gomez (Editors) *Autism: an integrated view from neurocognitive, clinical, and intervention research* Oxford, Blackwell Publishing.

MMR/Pneumococcal vaccine comes too early to provide Health Visitors with a suitable case finding opportunity and the 3-4 years vaccination is arguably too late.

The national level vaccination/immunisation programme is based upon a firm evidence and policy base. However, the Review Team has concluded that there may be *missed opportunities* linked to a potential ASD case finding role for Health Visitors within the existing child development/screening programme. This also applies to the wider issue of detecting general childhood developmental delay during the 15 month to 3-4 years period. Given that evidence now shows that a diagnosis of Autism can be made at 2 years, the Review group recommends the re-establishment of a home visit/assessment at 24 months. Home visits provide a better opportunity for a full assessment within an environment which is familiar to the child, rather than the current clinic based situation combined with immunisation.

The Review also recommends the inclusion of additional information about child development within the Parent Held Records. The personal child health record could include advice on the overall development of children around the age of 24-30 months. The red flags for autism – from the Autism speaks USA website -provides one potential format for this. There is also a web resource for primary health teams provided by the Autism Centre for Education and Research (University of Birmingham) for the Scottish NHS. See [www.nes.scot.nhs.uk/asd](http://www.nes.scot.nhs.uk/asd).

#### *Case Detection - Older adolescent/Adults*

A range of screening tools can be used for adults. Various screening tools are outlined in other publications, including the Report of the Task Force on Autism published in 2001 by the Department of Education and Science. These checklist type instruments are recommended for use with clinical judgement. Even with appropriate case finding tools and associated systems, there will be instances when individual cases of ASD do not come to light in childhood. While adults with 'unrecognised' ASD may be able to adapt and cope with the world around them, a time may come when significant problems become evident, for instance as they take on an increase, or a change in responsibilities. Initial presentation may also be through the identification of associated mental health problems, which are much more common (up to 35% higher) when compared to the general population.

However, there are significant ASD skills and knowledge gaps with professionals seeing older adolescents and adults. The majority of these practitioners are unlikely to be able to help adults with ASD with diagnosis or treatment or other interventions. For the practitioner based within adult services, this is made worse by the fact that symptoms of ASD at this age often also characterise other disorders, as well as autism spectrum disorders.

Case finding can be helped through improved practitioner awareness training and other development initiatives, together with appropriate access to the new 'expert' diagnosticians and specialists referred to in this report.

### *Performance Management*

The Review Team wishes to highlight the need for maximum waiting times for the interval between initial referral from the General Practice or general community setting and the first assessment within more specialist services within Trusts. The Review recommends that this should not exceed 13weeks.

Within the proposed ASD Network the Review Team recommends that a regional Performance Management process should be put in place as part of an overall monitoring mechanism. This should be based on appropriate 'quality' indicators to help determine the effectiveness of service provision. These indicators could include:

- Age of initial referral (from General Practice/general community setting)
- Interval between initial referral and first assessment
- Interval between first assessment and definitive diagnosis
- Age of definitive diagnosis
- Proportion of children diagnosed before the age of 3yrs and average age of diagnosis (excluding Asperger Syndrome cases).
- Interval between definitive diagnosis and provision of prescribed services.

It would also be important to track the total number of cases diagnosed each year within each Trust, and to carry out a comparison with the theoretical rates per Trust area.

A baseline figure for an agreed regional dataset should be set within each Trust area from which performance data across the region should be tracked.

## **ASSESSMENT & DIAGNOSTIC SERVICES**

### **Local and General services**

The assessment by general services within Trusts is important because this also determines the need for access to more ASD specific specialist services. It is expected that in **all cases** where general services suspect the presence of ASD, a referral to the proposed new ASD specialist services should follow.

In the case of children, most, referrals to secondary care Trust services will be to general community paediatric services. This might follow referral from Health Visitors, Speech and Language Therapists, general childcare social services or occasionally referral from parents. Initial referral may also be to other services including child & adolescent mental health and Speech and Language Therapy services. Older adolescent and adults with previously undetected ASD, may be referred to any one of a number of secondary care services, and most likely to mental health or learning disability services within Trusts. At present, adults with ASD can fall between these two services. The availability of these adult services should be based on need, rather than narrow criteria such as IQ.

The development of the proposed ASD specialist teams will help general services within Trusts because day to day pressures from ASD will be shared with more targeted ASD resources. However, care should be taken to ensure that individuals are not merely 'shunted' from one Trust setting to another without good reason.

The Review Team notes the differences in how general services are organised within different Trusts. The Review is not in a position to give detailed comments about potential deficiencies that may be present within these services, however the Review Team recommends that the assessment of potential ASD cases should be undertaken by frontline general services through a more standardised regional format. ASD referral processes for children should link with the UNOCINI referral

pathway, to avoid duplication of assessment models and to ensure that models and procedures are complementary.

The content of the diagnostic and assessment process should be included within the initial aims and objectives of the proposed regional ASD Network.

The ability to diagnose ASD accurately requires in-depth, highly specialist training. The diagnostic process should be based on either the Diagnostic Statistical Manual DSM-IV Tr (APA, 2000) or the International Classification of Diseases (ICD-10), or the most current version of these systems. The Review Team wishes to highlight that formal diagnosis should be based on *a combination of valid approaches* using more than one source of diagnostic information. For example experienced clinical judgement, use of specialist observational tools and assessments, and also structured parental interviews.

The development and *local implementation* of an agreed regional ASD Care Pathway should include referral criteria and the expected diagnostic and assessment processes for local settings. This could be achieved through the development of standardised forms to guide practitioners working in both children's and adult settings and would also provide specialist ASD teams with a standard 'package' of baseline information.

The proposed ASD specialist team will form the focus for local community assessment services, for children, adolescents and adults. The access routes to these services will need to be identified and *similar* models of care developed across NI.

### *Care Plan*

The basis of the frontline assessment process should be the Care Plan, drawn up in partnership with the individual and families or carers. This should set out the treatments and support inputs required. All care and interventions for ASD should be taken forward by the proposed ASD specialist teams. However, input from other Trust services may be required, e.g. childcare, social care etc. This requires coordination between a range of services or agencies and may involve decisions

about which service or agency should be given the lead role. Consideration should be given to expanding this process to include a case review mechanism. Trusts may wish to consider the development of ASD family support practitioners able to carry out this care coordination role. The one stop shop approach set out in this Review provides one potential source of support.

#### *Early support for children & empowering parents*

The interval between initial suspicion and confirmation of ASD is crucial for both the child and the parent. The need for early intervention has already been stressed. Parents, who may be distressed following an initial diagnostic suspicion, can find that they have no-one to turn to for advice and support, and that services do not seem to have the time to talk to them at this difficult time. The Review Team recommends that the interval between referral from general Trust services to ASD specialist services should be no longer than 4 weeks. This interval should be monitored as part of the regional ASD performance monitoring procedures.

The Review Team also recommends that initial ASD support services should be put in place to 'cover' that 4 week maximum interval. Where a diagnosis of ASD is either made or provisionally suspected, an 'early' package of care should be provided to children and parents to support them until they receive specialist ASD services. The Review Team recommends that during this interval sufficient service capacity should be established to provide each child and their family with, an average, of 4 hours initial advice and support. More specialised, individually tailored support packages would follow on later when a more formal course of early intervention involving structured social communicative and behavioural intervention and therapies will be provided. The voluntary and community sector may be well placed to make a positive contribution at this stage.

#### *Access to services - eligibility criteria (IQ)*

The Review Team has noted that access to some disability services can be dictated by Intelligence Quotients (IQ). It is well established that children with ASD may have significant learning difficulties, but they may also have an IQ in the normal range. In some cases a 'normal' IQ has prevented access to a range of potential supports and services.

The Review Team recommends that IQ should be removed as a way of deciding on access to services. The Review Team recommends that access to services should be determined by the individual needs of the child or adult, and the family. This would also be in line with policy and practice recommended by the Department of Health in England.

#### *Practitioner skills and competencies*

Any practitioner diagnosing ASD, including those within the private sector, should have the necessary experience, skills and expertise to carry out such work. It should be possible to review and appraise practitioner competence using established Trust appraisal and development processes (e.g. the 'Knowledge, Skills, Framework' associated with the national Agenda for Change process and the annual Consultant Appraisal process for medical practitioners). It may be more difficult to assess competence within the private sector. The onus will be on parents who engage with private sector practitioners to ask for evidence of competence in ASD. This should go beyond checking for the possession of a degree or college registration certificate. Improved access to statutory services may reduce the number of parents looking for services from other sectors.

The need for ASD competencies and skills within the Health and Social Care Sector should be graduated, depending upon whether the individual practitioner is engaged in general or more specialist ASD work. The proposed regional ASD Network should include practitioner training and professional development within its aims and objectives.

#### *Older adolescents and Adults*

While much of the focus is on children's services, it is important to take account of the needs of older adolescents and adults. It is important to recognise the key role of practitioners within adolescent and general adult services in terms of making, or suspecting, a diagnosis of ASD. GPs and other sources of referral are most likely to make initial contact with their local mental health or learning disability services. The Review Team recommends that, at the level of ASD diagnostic experience among

front line practitioners working in these services in Northern Ireland needs to be improved.

The main professions with a diagnostic role are psychiatrists and psychologists working within mental health or learning disability services. Other practitioners also have an advisory role, particularly the Allied Health Professions (AHP). While there are a number of key staff with a relatively high level of diagnostic experience, the overall number with these skills and experience is small. Some practitioners may have a high level of ASD specific knowledge, but they may not be working in ASD services, Instead, they may have a range of 'general' duties within the Trusts. Overall, the vast majority of practitioners are not well skilled in ASD diagnosis and support.

The Royal College of Psychiatrists recommend that practitioners carrying out the diagnosis of ASD should undertake the appropriate training, followed by adequate service experience. This will involve examining the professional training programmes of those undertaking formal training in psychiatry and clinical psychology. *[See the Psychiatric Services for adolescents and adults with Asperger Syndrome and other autistic spectrum disorders, Royal College of Psychiatrists, Council Report CR136, April 2006.]*

The Royal College also recommends that senior practitioners working at consultant level in *general services* need to have 'second level' ASD specific diagnostic skill. They should be able to undertake a comprehensive assessment of need and be able to diagnose non complex cases of ASD. This should be taken forward within a multi-disciplinary setting which includes an appropriate range of suitably skilled practitioners (i.e. as per recommended within children's services). This raises the need for additional in-service ASD training, together with a training resource for those already working within adolescent and general adult psychiatry or learning disability services across the 5 NI Trusts.

The training needs of practitioners will range from the need to have sufficient knowledge and experience to recognise ASD, through to the potential 'area' ASD specialist, whose main role might be to support other psychiatrists/psychologists and

practitioners. The Review Team recommend that this should be taken forward by senior practitioners working on a regional basis within the proposed ASD Network arrangement.

The Review Team also recommends an ASD specific specialist resource within adolescent and general adult services for each Trust. This will cover more specialist diagnostic and intervention needs. In addition to their direct service provision roles (diagnosis/assessment and intervention/support), these practitioners should coordinate, and help to deliver the ASD training programme within the regional Network.

#### *General Assessment Services – Output/Next Steps*

After completion of the developmental assessment, case planning options should include: (i) ASD confirmed or likely, awaiting entry to ASD specialist services - early intervention/support services to commence or (ii) Uncertain diagnosis, awaiting entry to ASD specialist services - early intervention/support services to commence, or (iii) ASD confirmed not present: sign-posting to other services/agencies (i.e. non ASD) for early intervention.

## **ASSESSMENT & DIAGNOSTIC SERVICES**

### **ASD SPECIALIST DIAGNOSTIC SERVICES**

*The need to develop specialist ASD assessment and treatment services within Health and Social Care Trusts is central to the main recommendations set out in this Review.*

The Review has found that most ASD specialist services are underdeveloped and under-resourced. Although some funding was identified over recent years to develop services, this fell far short of what was needed to establish the level of service provision needed. Therefore some 'baseline' progress has been made towards the development of ASD diagnostic provision within children's services across Northern Ireland due to the investment made by DHSSPS over recent years. The same cannot be said for treatment services, which in some places are minimal or almost non-existent.

The situation for older adolescent and adult services is even less favourable. Both ASD specific diagnostic and support services are inadequate across Northern Ireland.

*The Way ahead – A future model for providing services*

The Review recommends that ASD specific diagnostic, assessment and treatment teams should be established in each Trust area. These services are required across child, adolescent and adult services.

These services should be integrated with the other child, adolescent and adult services within Trusts. It is not recommended that these new services should be stand-alone, or established within separate 'silos', but rather as part of a joined-up, 'wraparound' service which brings together the necessary service inputs from different disciplines and sectors within a child, person or family centred model of care. Many of the issues which affect children and families with ASD also affect children and families with other disabilities.

Where a diagnosis of ASD is either likely or provisionally suspected within child, adolescent or adult services, the Review recommends that these cases should be referred to the proposed new ASD specific diagnostic and support services. The aim of these services will be to:

- Build on the existing diagnostic and assessment work within general adolescent and adult services, carry out more comprehensive or specific ASD evaluation and assessments, and work towards a precise diagnosis - or recommend other services where ASD is confirmed as unlikely or not present.
- Create a Care Plan which covers multi-disciplinary inputs, including those from other sectors (e.g. Education, Voluntary, Community or private). Care Planning should also take account of wider care and the needs of the family, including siblings.
- Coordinate the delivery of the prescribed treatments and support services, including:

- Delivery of ASD specific interventions and services – from parental advice to more advanced parent training to help them to deliver home based, therapeutic services.
- Highly specialist and ASD specific Structured Communication, Cognitive and Behavioural Interventions delivered by teams of experienced ASD trained practitioners (including awareness of sensory issues which may require specialist advice and support).
- Arranging other services and agencies as required, e.g. occupational therapy. In older adolescents and adults, there is likely to be a need to consider transition planning and engagement with a range of other agencies covering housing, employment, advocacy services, etc. There is also the need to consider the risk that an individual may not always be recognised as a vulnerable adult.

With existing HSC services at a low baseline, particularly adolescent and adult services, the need to establish and deliver the service inputs needed will require a significant additional financial investment. This raises the need to consider cost and affordability.

The Review is aware of the broader, challenging, economic circumstances facing the HSC at present. Therefore any proposals need to be realistic and affordable, yet capable of delivering measurable benefits to individuals and families over the short to medium term.

The scope of this Review should not be restricted by short term financial circumstances, therefore a longer term picture of service development is also proposed for ASD services in N. Ireland. The Review has set out to identify a level of service provision that would make a real difference to children and parents affected by ASD.

#### *Assessment and Diagnosis - level of service provision required*

While national level documents explain the need for specialist ASD services, and highlight the range of services required, this guidance generally does not provide details of what these services should include. This 'benchmarking' information,

where available, helps with the planning of the services needed. Benchmarking information on adult services is particularly scarce.

This type of planning should be based on locally assessed need, together with an examination of evidence available from service providers. Up to date, accurate information systems are also needed.

The Review notes that, for a variety of reasons, existing information systems within Trusts do not provide an accurate picture of the true number of ASD cases within the general population. In addition, given the limited level of ASD services, the number of cases diagnosed at present may not reflect the true number of cases.

Accurate up to date information is needed to inform a plan for an appropriate assessment process. The Review therefore notes the need to establish effective robust information systems capable of providing up to date information on the numbers of people affected by ASD in Northern Ireland. This links with earlier recommendations linked to performance management which will also require effective information systems to be in place within Trusts. The data systems in place within the Education sector, only capture the 'statemented' population. This may underestimate the total number of ASD cases within pre-school and school settings.

In the absence of 'benchmarking' information, and given the very limited time available, the Review has had to adopt a practical approach to determine the ASD services needed for specific inputs needed for (a) diagnostic/assessment services, and (b) treatment/intervention and support services for children, adolescents and adults who may potentially have ASD.

ASD specific specialist diagnostic services are first considered for children followed then by services for older adolescents/adult.

*This approach focuses on specialist ASD services. The Review is well aware of gaps across the broader range of childcare and adult services. Any evaluation of these broader service deficits would be beyond the scope of this Review.*

## CHILDREN'S SERVICES

This exercise assumes that *every child* with either a suspected or likely diagnosis of ASD is referred from general childcare services to the proposed ASD specific specialist diagnostic team.

Taking account of the numbers living in the 5 Trust areas along with recent birth rate patterns 2004-07, combined with the current '90 per 10,000' ASD prevalence figure, produces the estimate shown of the likely number of new cases requesting ASD specialist diagnostic services per year:

<i>Trust</i>	<b>Northern</b>	<b>Belfast</b>	<b>S. East</b>	<b>Southern</b>	<b>Western</b>	<b>N. IRELAND</b>
<b>population</b>	444,700	333,000	336,000	334,800	293,000	<b>1,741,500</b>
<b>Av. births/year</b>	<b>5,597</b>	<b>4,112</b>	<b>4,117</b>	<b>4,853</b>	<b>3,931</b>	<b>22,610</b>
<b>predicted number of incident cases per year</b>	50	37	37	44	35	<b>203</b>

The above data shows that approximately 200 new cases of ASD could be expected per year in N. Ireland. However, when estimating diagnostic/assessment service capacity, additional capacity needs to be factored in to take account of (a) referrals with a provisional diagnosis or suspicion of ASD which are later confirmed as not present, (b) the backlog of cases already on Trust waiting lists plus the potential number of older cases still to be identified.

With regard to (a) above, many 'suspected' cases will be referred to specialist services where a diagnosis of ASD will eventually not be confirmed. Referral to other services then becomes likely. These cases must be taken account of when determining the potential workload of the specialist services proposed in this report. *All referred cases will require a full assessment regardless of whether ASD is confirmed as present or not present).*

Experience shows that, for every 3 'suspected' cases referred, there will be 1 'confirmed' case.

Taking this approach, the specialist ASD diagnostic/assessment services proposed by the Review will need to be able to deal with around 600 referrals per year. At present, the existing secondary level 'general' services within Trusts in Northern Ireland receive around 700-800 referrals per year. However, existing referral patterns are unlikely to reflect future patterns within the proposed regional ASD Network and associated Care Pathway (rollout of training initiatives, well promoted/understood referral criteria and overall general practitioner awareness). This is likely to impact upon both the quality and number of referrals across Northern Ireland. The Review anticipates that given the ASD service infrastructure proposed in this report, there would be a decrease in the number of cases referred where ASD is not eventually confirmed. These cases would be referred to other, more appropriate services at an earlier stage.

The need for additional service capacity to address the backlog of existing cases, (see (b) above), should also reduce over time, given the establishment of ASD service infrastructure proposed by the Review.

The Review set out to identify a level of service capacity that would, on average, allow a comprehensive diagnostic workup to be completed, with a detailed Care Plan for each case referred within the ASD specific specialist service setting. However, as mentioned above, the Review has not identified 'evidence based' ASD specific guidance for diagnostic capacity planning.

The Review has concluded that an initial effort must be made to estimate the level of ASD specialist services needed. It is recommended that the proposed ASD Network will, in due course, gather the appropriate service capacity mapping information based on actual service experience.

Each child (and family) is unique, with their own range of needs, so the concept of an 'average' case can be difficult to accept. However, based on the experiences of

existing practitioners within Northern Ireland, the Review has determined that a robust diagnostic workup could be completed where future service capacity was based on an average of 24 hours total practitioner 'assessment' input per child (and family: some cases will require smaller 'amounts' of practitioner time while others will require longer). This can be checked and reviewed over time with more experience of the proposed regional Network process.

The 18 hours capacity figure is based upon the diagnostic/assessment and overall Care Planning process requiring a total service input equivalent to 6-8, two/three hour practitioner sessions per family/child. This input would be provided by a range of consultants - mainly community paediatricians but also psychiatrists and psychologists, specialist Allied Health Professionals (SALT, OT, and physiotherapists) and other practitioners (e.g. social workers). This input could be deployed in different ways depending on the needs of the child and the family, for example, as a series (8-9) of individual 2 hour practitioner assessments or, alternatively, based upon a team of (2-3) practitioners carrying out intensive assessments of 2 to 3 hours over a short 1 to 2 week period. The degree of specialist/professional input required means that all practitioners involved in the future ASD specialist service model should be able to demonstrate the necessary experience, skill and expertise.

Summary table 3 (p.64) sets out the whole time equivalent ASD specialist assessment practitioner resource that would be needed within each Trust to deliver the 24 hours service input per case model – this takes account of annual leave and a 75-80% commitment to clinical duties (i.e. 20-25% allowed for other practitioner commitments such as professional development and training). The table also includes the existing ASD specialist practitioner resource already in place within Trusts taking account of the fund provided by DHSSPS since 2004/05.

The level of existing ASD assessment resources varies considerably between the 5 Trusts – not only in terms of the total number of practitioners, but also their type and grades. This unsatisfactory situation appears to be the result of investment decisions made in the previous 17 Trusts in place in Northern Ireland prior to 2007 and the lack of coordination across the region.

It is not possible to justify the significant variation in provision between the 5 Trusts and this cannot be excused by resource allocation decisions made in the past. The Review therefore recommends that **DHSSPS and the anticipated new Commissioning Board** should ensure that the proposed ASD Network arrangement has a more equitable and consistent level of service provision

There is a **significant backlog of cases accumulating in (diagnostic/assessment) waiting lists in Trusts and, in addition, the Review notes the probability of a number of older, as yet, undetected cases which will emerge in years to come.** This is due to a combination of factors, in particular, lower detection rates in the past and the absence of specialist ASD specific resources prior to **2000/01**.

This points to a need for a regional initiative to clear the backlog of cases awaiting assessment. It is therefore recommended that short term funding (i.e. 2 year period) should be identified to increase ASD diagnostic services within each Trust. Aside from the issue of funding, the availability of practitioners available to undertake this additional work will need to be addressed. These practitioners are a scarce resource – and ASD diagnosis/assessment is highly complex work. Therefore any practitioner recruited into services must be competent to undertake such work, given the lifelong implications for the child/individual concerned.

**The Review proposes that a resource of approximately £375,000 for each year of the proposed 2 year ASD waiting list initiative, distributed across the 5 Trusts, i.e. a total of £750,000, would enable the backlog to be addressed. This would increase existing service provision by roughly 50% over the proposed 2 year period. By clearing the existing backlog, Trusts would then be in a better position to address the incident cases.**

It should be noted, that any 'waiting list initiative' will, in turn, create a surge in children and families requiring access to intervention and support services. Additional resources are required to cover this.

### *Educational Psychologist input*

The need for multi-agency input has been noted elsewhere in this report. The Review notes the benefits of Educational Psychologists and also teachers participating in existing ASD diagnostic and assessment services within some Trusts. Although not explored in any significant detail by the Review, Educational Psychologists are an integral part of the diagnostic teams. The Review recommends that HSC and Education Sector agencies should formally explore the potential input of Educational Psychologists into the proposed new specialist ASD teams. The Review estimates that approximately 0.15 whole time equivalent sessional input would be required per Trust team. This, should be considered as an initial estimate of need. Some input is already provided within the 5 Trusts.

### *Assessment/diagnosis - day to day service model*

The Review expects that local ASD specialist teams to adopt the general day to day service model developed by the proposed *regional ASD Network*. *This would be consistent across the region*, and should include, for example:

- Referral/acceptance criteria
  - Diagnostic & assessment methodology - process and procedures (including any need for a regional specialist assessment process)
  - Team structure – practitioner inputs
  - Structured Communication and Behavioural Interventions – using a range of approaches based upon the needs of the individual child (and family)
  - Management arrangements – communication with broader Trust services
  - Input of other services and agencies, e.g. Education.
  - User and Carer Support: support strategies for families, carers and siblings
  - Training and Professional Development
- 
- Skills needed by team practitioners
  - Indirect work with practitioners in Tier 1-2 services (and other agencies and sectors): while Tier 3 ASD practitioners carry out direct work with children and families, they should also offer indirect consultation and advice to practitioners in other services (to help them provide general support to those with ASD)

- Performance Management and evaluation of services

#### *Team management within Trusts*

ASD diagnostic team resources should be based in childcare service directorates within Trusts. It is important that ASD services are integrated across children's services within Trusts to provide the necessary child and family centred model of care. This may require operational policies and procedures to allow proper integration with key services, including general child disability, child & adolescent mental health services, with input from other agencies and sectors. As mentioned previously co existing problems and issues should be identified and addressed with the necessary inputs set out in the individual Care Plan. Any practitioner managing or assisting with the case should be familiar with the broader needs of the individual child, and ASD in general.

#### *Care Plan*

One of the outcomes of the ASD specialist assessment process should be a detailed Care Plan, drawn up in partnership with families or carers, taking account of treatment and support services needed.

Children and families should receive the range of interventions and support they need including (a) Early Intervention, (b) more specialist Structured Communication and Behavioural Interventions, (c) ASD Family Support services and (d) other supports and care, in addition to specialist ASD services. This may include input from other sectors and agencies (including Education and Library Boards and voluntary or private sector input and support).

Children and families should receive support services with the minimum of delay. The Review proposes that receipt of formal Early Intervention services should start within a maximum 4 week period, i.e. following initial request for such input. (This should be incorporated as one service quality indicator within the new Performance Management process within the regional Network process).

## **SPECIALIST ASD ASSESSMENT/DIAGNOSIS - OLDER ADOLESCENTS AND ADULTS**

Diagnosis is the crucial first step in planning the care of an adolescent or adult presenting with symptoms of ASD. It is a starting point for the individual and others to see themselves and their difficulties in a new light, making the process more understandable and the need for support much clearer. Diagnosis leads to a more realistic assessment of the individual's coping skills and needs, can inform care-planning including issues such as accommodation, education, occupation and successful integration into the community. It opens the door to other information, specialist groups and resources, including financial benefits. Early diagnosis can help to prevent secondary disabilities arising from the struggle to cope with undiagnosed disabilities.

As with children's services assessment and diagnosis should be part of a broad, multi-disciplinary process based on a combination of developmental history and observed behaviour. However, unlike childhood, where there are opportunities for direct and continuous observation in a variety of social settings at school, or at home, in adult-hood and older adolescence there is less opportunity for this and there is, therefore, a greater emphasis on face to face interviews. Developmental history is always desirable, but it may be necessary to draw on collateral histories of others, including friends or other carers.

Specific diagnostic instruments can help collect the information needed for matching against agreed criteria. A variety of diagnostic instruments are available. Some use structured interviews such as ADI (Autism Diagnostic Interview) or the broader tool DISCO (Diagnostic Schedule for Social and Communication Disorders). Other instruments for Asperger syndrome have also been developed.

The Review recommends that the overall model for diagnosis and assessment for older adolescents and adults should mirror that recommended for children's services. However, the overall number of new cases to emerge within any Trust area is likely to be quite small. This would be all the more likely within the recommended future scenario of more robust ASD diagnosis capacity within children's services, with improved case detection and reduced likelihood of non

detection. Even with this infrastructure, there will inevitably be some cases which come to light at a later stage, to perhaps as a result of some crisis or loss of a carer. This is more likely for those with Asperger Syndrome, although there will be adults with learning disabilities in addition to their ASD whose true needs are only identified in later life due to a crisis, or staff's increased awareness of ASD.

Given the relatively 'low volume' of diagnostic work, the need for the proposed regional Network arrangement is particularly important for the establishment of a body of knowledgeable and skilled practitioners.

The need to target ASD training towards frontline practitioners has already been covered. Existing psychiatrists & psychologists (and some AHPs), working within general adult and learning disability services need to have adequate skills to be able to determine the potential presence of ASD and also undertake the necessary baseline assessment of individual need. The Review has also noted the need for a specific programme of training for practitioners dealing with older adolescents and adults in line with, for example, the recommendations of the Royal College of Psychiatrists.

ASD specialist resources for older adolescents and adults are so low that the Review proposes that a specific team resource should be established in each Trust area. Given that these such teams would be small, it will be important that they link together effectively within the proposed Network arrangement. The main focus of the proposed older adolescent and adult ASD specialist resource will be on Intervention and Support rather than diagnosis/assessment. The role and function of these teams will be set out in more detail in the section on specialist ASD Intervention and Support services.

## **ASSESSMENT & DIAGNOSTIC SERVICES**

### **REGIONAL COMPLEX CASES**

#### *The Regional Network:*

The proposed new specialist ASD services (& Trust Lead ASD Coordinators) from the 5 Trusts should join together within a regional system in an effort to collaborate and share expertise. This will help with development of professional ASD services across the region. As part of this process, a regional ASD Care Pathway should be developed. This should set out details of the child/individual 'journey' through services from initial parental suspicion, through primary care/community services, developmental assessment with Trust services, then entry into more formal ASD specific diagnostic and treatment services. The regional Care Pathway should set out a standard approach to the care and management of children with ASD.

The ASD Network should improve service quality rather than direct patient/family care. However, a small element of direct care would be necessary for the Network to provide a forum where 'difficult to diagnose' or complex cases could be presented to a regional peer group (after consent issues have been addressed).

The Network should enable local teams to obtain 'second opinions' from practitioner colleagues across NI. In addition, where external advice or treatment input may be required from outside N. Ireland, the Network would be able to develop relationships with other national level centres of excellence.

It should be noted that a formal regional service is not proposed. Rather, given the need for close integration with the broader range of children's service within Trust localities, it is important that the specialist ASD teams proposed by the Review are based near local generic childcare, adolescent and adult services within Trusts.

The Network should carry out a range of roles including:

*Care Pathway development* – as set out above

*Training / professional development* - the Network should develop and take forward a programme of ASD training to help improve knowledge and skills across NI,

including general level practitioners and primary care, specialists and key ASD practitioners, and also offer training initiatives to Education/Voluntary sectors and other key agencies as required.

*Performance Management* - To provide evidence of service quality, the Network should promote a range of performance management standards.

*Participation of Teams within the Network - Service Capacity*

The Network will have a key role in the development of high quality services across Northern Ireland. Local services must therefore have the capacity to release practitioners to engage in such duties. Therefore, to allow practitioners across the region to address and attend to Network issues, the Review proposes that each locality specialist ASD team should include the service capacity to enable the release of Trust practitioners to attend to regional Network duties.

The Review therefore proposes 2 days equivalent input from each team into the Regional Network process per month, i.e. 'lead practitioner' or Trust coordinator.

## **INTERVENTION & TREATMENT/SUPPORT SERVICES**

The Review considers that, taken together, the range of services proposed within this report can make a significant difference to the day to day lives of children, adolescents and adults with ASD their families in N. Ireland. However, the Review is mindful that the scale of new investment available to develop services may be limited and that any recommendations associated with a significant revenue demand need to be 'evidence based' and potentially affordable.

The Review recommends that the following services should be developed and made available within each NI Trust. These are considered in more detail within subsequent sections of the report:

***Early Intervention Services*** - the Review recommends that all children and families should receive a package of intensive early intervention and support within 3-4 weeks of confirmation of a formal diagnosis of ASD by specialist diagnostic/assessment services.

The Review has also noted the need for additional 'early' input to support parents and bridge the gap between initial diagnostic suspicion and entry into ASD specialist services .

***Specialist ASD specific Structured Communication, Cognitive & Behavioural Interventions*** - the Review recommends that teams of specialist practitioners should be developed within Trusts to enable the provision of ASD therapies and specialist interventions.

***Continuing care & support: Family Support Services; Voluntary and Private Sector support*** - in addition to specialist ASD services, families also require access to a range of other support and services - on a potentially long term basis.

The Review is aware of the need for support and input from services and schools within the Education Sector. A detailed exploration of such input is beyond the scope of this Review. However, it is essential that all these inputs are included in the individual child and family Care Plan. Close liaison between HSC and Education sector is therefore essential. The Review recommends that DHSSPS and DENI representatives, including other Departments and agencies (e.g. DEL & DSD), should determine how services from the various agencies can be better integrated and planned across all sectors.

Existing networks at senior civil service level offer a means of supporting and establishing this type of co-ordination and communication. If, however these systems cannot be established by this means, the Review Team recommends that consideration should be given to legislation to establish the interdepartmental systems needed. The Review Team also considered the question of how ASD-specific legislation might strengthen, promote or require the provision of services for people affected by autism. It was noted that additional statutory resources for autism services have been secured using existing legislation, and that none of the recommendations within the Review Team Report would require additional legislation to become reality. Given the NI budgetary structures, the requirement to ensure equality for people affected by every disability, and the broad scale and scope of existing Health legislation, the review Team would not recommend additional legislation **at this stage**.

## **INTERVENTION & TREATMENT / SUPPORT SERVICES**

### **EARLY INTERVENTION SERVICES**

*Given the need for targeted intervention as soon as possible during the early years of development, this section refers to children rather than older adolescents or adults.*

Together with the need for early diagnosis, the National Autism Plan (NIASA, 2003) recommends early intervention services immediately after the suspicion of ASD. This aims to provide basic knowledge and skills to parents, in parallel with the more specialist Interventions provided by the ASD treatment and support team.

The need for 'early' support and advice to families during the interval between generic and specialist diagnostic/assessment ASD services should be co-ordinated with the more formal Early Intervention services.

The Review notes that a multi-centre trial is currently underway in England of parent-led communication services. A pilot study of this proved effective in a *random controlled trial (RCT)*: (PACT: Aldred et al., 2004). Other interventions have also been effective in Northern Ireland including Keyhole, TEACCH, and Applied Behavioural Analysis (see Appendix 1 for details of reviews of interventions).

Early Intervention services will generally work with the child and parents providing home based or outreach support during the initial 6-12 month period post-identification. They aim to help parents to become 'co-therapists'. Parents of newly identified pre-school children should receive standard information and training on Autism and ASD, and how this affects their child. This would include, reviewing the communication, cognitive, social, behaviour and sensory processing difficulties being experienced by their child and ways to help. Parents can be shown, for example, strategies that in many cases will help to address behavioural and communication problems. The Programme should aim to help the parents to promote positive behaviour, developing communication and helping the child to learn. More formal training may include programmes to help with communications and visual communication strategies.

Early Intervention services should include group based approaches, for example, the promotion of social skills, which encourage social understanding and facilitate relationships with a parent or carer, and then friendships with groups of peers.

Practitioners can work with parents for 6-12 months to develop practical skills and better understanding of their child with ASD. Other services could include ASD Family Support with Structured Communication together with Behaviour Interventions, where indicated.

Other people involved in the child's daily care they will also need support and training. An Early Intervention 'package' of care might involve 20 half day sessions, 14-16 home visits, 2-3 nursery or school visits and 1-2 transition/coordination meetings (e.g. with Education staff).

The Review recommends that formal Early Intervention programmes should be available to all children and families within 4 weeks of diagnosis. Access to Early Intervention services should not only follow a confirmed 'ASD diagnosis'. This would penalise those who are most difficult to diagnose, or have additional complications, but whose needs may be most severe (NIASA made a strong case for a needs-led approach and this is supported by other evidence).

The Review will not propose any particular exact 'Early Intervention' model of service provision. This should be explored through the proposed regional Network approach. However, it would be important for the proposed Network to select interventions that:

- can quickly support and skill parents,
- have some evidence of effectiveness,
- address the basic characteristics of ASD,
- can complement other interventions so that all of a child's needs can be met,
- have clear outcome criteria which can be measured and evaluated, and
- are understood and accepted by parents (albeit after training).

Whatever is put in place should be monitored and each Trust should conduct evaluations of its 'parent training package' to check that it continues to be 'fit for purpose'.

#### *Needs assessment*

The numbers of new 'incident' cases requiring access to formal Early Intervention services can be predicted each year. The actual numbers will be considerably higher over the short to medium term, given the backlog of cases within Trusts.

Based on (a) Early Intervention support of 2 sessions (i.e. 4hrs total input) practitioner input during the interval between general and specialist ASD diagnosis and (b) formal Early Intervention 'package' of 20 sessions (2-3 hrs input per session) of practitioner input, details of the following whole-time equivalent practitioner resource required within each Trust ASD Intervention and Support team is details in the summary table 1 at the end of this section.

#### *Current Service provision:*

The Review recommends that Early Intervention services should be available within each Trust area. With recent funding provided by DHSSPS in recent years, most Trusts have already established these services.

Sufficient Early Intervention service capacity should already be in place within Trusts, however, there is still considerable variation. The significant variation in provision between the 5 Trusts cannot be justified and the Review again recommends that **DHSSPS** should ensure that within the proposed ASD Network arrangement a more equal level of service provision is established across Northern Ireland.

There is also the need to consider 'early input' support, a separate service to help families over the gap between general and specialist ASD diagnostic and assessment services. This is not currently available in any Trust area. There is a need to consider whether additional investment should be provided to provide early support or whether this can be achieved through a re-organisation of existing ASD Early Intervention services within Trusts.

## **INTERVENTION & TREATMENT / SUPPORT SERVICES**

### **STRUCTURED COMMUNICATION, COGNITIVE AND BEHAVIOURAL INTERVENTIONS**

This represents the main area of unmet need. The Review Team has noted that some progress has been made towards the development of assessment and diagnostic, and early intervention services for children's services. However intervention/treatment and support services are almost non-existent in some areas.

Services for older adolescents and adults are in an even worse position with negligible levels of service provision including assessment, diagnostic and intervention services. Given this deficit of treatment and support services, it is understandable that parents have looked beyond the HSC sector for help. The Review Team recommends that this unfortunate situation should change. In hindsight, given the very limited resources available, it would appear appropriate for the initial focus to have been upon the development of assessment/diagnostic service capacity, in particular within children's services in Northern Ireland.

The Review Team is aware of worldwide debate about evidence based ASD treatment and supports. Given the terms of reference for this Review, it would not be appropriate for the Team to undertake an in-depth appraisal of different therapies or interventions. However, a brief summary of potential interventions is provided in Appendix 1.

*Support services for children will first be considered followed by services for older adolescents and adults.*

### **SERVICES FOR CHILDREN**

Similar criteria should be used for the selection of interventions for childcare as for the Early Intervention Services. However, the main focus of the interventions should be direct input with the child, rather than working with parents. This will develop their skills and understanding. Consideration should also be given to interventions that continue to support parents to work with their child (especially pre-school) where:

- the child does not have access to high quality interventions delivered by suitably trained professionals
- parents prefer to work with their child at home and they (and the siblings) can be supported in this.

Within the HSC sector the Review Team proposes that the regional ASD Network should take the lead in identifying an agreed position across the five Trusts for potential therapeutic approaches and interventions.

While parental choice should, of course, influence the therapeutic strategies and treatments adopted across NI, any decision will also be heavily influenced by the availability of practitioners within the Network system.

## **RESOURCES REQUIRED**

Given the absence of 'benchmarking' data to assist with planning for adequate service teams and the limited time available, the Review Team has had to estimate the ASD treatment and support services required in N. Ireland.

The approach used assumes that each child with a confirmed diagnosis of ASD will move to more specialist ASD treatment services. It should not be assumed that these services are separate from other general services. Specialist' ASD services should lie within and be fully integrated with the broader range of children's services provided by Trusts.

The Review Team proposes that particular emphasis should be placed on providing specialist ASD treatment over the initial 3 year period after identification. Access to a range of services may be required beyond this time and the Review Team is aware of the changing needs of children with ASD as they get older and progress through different life stages into adolescence and adulthood.

There is uncertainty about the quantity or level of service inputs needed to create a suitable ASD treatment model. The Review Team proposes that, given the present resources, the initial aim should be to set up a baseline level of specialist service within Trusts, and build on that with the proposed regional Network, and additional

resources in the future. Given the anticipated learning that will be generated within the Network, it is hoped that a more accurate appraisal of treatment service capacity can be provided in due course.

In the absence of benchmarking guidance, sufficient treatment service capacity should be put in place to allow children and families to receive a meaningful package of specialist treatment and support with Structured Communication, Cognitive and Behavioural Interventions. These services should be delivered by Clinical Psychology and Allied Health Professional (AHP) staff with adequate training in ASD therapeutic and support approaches. This direct child and family work may include the use of internet-based training and support programmes.

The Review Team proposes that the *baseline level service* should be based on establishing enough service with capacity to provide each child and family with Structured Communication, Cognitive and Behavioural Interventions over the three year period post identification. The practitioner inputs would be provided in addition to Early Intervention services.

**Medical/Psychiatric review:** - Three x 1 hr sessions per year (mainly review based work)

**Clinical Psychology services:** - Eight x 1hr sessions per year

**AHP services:** *Speech and Language Therapy & Occupational Therapy:* - Eight x 1hr treatment sessions: 3 blocks of intervention per year, *i.e. 24hrs input per child per year*

*The Review Team recommends that the above services, together with specialist ASD specific assessment and diagnostic practitioners, should be provided by a specialist Trust ASD team resource which has been firmly embedded within Trust childcare directorates.*

Children and families have different needs. The proposed practitioner services listed above should be used flexibly across the wider team resources managed by specialist ASD services and targeted according to the needs of children and families.

Using this approach along with earlier data on the anticipated number of new cases per year, allows an estimate to be made of the level of service provision required within Trusts which are details in the summary table 3 at the end of this section.

The proposed Structured Communication, Cognitive and Behavioural Interventions within Trusts should be based on an **overall team resource between 5.3 – 7.5 whole time equivalent practitioners**, with a total overall regional ‘Intervention’ resource equivalent to around 30 whole time equivalent specialist ASD practitioners. This contrasts with the existing regional total of only 13.6 whole time equivalent specialist ASD practitioners currently in place within Trusts. Using these calculations, the total regional Support service deficit amounts to 16.72 whole time equivalent plus administrative support service inputs. Based on the average level of service provision, current service levels are approximately 45% of what we need.

*Intervention/Support services: existing and required whole time equivalent practitioners*

<i>whole time equivalent</i>	Northern	Belfast	S East	Southern	Western	N.I.
<b>TOTAL REQUIRED</b>	<b>7.51</b>	<b>5.51</b>	<b>5.52</b>	<b>6.51</b>	<b>5.27</b>	<b>30.32</b>
<b>Existing practitioners</b>	5.0	3.8	2	0.6	2.2	<b>13.6</b>
<b>Deficit between existing &amp; required</b>	<b>2.51</b>	<b>1.71</b>	<b>3.52</b>	<b>5.91</b>	<b>3.07</b>	<b>16.72</b>

*Funded position as of 31/03/08*

This shows that the largest gap between existing and proposed Support services is in the Southern Trust area, while the smallest is in Belfast.

Given the considerable variation between existing levels of ASD services within Trusts, The Review Team recommends that **DHSSPS** should promote consistent levels of ASD service provision across Northern Ireland.

The Review Team also recommends *increased recurrent funding levels* to create 16.7 whole time equivalent new posts to bring regional service provision up to the required proposed level of 30 whole time equivalent specialist practitioners. This would require a recurrent investment equivalent to £750,000 (2008/09 costings).

## **THE GAP BETWEEN EXISTING AND PROPOSED 'MORE IDEAL' LEVEL OF SERVICE PROVISION - SUMMARY**

The overall total of resources need to increase services as outlined by the Review team is summarised below. This section sets out the scale of recurrent investment necessary to put that in place.

To address the almost total absence of ASD specific services for older adolescents and adults, the Review Team recommends an initial level of service investment to begin the process of service development – an investment of circa £1 million to provide an initial foundation level resource of 18.0 whole time equivalent practitioners across the 5 Trusts in N. Ireland. This cannot represent the longer term vision for services for older adolescents and adults and should be considered an initial 'start up resource'. The Review team therefore proposes that the impact of these services should be reviewed after the proposed resource has been put in place. This would allow a longer term plan services for older adolescents and adults to be made – given the time needed for such services to be put in place, this could be undertaken by 2012/13. It is difficult to at this time to establish the gap between existing (almost absent) and the 'ideal' level of service provision.

This summary also covered services for children and takes account of the available / proposed resources required across (a) Diagnostic/assessment (b) Early intervention (c) Structured Behavioural Interventions, i.e. Intervention/Support services and (d) Family Support services as outlined in this report. The overall regional position can be summarised in the following table:

Summary Table 1 : Existing ASD Service provision

	Northern	Belfast	S East	Southern	Western	Total
<b>Area Specialist Assessment</b>	4.9	1.9	3.9	0.9	4.7	<b>16.3</b>
<b>Early Intervention</b>	1.0	2.0	5.5	6.1	2.0	<b>16.6</b>
<b>Structured Behavioural Interventions</b>	5.0	3.8	2.0	0.6	2.2	<b>13.6</b>
<b>Family Support work</b>	0.0	0.0	0.0	0.0	1.0	<b>1.0</b>
	<b>10.9</b>	<b>7.7</b>	<b>11.4</b>	<b>7.6</b>	<b>9.9</b>	<b>47.5</b>

Summary Table 2 Proposed ASD Service resource

	Northern	Belfast	S East	Southern	Western	Total
<b>Area Specialist Assessment</b>	3.2	2.3	2.3	2.7	2.8	<b>13.3</b>
<b>Early Intervention</b>	2.9	2.1	2.1	2.5	2.0	<b>11.6</b>
<b>Structured Behavioural Interventions</b>	7.5	5.5	5.5	6.5	5.3	<b>30.3</b>
<b>Family Support work</b>	2.5	1.8	1.8	2.1	1.7	<b>10.0</b>
	<b>16.0</b>	<b>11.8</b>	<b>11.8</b>	<b>13.9</b>	<b>11.8</b>	<b>65.2</b>

Summary Table 3 : Existing ASD Service provision & Proposed ASD Service resource

	Existing Resource	Proposed Resource	Deficit
<b>Area Specialist Assessment</b>	16.3	13.3	<b>3.0</b>
<b>Early Intervention</b>	16.6	11.6	<b>5.0</b>
<b>Structured Behavioural Interventions</b>	13.6	30.3	<b>-16.7</b>
<b>Family Support work</b>	1.0	10.0	<b>-9.0</b>
<b>Total</b>	<b>47.5</b>	<b>65.2</b>	<b>-17.7</b>

The available data indicates that, taken together, an additional 17.7 whole time equivalent practitioners are required to bring ASD service provision within N. Ireland up to the more suitable level set out by the Review Team – this would require a service investment resource of approximately £750,000.

In considering the above data, the following points should be noted:

- *Intervention/Treatment Deficit:* The main service deficit lies within Treatment and Support services while Diagnostic/ Assessment and Early Intervention services are comparatively better resourced. This reflects the investment decisions made by legacy Trusts across the region prior to 2007.
- *Variation between Trusts:* As outlined within this report, there is a significant variation between Trusts in terms of the existing number of practitioners and also, the range of practitioner resources. It has been proposed that this should be addressed by DHSSPS or the proposed new Regional commissioning structures. The following table presents the existing total practitioner resource on a per 100,000 total population basis:

<i>Whole time equivalent</i>	<b>Northern</b>	<b>Belfast</b>	<b>S East</b>	<b>Southern</b>	<b>Western</b>	<b>NI</b>
per 100,000 TOTAL population	<b>2.45</b>	<b>2.31</b>	<b>3.39</b>	<b>2.27</b>	<b>3.04</b>	<b>2.67</b>

Viewed in this way, the Belfast and Southern Trusts have about 15% less than the regional average level of provision, while South Eastern Trust have about 27% above the regional average.

- *Existing resources:* the Review Team notes that while there is now a significant service resource in place amounting to approximately 47.5 whole time equivalent (Summary Table 1) practitioners across Northern Ireland, a significant proportion of this is only recently established reflecting DHSSPS investment in 2007/08. It is therefore unlikely that children and families will have felt the full benefit of these recent additional resources. The Review Team also notes that there is likely to be some ‘lag time’ between practitioners being recruited and becoming fully effective

and competent as practitioners, given the need for additional training, practice development, etc.

- *Backlog of cases requiring access to services:* The Review Team proposes that there is an additional need to increase the available level of service provision over the short term to address the backlog of cases awaiting services within Trust waiting lists and also to address undetected cases which are likely to emerge over the coming 2-5 year period.

The Review Team wishes to thank the Health Boards and Trusts for providing the statistical information needed to allow these tables to be completed. It is understood that part of the data had to be obtained at relatively short notice without going through the normal statistical procedures designed to promote consistency and accuracy.

The Review Team recommends that consistent statistical information on ASD waiting lists and overall numbers of cases, together with details of service provision should be prepared on an ongoing basis to identify and monitor ASD needs and services. This information, plus other data recommended elsewhere, should provide evidence of the work being undertaken and the levels of service needed.

## **TOTAL INVESTMENT REQUIRED**

Given the above, the Review Team proposes that a total recurrent investment of £1.75 million is required:

Children's Services = £750,000

Older adolescent / adult services = £1,000,000.

In addition, there is a need for non recurrent resources to address the acknowledged 'backlog' of cases requiring access to services.

## **SERVICES FOR OLDER ADOLESCENTS AND ADULTS**

Service for older adolescents and adults need to mirror the model of service provision recommended for children's services with the promotion of ASD knowledge and skills among *existing* general services and the development of local ASD specialist resources within each Trust, with teams joining together within the proposed NI Network arrangement and associated Care Pathways with referral criteria, diagnostic tools and specialist intervention.

There is a need for improved skills and training among existing frontline practitioners, mainly within mental health and learning disability services. Beyond the need to improve knowledge/skills in generic level services, the Review Team recommends the establishment of an ASD specialist team resource in each Trust area for confirmation of ASD diagnostic, individual care planning and provision of structured psychological therapies. Increasingly specialist treatment programmes are being described and recommended.

Following confirmation of a diagnosis of ASD, a range of non-clinical services will be provided, including family support, peer support, a growing number of self-advocacy groups, educational support across school, college and university and occupational and social services. Help may be required for specialist support to help with accommodation (only 16% of adults with ASD live independently - CR136 – p12), or with education and employment. Local ASD specific specialist teams should liaise with other agencies and sectors to provide access to services such as education or vocational training, housing or leisure. This liaison work with other agencies and sectors should depending on the circumstances and needs of the individual, either be undertaken directly by the ASD specialist team, or more likely, in partnership with other Trust services based within Community Mental Health or Learning Disability teams.

Day to day care for an individual should focus on improving their symptoms by adopting techniques and strategies that reduce anxiety or increases comfort and a sense of well-being. Management should be based on a biological, psychological, social and educational perspective point of view, (bio-psychosocial educational, combined with treatments to reduce anxiety and distress). Biological interventions

include treatment of other physical problems and pharmacological management of associated psychiatric disorders or for the anxiety relating to the ASD itself.

Psychological interventions range from behavioural approaches to more specific in-depth therapy, and will depend largely on the cognitive ability of the individual and their symptoms. Specific psychological approaches, e.g. relaxation techniques or anger management training may be of benefit. Psycho-education of family and others can reduce the level of emotional stress, and help create a more autism friendly world for the individual.

Social and educational interventions will also help to support the individual and develop his or her environment to make the world an easier place in which to live.

Not all individuals with ASD require external supports. Many want to have full lives which are independent from that type of help. However, many individuals with ASD will require support from a variety of different agencies. This will involve families and carers, and needs to extend beyond health, education and social services, to include, occupational, recreational, legal and voluntary services. Specialist psychiatric services may be one part of this system for a minority of people with ASD

#### *Voluntary and Community Sector input*

The Review Team wishes to acknowledge the voluntary and community sector groups who work within individuals and families affected by ASD. There are issues linked to the competition for resources available to support such groups. Given their limited capacity, the main focus of many groups has been the support of children and families. These groups would also have a number of roles in terms of supporting older adolescents and adults with ASD. The voluntary and community sector should therefore be supported in their efforts to provide help to individuals across the full age spectrum. This raises the question of providing the necessary resources to the voluntary sector, and the need to promote value for money and measurable outcomes.

### *The role of ASD specialist teams*

The main role and function of ASD specialist services for older adolescents and adults will include:

- Diagnosis/Assessment – i.e. while most cases should ideally be detected in childhood, a small number of new ‘incident’ cases will inevitably emerge in later life. The majority of cases should, however, already be known to services, including older children ‘graduating’ from the proposed ASD services within the childcare system.
- Treatment and Support – Psychological therapies and helping with broader social and emotional needs
- Transition issues – the provision of skills and strategies required to help people with relatively minor life events but also more significant situations.
- Health needs – e.g. management of additional health problems, providing access to health promotion initiatives (screening, annual health checks, etc): requiring close working with the individual’s GP and the primary care sector;
- Training and development role – i.e. promote knowledge and develop skills among frontline services and also other key individuals within other settings and agencies.
- Information – provision of ASD and also general information to individuals, family, siblings and those working in other agencies/settings.
- Regional Network. The development of the Network to promote effective ASD service delivery across Northern Ireland.
- Occupational/Vocational needs – to establish independent living skills
- Housing/Residential needs – independent / supported living needs: a range of accommodation options to help people with different levels of ability.

The proposed specialist ASD practitioners should work closely with counterparts in frontline community mental health and learning disability services to ensure that the broader needs of individuals are met. Specialist ASD practitioners will therefore have a range of other health and social care roles, including liaison duties with practitioners across Trust services to help those practitioners work more effectively with individuals with ASD.

Older adolescents and adults with ASD may need a specialist “hands on” service, with a support worker to introduce them to a leisure or educational services; or a support worker to provide a carer with some few hours of respite; or a support worker to help the individual in new housing or accommodation. All these supports should form part of any new range of service provision. They will require a funding source.

#### *ASD specialist teams – Resources required*

While the role and function of services to support older adolescents and adolescents can be defined (using key national sources of advice,) there is less guidance available about the planning of services, their scale/size, or day to day operation, or the provision of local services to deliver these services.

The Review Team has again had to estimate the levels of ASD treatment and intervention and support services needed in N. Ireland.

The Review has again had to be realistic about the current economic climate and likely levels of new resources available. It is unlikely that the level of new funding available could ever take account of all the needs of all those children and adults with ASD. A fully functioning, fully staffed, stand alone ASD service to manage all older adolescents / adults with ASD would not appear to be realistic at this time. The Review Team has therefore avoided ‘blue skies’ thinking, but has tried to promote the view that a reasonable ‘start’ should be made to develop the required services within the HSC sector.

The very limited level of service provision available to older adolescents and adults with ASD is generally derived from existing community mental health and learning disability services across Northern Ireland. Nevertheless, it is important that any new ‘older adolescent and adult’ ASD specific resource established should work closely with existing services, in order meet the needs of more individuals than they can at present.

The Review Team proposes that a separate ASD specific team resource should be established in each Trust area to work with older adolescents and adults with ASD

and, to promote the development of skills and knowledge across existing frontline services.

Children's services, should be an initial 'foundation level' of services from which regional capacity can develop and capacity increase over time, e.g. as experience within the service grows and potential new resources and investment become available.

It is proposed that a senior/consultant level specialist ASD posts should be established in each Trust area. Both psychiatry and psychology posts are needed. In addition, each team should include ASD specialist professionals to undertake direct therapeutic work and structured therapies plus the required 'indirect' work to develop skills/knowledge across other Trust services and also other settings and agencies to promote ASD specific skills and knowledge.

The Review Team recommends that this resource should be multi-disciplinary and multi-professional to reflect the range of work and inputs needed. Each team should therefore include specialist nursing, social work and AHP inputs.

Given the likely level of new resources, such teams will inevitably be quite small, emphasising the important role of the proposed Network arrangement – however, a minimum level resource of 3.0 whole time equivalent is proposed for in each Trust area (with actual team size adjusted to reflect the different population of the 5 Trusts). An important decision will be the identification of the 'key worker' assigned to support the individual with ASD. However, given the relatively small size of the initial 'foundation level' ASD teams, this duty would, in most cases, remain with existing frontline mental health / learning disability teams within Trusts. With the support of ASD specialist teams they should be more able to provide care and support than previously.

*Proposed Trust ASD specific team resource*

<b>whole time equivalent</b>	<b>Northern</b>	<b>Belfast</b>	<b>S East</b>	<b>Southern</b>	<b>Western</b>	<b>N.I.</b>
<b>Consultant level</b>	0.77	0.57	0.58	0.58	0.50	<b>3.00</b>
<b>ASD professionals</b>	3.83	2.87	2.89	2.88	2.52	<b>15.00</b>
<b>TOTAL</b>	4.60	3.44	3.47	3.46	3.03	<b>18.00</b>

An overall regional resource of 18.0 whole time equivalent specialist practitioners is therefore proposed - each team will require an additional administrative resource. As an initial estimate, this will, require £1,050,000 at 2008/09 cost levels, including admin support. This level of resource, while relatively small-scale, could be considered affordable taking a 3-5 year viewpoint. This would be in addition the significant level of new funding required to develop children's services as set out elsewhere in this report.

Locally, teams would need access to a domiciliary support, personal care and vocational budgets to enable them to provide day to day care inputs required by older adolescents and adults with ASD.

## **CONTINUING CARE & SUPPORT SERVICES**

### **FAMILY SUPPORT SERVICES; ACCESS TO INFORMATION & ADVICE**

The Review Team could have made an exhaustive range of recommendations about the need for additional treatment and support services. However, the Review Team recommends that a priority, over the medium term, should be the development of ASD specialist treatment and support services across both children's, adolescent and adult age ranges. Over the longer term, there is a need to develop a *wider range* of services and support. A broad range of support services are required, including respite services. Those with the most intensive needs require specific housing support with longer term care options.

Children and families and individuals with ASD need access to a range of services and support, both over the short and longer term. Given the range of inputs from both statutory and non statutory sources, there is a risk that the full range of multi-

agency inputs may not be properly coordinated. This underlines the need to plan and review the care provided in partnership with service users and their families. This will require effective communication and coordination with the range of providers and agencies providing the care of the individual with ASD.

The Review Team recommends that this coordination and liaison role with families should be taken forward through the development of ***ASD Family Support Services*** with a named worker:

## **ASD FAMILY SUPPORT SERVICES**

In addition to specialist therapies and interventions, ASD Family Support services should be developed within Trust based ASD specialist teams to provide advice and support over the longer term to children/families and older individuals with ASD. Ideally, each individual or family should be allocated a named worker who will be responsible for (a) developing personal links and promoting awareness of the particular needs of each child or family in a prompt and responsive way and (b) carry out a coordinating role across the range of prescribed services and inputs. This would allow services to be *person centred* rather than only clinic based and therefore avoid the perception of a 'medical only' model of provision. The development of a named worker model would allow links to be developed across the wider range of services and providers, broader family support (including sibling needs) and also the voluntary and community sector. Families and older individuals with ASD might also need advice and support about general entitlements, signposting to relevant community services and liaison with the Education sector or other statutory bodies.

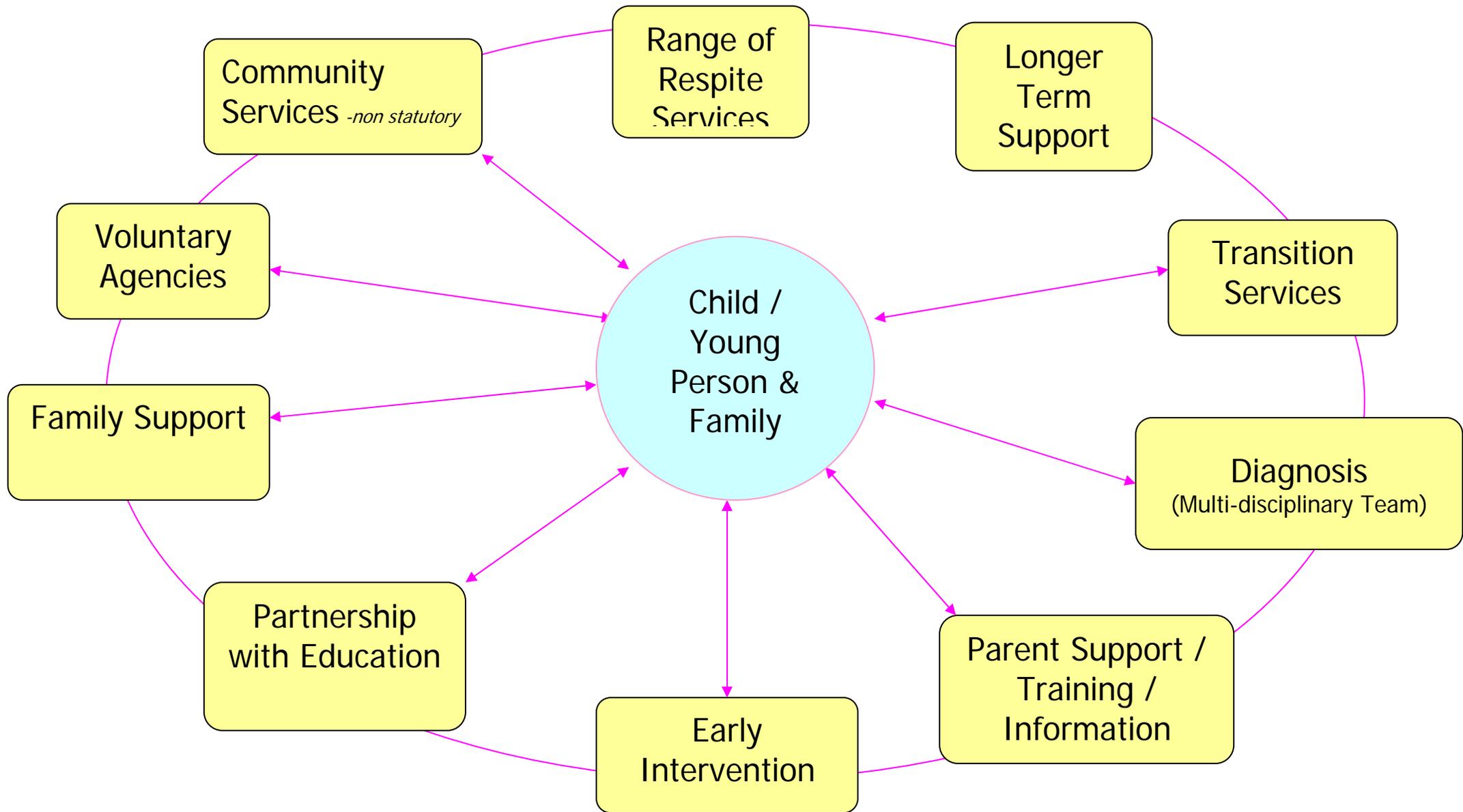
The named worker model also takes account of the fact that the needs of a child or family are likely to evolve and change over time; they will therefore require a link into services on an ongoing basis. This approach would provide parents and families with a 'one stop' access point to both the correct professional inputs, i.e. on a personal basis through the named worker, and also general access to other services and sectors.

ASD Family Support Workers should be developed within each Trust, as part of the ASD specific specialist Intervention teams within childcare directorates. Other service delivery options include the delivery of this service by the Voluntary/community or private sector.

The Review Team recommends that a resource equivalent to 10 whole time equivalent Family practitioner support practitioners should be established. This resource should be distributed across Trusts on the following basis (assuming allocation takes account of the respective child population within each Trust).

<i>Whole time equivalent</i>	<b>Northern</b>	<b>Belfast</b>	<b>S East</b>	<b>Southern</b>	<b>Western</b>	<b>TOTAL</b>
<b><i>Family Support Worker</i></b>	2.48	1.82	1.82	2.15	1.74	<b>10.00</b>

# Range of Services for Children / Young People with ASD



## **ACCESS TO INFORMATION & ADVICE**

The Review Team met with many families as part of the Review and noted their need to have services which are more patient and family centred. Children and young people, and their parents must be full partners in both individual and service delivery decisions.

To achieve this aim, individuals and families need knowledge, skills and support. They need services to be developed which provide access to the necessary knowledge and skills. Around the time that ASD is first suspected/confirmed parents and families need particular help with finding the best advice, information and general support. Some families reported that they found themselves overloaded with information from too many different sources and organisations.

Faced with a potential array of information sources and assessments models, (including UNOCINI the single assessment model developed for all referrals to children's services) within the HSC sector and to prevent unnecessary distress, families should have access to clear and relevant information. This should be available without delay, avoiding any need to be redirected through various HSC services and structures.

Day to day practice within statutory services should not only be challenged and informed by best evidence and latest research but also the experience and findings of service users and carers. The development of the proposed regional ASD Network should be based on multi-agency working including the input of service users, carers/families and the voluntary and community sector.

It is widely accepted that the future model of care should be more multidisciplinary. Where appropriate this should involve partners and agencies from a range of sectors. Increasingly these services must be based on pathways, delivered by teams to a consistent standard, in managed networks spanning all sectors and organisations, in a culture of continual improvement. Services therefore need to be redesigned so that they are "facing the right way", i.e. centred around the needs of the individual and family and appropriately signposted. In addition, a continuing challenge is the need to ensure services are person centred and well coordinated.

Individuals and families often see statutory based care systems as daunting and challenging. Navigating the system and finding the correct information and support services can be daunting, especially if those services are poorly signposted.

The proposed ASD Family Support Services, with a named worker would help provide access to appropriate information sources. In addition, the role of the voluntary/community and private sectors is clearly important for advice and access to a range of other resources and services. Trusts should therefore ensure that robust links are developed with these other sectors to help them to deliver the full range of support. The Review Team also wish to promote a 'One Stop Shop' concept in an effort to bring information sources and agencies together.

### **INTEGRATED TREATMENT AND ADVICE CENTRES**

People affected by ASD should be encouraged and empowered to speak for themselves and, as far as possible, should be enabled to take charge of their own lives. Each family and child or adult should be at the centre of the choices they make. Being able to find the right help at the right time is a vital part of tackling difficulties and challenges.

*Ideally, a single source of advice and treatment* would be both virtual and centre based. As well as being a resource for individuals seeking help, it would signpost people to other organisations specialising in a particular issue. This would help prevent people ringing the wrong centres for information and avoid delay in getting the information and advice they need. The overall aim would be to ensure that families and their carers receive accurate and relevant information about the services available to them.

A centre of this type could be located within Health and Social Care or local government premises. The plans for 35 Community Health and Wellbeing Centres across NI could provide access to a range of services within a single 'umbrella' setting. The Review Team recommends that Health and Social Care Trusts should highlight the need for physical space for the type of purposes outlined in this Review at an early stage in the planning for these Community Health and Wellbeing Centres

in their area. Local government may be well placed to provide access to a range of facilities (e.g. local government buildings, leisure centres, etc) which are located across all areas and towns in Northern Ireland in addition to, or in the interim before the completion of the centres. The Centres could also have a role in organising and providing regular training courses for the benefit of individuals and family, professionals and stakeholders from other key settings and agencies. This could provide access to other Centres, and other services including befriending, social skills, activity groups, drop-in centres, one-to-one therapeutic intervention, outreach services, access to specialised library services, independent living, health, employment and education services etc.

With access to these type of facilities, partnerships between the various agencies and specialist ASD teams could be established, including the pooling of resources to promote social inclusion and accessibility. The integrated treatment and advice centre approach could enable a range of resources to become available. This could include access to electronic and computer based media. In addition, advisors from relevant agencies could be contracted, or could be in attendance, and could provide access to a range of resources.

### **THE 'WRAPAROUND MODEL'**

The 'Wraparound model,' which operates within the Southern Health and Social Services Board area brings together a range of stakeholders, including parents, young people, professionals and agencies to a series of forums held on a regular basis, within one location. An additional benefit is that actions from previous meetings are reviewed and potential new issues and areas of service development can be considered at individual, operational and strategic levels. It may be possible to develop this, with other models such as 'Team around the Child', highlighting ways of working more closely with local Government.

It would be important that local treatment and advice centres provide balanced and unbiased source of advice and assistance. It would be essential that sources of advice, whether statutory, private or voluntary and Community sector based, are inclusive, and do not seek to exclude any mainstream approaches. Any additional resources required to maintain these facilities should include a requirement that all

participating groups ensure that they do not seek to exclude the provision of advice covering all mainstream approaches, interventions and types of assistance available to families affected by ASD.

*Local treatment and advice centres* could also have a role in the development of web-based resources which could form an electronic portal to a range of facilities, or could direct people to specialist organisations that can help with broader health issues, housing, education, employment and other social issues. Any such website would ideally be available on 'links' from other web-sites.

## **INTERNET-BASED RESOURCES**

The practice of modern health and social care is changing with an increasing focus on disease prevention, early intervention and more self-directed care. Self-directed care empowers individuals and families, enabling them to become equal partners in the decision making process and to help involve them as co-providers of their care.

Consideration should be given to adopting (or even developing) internet-based support systems for training parents and professionals to carry out suitable interventions (including assessing for targets, and evaluation of progress where sufficient local expertise is not available or is not cost-effective to provide). An example of this is *AutismPro* : <http://www.autismpro.com>). The best of these programmes empower parents (or professionals) to make effective choices of interventions which suit the target they are teaching, rather than feeling they have to adopt a single approach, or that this is all that is available, or all that they have been trained to do.

Many interventions are good at facilitating particular aspects of a child's development however none has been shown to be effective at meeting all a child's needs, nor to work well for every child. Internet-based services which allow access to a wider range of expertise than would otherwise be available, and could always be mediated by a local professional, where this was thought to be necessary.

In due course, parents would be able to review and adopt interventions of their choice and could be supported in carrying them out with their child - with input from

specialist practitioners. Such parent-led approaches have the advantage of empowering parents, and could assist in preventing feelings of antagonism with authorities.

Internet based resources should be investigated in more detail within the proposed regional Network to identify a preferred list of resources. Such approaches could be part of a Trust's provision to prevent isolation of geographically remote families, or to provide expertise where there is insufficient to meet local needs. From a rural perspective, internet or computer based resources may be of particular assistance to families living in areas which are more remote from service bases.

It can also be used to train and support insufficiently experienced professionals in their interventions with children. The availability of an agreed regional list of internet and computer based resources would also go some way towards preventing the exploitation of parents' vulnerability to unwarranted claims for any interventions which may not be as effective.

Overall, the Review recommends that lead professionals within the proposed regional ASD Network should work towards defining the preferred therapeutic strategies and treatments.

## APPENDIX 1

### **Evidence Base of non-pharmacological Interventions in ASD**

This section is concerned with particular named interventions most of whom (especially those from the USA) come with a cost, for the provision of materials, training, and supervision. Most, but not all, of them are targeted at pre-school children but some argue that the same approach should be adopted in the school setting or that children with ASD should attend specialist schools that follow this one particular intervention. An outline of the more common named approaches is given in the glossary below. This section addresses the questions that need to be asked of any intervention in order to determine its suitability for the child with an ASD.

### **The Research basis for intervention**

Research evidence may underpin interventions in one of two ways:

- *The Rationale for the Intervention.* There may be research evidence that shows that the intervention addresses areas of development that are affected in ASD and where development in those areas is likely to lead to a good prognosis. Interventions that target social and communication understanding and skills or that teach the child to develop a more flexible cognitive style would meet the criteria of interventions that were addressing areas that research has indicated are important to develop in ASD. In other words, there would be a justifiable rationale for tackling those aspects of development, although it would have nothing to say about which intervention was most effective, or for which children, in what contexts.

A stronger case for claiming a research rationale would be where there are direct links between research on the development and/ or learning style of children with ASD, and the intervention to address that identified need. That could be claimed for TEACCH, where, for example, structured teaching arose from research showing individuals with ASD were dependent on cueing for many cognitive processes and to control their behaviour. TEACCH also incorporates research showing that most (although not all) individuals with ASD have a visual and a detailed cognitive style, so that they need visual

structures that emphasise the goals of activities and help individuals function independently (of others, if not of structure),

Research on the difficulties with joint attention and early dyadic interaction has underpinned many of the interaction-based approaches (Son-Rise, DIR, SCERTS, Intensive Interaction), although they vary to the extent that the research linkage is made.

ABA approaches also lay claim to a research rationale but their case is somewhat different in that the research they rely on is based on learning theory, and more specifically, operant conditioning, as espoused by Skinner, rather than ASD research. Learning theory assumes that all learning, whether of animals, children, adults or people with disabilities (including ASD) follows the same invariant laws and that teaching (or more accurately, training) based on these laws would be effective in all cases. It is admitted that some children might take longer (i.e. would need more teaching trials) to learn than others but it assumes that we all learn in the same way. It is also a tenet of these approaches that by manipulating the setting conditions and the reward, any individual factors could be overridden. In that sense, then, ABA cannot be said to address ASD, because it does not recognize it as important. What it does, however, is address behaviours, which are associated with the difficulties in ASD, and claims that by building adaptive behaviours and eliminating maladaptive ones ('adaptiveness' being defined in terms of typical development, rather than what is adaptive to the actual individual with the ASD), one is in effect addressing (or even eliminating) the condition.

- *The Efficacy of the Intervention.* This is what is more commonly referred to when speaking of the research or 'evidence base' of an intervention. It is assumed that good quality research showing good outcomes for an intervention should be an important factor in selecting that intervention. As mentioned above, general outcome research on interventions may be important to those choosing among interventions to endorse or provide in a service, but for those concerned with individuals, they provide limited help. They would only provide useful guidance if they gave good detailed case

descriptions so one could make a judgment about whether the same results would apply in the particular case in which one is interested. For that kind of detail, one usually needs in depth qualitative research designs, which have little credence in the wider scientific community.

Most reviews of research evidence of outcome have used a model of scientific research that is clinical. According to this model, the highest scientific rating is given to what clinical researchers deem the 'gold standard' research design: the random controlled trial (RCT). This can make the review findings unbalanced, since very few of the research studies will have managed to adopt this design, so the number of participants in RCT studies is far fewer than in studies using other designs and the weight given to the outcome of these few is disproportionate to the numbers involved. This is especially true in a heterogeneous group like ASD, where the results from a small group of children cannot be safely generalized to the whole population of children with ASD.

An ideal experimental evaluation of an intervention has the following features:

- Participants are allocated to the experimental group (the group receiving the intervention being tested) on a random basis. In practice this is never done since there is almost never a pool of potential participants from which the samples can be drawn, using standard randomisation procedures. Instead, 'random' is usually accepted as meaning 'no systematic bias' so that potential participants, meeting criteria for inclusion in the study are allocated in accordance to a criterion such that the next child is allocated to a group other than the one to which the previous child was allocated.
- The principle of random allocation depends on large numbers of participants to override any individual differences. Since this is also very difficult to achieve, the experimental and control groups are usually matched on any assumed relevant variables. This can be done on allocation, for example, by matching participants in pairs, and allocating one of each pair to each group. Alternatively, group characteristics can be assessed after groups have been

formed to check that there are no significant group differences between the groups. On this basis, however, there may still be different individual profiles within the groups and it may matter that one group has, for example, a few children with very good language skills as well as some with very poor language skills, while the other group has children of a more uniform fairly poor language ability. Statistical regression techniques are used on the data to check the influence of factors such as initial language level on performance and to see if those different profiles could account for differences in outcome data.

- The criteria for matching participants across groups are usually age, language ability, IQ or developmental level (Mental age: MA or developmental quotient: DQ), and perhaps a measure of parental education or social class. Often, there are tests of adaptive functioning, depending on the age of the child. Given the rationale of the interventions, there may also be a measure of the degree of autism. Most diagnostic instruments cannot be used in this way, although ADOS, as an observation schedule, can be. CARS is sometimes used, although it is a rating scale and so its results are liable to be contaminated by the fact that those engaged in the intervention (parents and/or therapist) are the probable only available informants. Many interventions are geared to improving core diagnostic features such as social skills and understanding but there is seldom any pre-intervention measure of, for example, social and play skills as matching variables. Geographical areas should be matched, as areas, or matched as a variable in participants.
- Those measuring the participants pre and post intervention should be 'blind' to the purpose of the intervention and, ideally (although seldom achieved) to the 'status' of the children they are measuring i.e. they should not know if they are about to start the intervention or have completed it. This is very difficult to achieve when children are participants, except for very brief interventions, but a minimum requirement should be that those measuring the participants should have no stake in the outcome of the research. This means they cannot be the people who are conducting the intervention, or the promoters of the intervention, or the parents (who are often grateful for intervention, or have

invested a lot of time and money in it) who are often primed to look for gains. In intervention research it is almost impossible, unlike drug trials, to get a 'double-blind' study where no-one (participants, parents, teachers, therapists, intervention promoters) knows who has had the intervention and who has not.

- The same assessment tests should be used to assess the participants pre and post intervention but, if there is a danger the child will have learnt the test (as in short interventions) a test should be used where parallel testing items are used. The British Ability Scales (BAS) have been designed to measure IQ but in a way that can permit reliable and valid re-testing, whereas this is not the case with most IQ tests. Where the intervention lasts a long time (say 2 years) and the participants are young children with ASD there is another problem; there may not be tests for intellectual level that are validated for both the young and older child. There is no automatic relationship between an IQ gained with one of these tests and, for example, a DQ gained with another, so it is impossible to interpret changes between the two scores.
- Matching of the groups being compared should ensure that the groups are not significantly different at the start of the experiment. Apart from this adherence to the matching criteria, however, it must be ensured that no confounding variables occur in one group, as opposed to the other, over the time of the experiment. Even if the variable affects both groups, it must be allowed for in the final analysis, in case it interacts with one group more than another. For example, extra toys may be made available to all the children, in both the control and experimental groups, but in an environment where the child has to ask for toys in order to obtain them. If the intervention being tested was concerned with teaching children to make requests, then it is likely that the experimental group will gain more access to the toys, so any general improvements in functioning may be due to the extra time playing with toys, rather than the actual communication programme.
- The variables chosen to measure the success of the intervention should be ones for which there is a priori evidence that they will be affected by the intervention. Some studies have used measures that are far more related to

policy changes (inclusion of children in mainstream classes, for example) than to any presumed changes as a result of the intervention.

### The Evidence Base of Interventions

There have been a number of reviews of the evidence base for educational and psychological interventions in ASD over the past ten years. The conclusions are given in the table below.

<b>Authors</b>	<b>Date, place publisher</b>	<b>Title</b>	<b>Content &amp; Conclusions</b>
Jordan, Jones & Murray	1998 UK DfEE	Educational Interventions for Children with Autism: a review of recent & current research	Reviewed all published research evaluating educational interventions with 5+ participants over the prior 5 years and the results of a survey of local authorities, educational psychologists and researchers to report on research not yet published. There was no robust scientific evidence that any approach was better than another, but cumulative evidence that children with ASD who had early, individualised and targeted intervention were able to make significant gains in development and adaptive behaviour. There was no evidence on long-term effects and there was a great deal of individual variation, but with poor identification of the individual factors affecting outcome.
Heflin & Simpson	1998 USA Journal paper	Interventions for children & youth with autism	Review of evaluative research on 27 interventions in USA. Great variation in supportive evidence for interventions, with better evidence for ABA than others but no evidence for any intervention as the sole intervention and strong argument against it.
Rogers	1998 USA Journal paper	Empirically supported comprehensive treatments for young children with autism	Makes the case for systematic evaluations and identifies a number of interventions where there is support from evaluative evidence. No recommendation for a single intervention.
New York State Department of Health	1999 USA New York State	Clinical Practice Guideline: Autism & PDD/ Assessment & Intervention for	Review of literature and evidence from clinicians. Concluded that behavioural treatments had best documented outcome research but no evidence on their use as a sole approach nor for the 40-hours/

	Department of Health	young children (0-3 years)	week level of intensity. Suggest some evidence for 20 hours a week, plus additional support from trained parents. Suggest intensity should be guided by age of child, severity of autism, rate of progress, other health considerations, tolerance of child for intervention, family participation.
Hurth, Shaw, Izeman, Whaley, & Rogers,	1999 USA  NECTAS & OPES	Review of Early Intervention in Autism	Recommend sufficient hours and intensity of services, comprehensible environments with access to typical peers specialised curriculum with an appropriate scope and sequence, family involvement, problem-solving approach to challenging behaviours, appropriate evaluation tools to monitor progress. No single approach recommended.
Bassett, Green & Kazanjian	2000  Canada  NHS Review	Autism and Lovaas treatment: A systematic review of effectiveness evidence.	Reviewed published scientific studies related to the claims for 'recovery' or 'cure' following EIBI. Concluded that, although there was evidence that many children gained from EIBI, there was insufficient evidence to substantiate the claims of a causal relationship between EIBI and 'normal functioning'.
Task Group on Autism	2001  Northern Ireland  Dept. of Education	The Education of children and young people with ASD: Report of task group on Autism	18-month working group reviewing evidence from published accounts and from witnesses.  Concluded that interventions should have the following features: a well developed and assessed individualised programme, provided with 'suitable' intensity, using trained staff, an emphasis on meaningful outcomes, addressing the triads of impairments, involving parents, and giving opportunities for integration with mainstream peers.
Lord & McGee	2001 USA National Research Council	Educating Children with Autism	Report of committee reviewing evidence and making recommendations.  25 hours a week, centre home & community based, based on multidisciplinary assessment and addressing key areas in ASD. Behavioural interventions have most evidence of effectiveness but no evidence that children with ASD need only one educational approach.
MRC	2001  UK	Review of Autism Research: Epidemiology and	Reviewed research literature and heard evidence. Concluded on interventions that no definitive robust scientific evidence on interventions in ASD.

	Report	Causes	
Evans, Castle, Barraclough & Jones	2001 UK Report for LGA	Making a Difference: early intervention for children with autism	Found few criteria for choice of interventions or for funding of parental choice. EIBI was often chosen by parents as a 'last resort' when they were offered little else. Very limited opportunities to monitor or even get information on progress of children undergoing EIBI, even when paid for by LEA
McConnell	2002 USA Journal paper	Interventions to facilitate social interaction for young children with autism: review of available research and recommendations for educational intervention & further research.	<p>Review of aggregated research on characteristics of social interactions of children with autism and methods to enhance these. Report for National Research Council.</p> <p>Found some ecological interventions (structured activities, developmentally integrated play groups) necessary but not sufficient for effective interaction. Also some aspects of collateral skill training (play and sociodrama skills training) effective in increasing interaction, but again not always sufficient.</p> <p>Child-specific prompting (for social initiations, responses to others) can help children generalize learnt skills and assist interaction.</p> <p>Peer mediated effects are strong and robust across interventions.</p> <p>Too few examples of comprehensive approaches to evaluate.</p>
Connor	2003 UK Journal paper	Monitoring and reviewing early behavioural intervention in autism (Lovaas)	Reviews issues facing local authorities asked to support EIBI interventions in the light of the research evidence and the context of 20 case studies.
NIASA (Chair Le Couteur)	2003 NAS	National Autism Plan for Children  Report of NIASA group	<p>Report of working party on diagnosis, screening and early intervention/ education in ASD. Reviewed research literature and heard evidence</p> <p>Recommendations for evidence did not include exclusive use of any one intervention and instead suggested a multi-disciplinary approach to assessment and intervention, which became the basis for the National Services Framework exemplar in ASD.</p>

Perry & Condillac	2003  Canada  Report for Children's Mental Health, Ontario	Evidence-based practices for children and adolescents with ASD: Review of the literature and practice guide.	Review of published evidence and consultation with a 'consensus group'. Suggests some approaches (e.g. ABA) have sufficient evidence for use while others (e.g. TEACCH) need to be applied with careful monitoring of individual effects. Does not positively support use of only one approach for all. Recommends a variety of strategies derived from different approaches.
Roberts	2004  Australia  Report for Government	A Review of the Research to Identify the Most Effective Models of Best Practice in the Management of Children with ASD	Review for Department of Ageing, Disability & Home Care. Review of research publications. Concluded that the evidence supports a range of treatment and intervention models, across the range of individuals with ASD. Supported a multi-dimensional, multi-professional approach to the treatment and management of ASD. No support for a single approach.
Hume, Bellini & Pratt	2005  USA  Journal Paper	The usage and perceived outcomes of early intervention and early childhood programs for young children with ASD.	Survey of parents on effects of early intervention in ASD. Found parental engagement a crucial feature of satisfaction in parents.
Diggle, McConachie & Randle	2005  UK Cochrane Review	Parent-mediated early intervention for young children with ASD	Systematic review of randomized or quasi randomized studies involving children 1-6 years with ASD.  Only 2 studies met criteria and were not comparable so no real evidence of effectiveness
New Zealand Government	2006  New Zealand  Report	Guidelines on Evidence based Practice in Autism Spectrum Disorders	Review of evidence from published studies and consultation. Conclude that there is a sufficient evidence base for behavioural, social communicative and developmental interventions but no support for a single intervention.
Humphrey & Parkinson	2006  UK Journal paper	Research on interventions for children and young people on the autistic spectrum: a	Examine the theoretical and methodological limitations of intervention research in ASD. Point out the shared aspects of many interventions and the futility of looking for a single 'best' intervention. Takes

		critical perspective	an educational, rather than clinical, stance.
McConachie & Diggle,	2007 UK Journal paper	Parent implemented early intervention for young children with autism spectrum disorder: a systematic review	Children with ASD 1-6 years. Published research of all parent mediated studies with at least some control. Found only 2 RCT but some evidence of efficacy for parent mediation. Recommended further scientific research.
SIGN	2007 Scotland Report	Assessment, diagnosis and clinical interventions for children & young people with ASD	Systematic review. Found some evidence base for parent mediated strategies, for social communication training with use of visual supports, for Lovaas behavioural interventions but no good evidence for 'recovery', and interventions based on individual assessment. No recommendation for a single approach
Spreckley & Boyd	2007  Australia  Systematic review and meta analysis	Efficacy of applied behavioural intervention for pre-school children with autism on cognitive, behavioural, and language outcomes	Review of published research (RCTs or controlled studies only) on the outcomes of ABI (applied behaviour intervention) for pre-school children with ASD. 13 studies met criteria for inclusion. 5 had good methodology and were used in meta-analysis. All were comparison rather than controlled studies – comparing ABI with standard care. Intensity ranged from 4 to 39 hours per week. Duration varied from 3 months to 4 years. Conclusion: ABI time-consuming, & costly. For these children with significant difficulty ABI did not offer significant advantages over standard care.

### **Recent important studies of early interventions**

This section is included because the studies are too recent to have featured in any of the reviews above – not because they have particular merit, beyond any in those reviews. Research is ongoing so this must not be taken as a final selection. It is also beyond the scope of this Review to provide a fully comprehensive account of all published research.

COHEN, H., AMERINE-DICKENS, M.M.S. & SMITH, T (2006) Early intensive behavioural treatment: replication of the UCLA model in a community setting *Journal of Developmental & Behavioral Paediatrics*, **27**, S145-S155

MAGIATI, I., CHARMAN, T & HOWLIN, P. (2007) A two year prospective follow-up study of community based early intensive behavioural intervention and specialist nursery provision for children with autism spectrum disorders *Journal of Child psychology & Psychiatry*, **48**, 803-812

REMINGTON, B., HASTINGS, R.P., KOVSHOFF, K et al. (in press) A field effectiveness study of early intensive behavioural intervention: outcomes for children with autism and their parents after two years. *American Journal of Mental Retardation*

TURNER, L.M. & STONE, W.L. (2007) Variability in outcome for children with an ASD diagnosis at age 2 *Journal of Child psychology & Psychiatry*, **48**, 793-802

None of the above studies produces any compelling evidence that a single intervention should be used as the sole approach in ASD nor that one intervention is either superior to all others or to some general or 'eclectic' mix for all children. What is common to all is the heterogeneity of the group in relation both to individual characteristics and to outcomes. Some children do very well under some forms of intervention but that is true of all the interventions studied, as well as in situations where there is 'no' designated intervention or simply 'treatment as usual'. Other children do badly in spite of being included in intensive interventions and that too applies whatever the intervention.

One common methodological flaw in the studies presented, where comparisons are made with a 'control' group, is that there is a general failure to properly characterise that group. Generally, there are missing data on:

- *The goals.* If the intervention being evaluated aims, for example, to improve the children's ability to conform to instructions, imitate actions, reduce stereotyped behaviour (all possible goals in the first year of an intervention with a young child with ASD) then the assessment tools to evaluate the intervention may reflect those goals; IQ tests, for example, will in part measure the child's capacity to sit still, conform and obey instructions so that IQ is likely to show an apparent improvement. In reality it is more likely to be a measure of what has been taught, rather than an actual increase in intelligence. This might not be so important except that the goals of the contrast group might be very different. If, for example, the goals in these setting were more to do with learning to interact with others and initiate play routines, none of the skills they will have learnt will be very helpful in passing IQ tests. Without more detailed information about the control group we have no idea whether the evaluation tools are equally valid for both groups. If we do not have assessments that are equally valid for both groups then we can only conclude that we are just comparing 'apples' and 'oranges' – not very enlightening.
- *Treatment Fidelity:* Community based programmes cannot expect to have the same degree of fidelity to treatment protocols and appropriate supervised training as those based in university led programmes. Lovaas himself has said that one should expect far reduced levels of success in community settings. This seems to be borne out in practice, but it means we do need to have some more detailed measures of how far the interventions being evaluated are in fact 'true' to their exemplar descriptions. We need this information if we are to make generalisations of the findings beyond the particular group studied to other situations where the intervention may be used. This fidelity refers to the training of the supervisors and the content of the sessions. For example, it is now common for ABA programmes to incorporate features from other programmes (e.g. visual structure from TEACCH, play routines from interactive methods) into their intervention. This is probably of great benefit to

the intervention but it makes it impossible to say one is evaluating ABA, when in fact one is evaluating an eclectic mix that includes ABA. The situation is further confused by the reluctance of ABA practitioners to acknowledge the eclectic sources of their programmes and to refer to all these additional methods as 'tactics of ABA'. Unless there is monitoring and recording of what is actually being done, rather than what people are professing to do, (or even doing unconsciously as in '*therapist drift*') there is no clarity over what is being compared; we may just be comparing one kind of eclectic mix with another.

- *Additional 'Treatments'*: In real life situations, especially in the UK, parents (and teachers) seldom follow one single intervention, even if they have contracted to do so as part of a controlled research study. Signing up to a research study may help prevent parents adopting significant alternative interventions but there are some additional 'treatments' that parents may not even recognise as such. Some children may be put on particular diets. Some may have regular treatment with alternative therapists such as chiropractors. Some may engage in leisure activities involving use of the trampoline, swimming, drama, joining playgroups, or horse riding. There is little evidence that any of these additional 'treatments' are effective on their own, although all are the basis of some treatments for ASD, but there is no research on cumulative effects or the interactive effects on the intervention being studied. This might not matter so much if one could assume that these additional treatments would be equally represented in the control group (although the interactive effects may be different). However, we do not know this, unless the researchers do careful research to find out. It could well be that parents who are proactive in getting their children into particular interventions are also the ones to try a number of other additional treatments, and so there may be more of these in the experimental group.

### **Deciding on interventions for a child:**

Some interventions can claim a better 'evidence base' in respect to outcomes than others. However, a better 'evidence base' in relation to an intervention itself does not translate directly into evidence for the benefits of using it in this particular situation with this particular child. Such evidence can give us a statistical probability of it being

effective but few parents or professionals would be happy to provide an intervention on that basis. We recognise the importance of individual characteristics and the constraints and opportunities in the environment and we would want to provide something to meet those particular conditions. We also recognise that different interventions are better at teaching different things (on a priori grounds, rather than research evidence) and it is certainly clear that children with ASD tend to learn what they are taught. Given that we would also want children with ASD to be socially included in our society and to be able to access their entitlement to a broad and relevant curriculum, there would have to be very powerful evidence in favour of a single approach to concentrate on such a narrow intervention. Such evidence does not exist, in spite of some claims to the contrary.

## GLOSSARY OF TERMS

ADOS	Autism Development Observation Scale. Children are observed in set situations (with different kinds of play material, in interaction with others and alone with the toys) and their observed play behaviours are coded and matched to a scale which gives a measure of ASD. There are different scales for different age groups.
Applied Behaviour Analysis (ABA)	A broad term used to describe interventions based on operant conditioning (Skinner, 1957). There are many versions but the commonest form in ASD is that developed by Lovaas (1987; 1993) and delivered as Early Intensive Behavioural Intervention (EIBI). This uses discrete trials and the use of rewards and punishers to build 'positive' behaviours (through processes of shaping, prompting and teaching imitation) and eliminate 'negative' ones.
Asperger's syndrome (AS)	Diagnostic category within autism spectrum disorders. Also known as 'Asperger disorder'. No cognitive or structural linguistic impairment.
Atypical autism	This is a category used to cover those who have characteristics in common with autism and Asperger syndrome but do not quite meet criteria for inclusion in either of those two categories. It is synonymous with Pervasive Developmental Disorder not otherwise specified (PDD-NOS).
autism	Diagnostic category central to the category of autism spectrum disorder. Also known as 'autistic disorder', 'Kanner's autism', and 'classical autism'. Sometimes divided into 'low functioning autism' (LFA) and 'high functioning autism' (HFA).
autism friendly	This is used to describe environments where there is special expertise available to support individuals with ASD, where the environment is adapted to deal with potential sensory issues, where there is a clear structure to reduce stress and where there is an atmosphere of trust and respect. Such environments will work through the child's strengths and use them to help the child cope with any difficulties. Often mainstream (and some independent) schools will claim to be autism friendly because of their small size, inherent structure and experience.
Autism-Pro	This has been developed in Canada with input from the USA and Belgium. At the moment it is only developed for children up to the age of eight years. It provides an on-line resource for parents to use directly, a similar programme for staff in school settings and a programme for clinicians to manage a case and share teaching across an interdisciplinary team. It is subscription-based with an initial joining fee and a monthly fee thereafter. As well as teaching about ASD, it teaches how to assess a child, develop a target and an activity plan and to

	<p>choose a teaching approach. It divides interventions (all major North American interventions) into 3 'types' of intervention (behavioural, social or developmental) and the user can choose to teach the target using one of these types with a video example of what that approach would entail, to guide the choice. It can empower parents and prevent worry about 'missing out' on any particular one. It can also provide education and support to professionals where this is scarce. It has been launched in the UK and is accessible on the internet but has not yet made an impact.</p>
autism spectrum disorder (ASD)	<p>Not an official diagnostic category but a group term covering autism, Asperger syndrome and a category either known as 'pervasive developmental disorder not otherwise specified' (PDD-NOS) or 'atypical autism'</p>
BAS	<p>British Ability Scales: An IQ test that has been standardised on UK children and where there are parallel items at the same level, so that different items can be used to test children at different times. This prevents any contaminating effects from the child memorizing the items between the two time periods. It is not widely used outside the UK.</p>
CARS	<p>Childhood Autism Rating Scale. This is a developmental behaviour rating list, with a cut-off point indicating an autism score. and other scores giving some measure of the severity of the autism.</p>
Child's Talk	<p>Developed in the UK by a SALT and based on HANEN (More than words). Differs in that the programme only lasts 6 weeks but has been shown to be effective in improving interaction and empowering parents to foster their child's development. After a random controlled trial evaluation produced positive results has become the basis of a UK wide evaluation programme called PACT.</p>
Circle of Friends	<p>Not specific to ASD but commonly used in mainstream schools to develop peer support for the child with an ASD, especially in free time periods. A group of peers 'troubleshoot' problems with the 'target' child and develop support strategies, under guidance from an organizer.</p>
COMFOR	<p>Developed in the Netherlands to provide training in the earliest forms of communication, usually for children with ASD who are without speech and are still at the sensory stage of meaning. At this stage the child is still responding to objects (including symbol cards and pictures) as purely sensory items to be licked, flicked, smelt, bitten and flapped. In a structured and functional programme, the child is taught to move from this sensory stage to one of presentation (where, for example, the child can pick up his own cup to indicate he wants a drink) and then to one of representation. At the representation stage any cup can stand for the meaning of wanting a drink and can in effect become</p>

	an 'object of reference'. At this stage the child is ready for a representational symbol system and then can finally be taught to move to a truly symbolic system such as speech or writing, or a system of arbitrary signs or symbols.
Comic Strip Conversations	Developed in the USA as an extension of Social Stories. Uses cartoon characters with 'speech' and 'think' balloons to help them understand what people say and what they think in different social situations. Helps to build some understanding of mental states and not to rely on literal interpretation of language.
Co-morbidities	Autism conditions seldom occur in a 'pure' form, so many individuals with ASD will have additional 'co morbid' conditions. This is a straightforward concept when the condition is different in its effects to that of an ASD, but there are problems when there are shared characteristics, deciding whether these are just common features or whether there is another disorder present. This can affect treatment in that ADHD, for example may be treated differently to attention abnormalities and hyperactivity that are part of an ASD. Specific language difficulties are common in classical autism whereas dyslexia and forms of dyspraxia are common in Asperger syndrome. Although anxiety is a common, some suggest universal, feature of ASD, adolescents with ASD often develop extreme anxiety disorders, which need specific treatment. These may take the form of phobias, obsessive-compulsive disorders or panic disorders.
Daily Life Therapy	Method based on Japanese primary school education and developed in Higashi schools first in Tokyo and then Boston. There is also an independent school in the UK that operates an adapted Daily Life curriculum. The method is based on group teaching and an age-based curriculum (regardless of developmental level) with an emphasis on regularising activity levels, emotional responsiveness, sleep and feeding patterns. The day is very structured and, in residential schools, operates a 24-hour curriculum. There are daily, sustained aerobic activity periods and drills for control of behaviour.
DIR/ Floortime	D is for Developmental. It enables Six Developmental Milestones for healthy emotional and intellectual growth. I is for Individual-Difference, recognizing the individuality of each child, including any biological differences. R is for Relationship-Based, building relationships with primary caregivers Floortime is part of the DIR approach where parents and key workers engage in 1 to 1 sessions to develop positive interactions as the basis for learning and teaching.
discrete trials	These are part of some types of ABA intervention (e.g. Lovaas style, or EIBI) where there is intensive one to one teaching in the form of trials marked by a clear instruction from the adult, rewarding of responses that meet set criteria and

	ignoring of responses that do not meet criteria. Any disruptive or 'off task' behaviour will be punished (commonly with a sharp 'no!', although the original Young Autism project slapped the child on the thigh). Trials continue until a pre-set percentage is correct and then a new target is set.
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4 <sup>th</sup> edition, published in 1994 by the American Psychiatric Association
Earlybird	Developed by the National Autistic Society (NAS) in the UK as an eclectic programme for parent training, post diagnosis but pre-school. Six families are trained at a time, over 12 weeks, by two trainers (local authorities who offer the training have to train two people with the NAS to deliver the programme). Programme structure based on Hanen with group training, home visits and video analysis of parental interactions with the child. Also in use of the OWL technique. TEACCH is part of the programme to help parents develop stress-free environments for the child and structure their learning and PECS is used to develop their communication. Some LEAs have included an educational liaison worker as part of the Earlybird scheme.
eclectic curriculum	This is a curriculum using more than one intervention or teaching approach. This may be an explicitly eclectic mix or may occur by default in that most interventions incorporate aspects of other approaches, even if they are not explicitly acknowledged. Sometimes used in research to characterise curricula that are serving as 'controls' for the intervention being evaluated.
Floor time /DIR	D is for Developmental. It enables Six Developmental Milestones for healthy emotional and intellectual growth. I is for Individual-Difference, recognizing the individuality of each child, including any biological differences. R is for Relationship-Based, building relationships with primary caregivers Floortime is part of the DIR approach where parents and key workers engage in 1 to 1 sessions to develop positive interactions as the basis for learning and teaching.
generic special school	This is a school catering for a range of special needs – usually focused on learning difficulties, but often including children with ASD. It is not solely autism-specific.
HANEN	A programme developed by speech and language therapists (SALT) in Canada, teaching parents to interact with their child through a process of Observing, Waiting and Listening (OWLing). Used by SALTs but adapted form used with ASD (see below). Group parent training sessions are supplemented by home visits where videos are taken of the parent interacting with the child and then analysed with the parent to increase their awareness of positive strategies to use with their child. A specialist programme – More than words – has been

	developed which adapts the programme for children with ASD.
HELP	A parent training programme, similar to the Earlybird programme and also developed by the NAS. It was developed for parents of older children who are already at school when diagnosed.
IABA	A broad based positive approach to ABA, which does not use aversives and emphasizes environmental as well as behavioural support to avoid challenging behaviour.
ICD-10	The International Classification of Diseases, 10 <sup>th</sup> edition published in 1992 by the World Health Organisation
inclusion	This is a philosophy determining that all of a society's services and institutions should be accessible to all and that all citizens have an entitlement to full social inclusion in that society. This includes education. It differs from 'integration' in that the onus is on the schools to be fully inclusive to meet the needs of all pupils, rather than being geared to some notional 'norm' to which children with SEN have to be supported to gain access. Most 'inclusive' policies by LEAs in the UK are in fact integration policies.
integration	This is the process by which children with special needs or disabilities are integrated into mainstream services, usually with the help of additional resources of some kind. It can be full or partial integration.
Intensive interaction	Developed in the 1970's in the UK, based on augmentation of early dyadic interaction (it was originally called 'augmented mothering'). It was developed for individuals (it can be used with any age) who had failed to develop relationships and who were fearful of others with a repertoire of negative and stereotyped responses to keep people at bay; most of these individuals had profound and multiple learning difficulties with probably unrecognized autism. It is based on following the individual's lead and joining in routines to establish joint attention, turn-taking, co-operative and early social skills. It is used mainly now in special schools.
Makaton symbols and signs	This was developed from research in hospital settings in the UK in the 1990s and was one of the first attempts to teach communication to individuals with no spoken language and significant learning difficulties. There was originally a tightly structured and monitored system for teaching signs in stages, although the actual order was difficult to justify. Symbols were used to cater for those, like those with ASD, who might find static symbols easier to use and interpret than dynamic signing. PECS has largely replaced Makaton in work with children with ASD, but Makaton has been incorporated into the National Curriculum for children with learning difficulties so children with ASD may well encounter it in

	this context.
More than Words	A programme specifically designed for children with ASD from the parent HANEN programme. Apart from adaptations to fit children with ASD, it can also be delivered by professionals other than SALTs. Used in some areas as a pre-school service delivered by SALTs or visiting teachers or even trained nursery nurses.
MRC	Medical Research Council. Government funded grant awarding body – conducted a review of prevalence and causes in ASD in 2001.
Musical interaction therapy	Developed at Sutherland House school (a local autistic society school) in the UK, this uses music, not as music therapy (which builds a relationship with the therapist) but as a way of structuring interaction between a key worker (or parent) and the child. The idea is that the routines, and the quality of the relationship built up in one to one sessions once a week (where a musician mirrors and emphasizes positive interaction), can be carried over into everyday life by the key worker. Used now in a variety of special schools and schools for children with ASD (usually by speech and language therapists) as well as clinic settings.
Music Therapy	This is different from music teaching since the goal is not to learn music but to use music as a medium to enable other skills or attributes. A specially trained music therapist works either 1 to 1 (more usual) or with a group of children with ASD. Music is known to have a structure that can be appreciated by children with ASD and music has a capacity to engage the emotions. The goals are often to do with increased spontaneity and participation, tolerance of different sounds, increased socialization, emotional awareness, use of musical instruments, turn taking and reduction in challenging behaviours. Music therapy is poorly evaluated but this is improving. Mostly only available in special or specialist schools or clinics.
PACT	PACT targets the core impairments in ASD of social interaction, language and communication. It aims to help parents adapt their communication style and respond to their child with enhanced sensitivity and responsiveness. There is a focus on increasing shared attention through eye-gaze, sharing, showing and giving. Parents are taught to use language tailored to their child's level of understanding. Parents are also taught strategies that facilitate child communication and participation, such as action routines, repeated verbal scripts and the use of elaborations, pauses, and teasing. It is undergoing a UK-wide random control trial at present, compared to treatment as usual, having published a preliminary RCT showing very positive results compared with

	'treatment as usual' controls.
PECS	Picture Exchange Communication System. Developed in the USA but widely used in the UK through a private system of trainers. Uses symbols in a structured 'sentence' format to teach the child to use symbols to make requests (I want ...) and then to make comments (I see ...). Did introduce helpful ideas of 'menus' from which the child could choose but now this has been superseded by idea of child carrying a 'book' of all known symbols. Based on Skinner's (1957) operant conditioning but emphasizing spontaneity in that there are no verbal prompts. Widely used but variable level of expertise among staff.
Pervasive Developmental Disorders	This is a term (abbreviated as PDD) used by diagnostic systems to group together certain clinical conditions and all the autism spectrum disorders (autism, Asperger syndrome and PDD-NOS) fall into this category. In addition it includes Rett's syndrome and Heller's syndrome (Childhood Disintegrative Disorder), which are generally not included as ASD because of their distinctive ontology and prognosis. Clinicians who use DSM-IV to diagnose are more likely to use PDD, but most in the UK will prefer ASD as a general term, The third category of pervasive developmental disorder not otherwise specified (PDD-NOS) is sometimes used but those using the ICD-10 system will prefer the term 'atypical autism' which is more descriptive and helpful to parents and staff.
RDI	This stands for Relationship Development Intervention from the USA. Developed to address core impairments in ASD, not addressed in traditional behavioural programmes. Claims to address 6 core deficits: emotional (social) referencing, social co-ordination, declarative language, flexible thinking, relational (context adapted) information processing, foresight and hindsight. Does this by teaching parents to slow down and make more explicit the typical processes of interacting with their child. Programme introduced to UK aimed at parents of pre-school children with ASD, but requiring trained consultants and ongoing support networks.
SCERTS	It stands for Social Communication, Emotional Regulation and Transactional Supports, It is a programme from the USA with training workshops and ongoing support. Aimed at parents and professionals and for all ages, including adults. It is a framework into which other treatments can be slotted. It stresses a multidisciplinary (including parents) approach and the teaching or enabling of functional skills in every day activities across settings. Newly developed and just beginning to be marketed in the UK at day presentations.
SEN	This stands for 'special educational needs', which are defined by statute as

	requiring special resources or consideration additional to or different from that provided for all children.
SENCO	There should be a special educational needs coordinator (SENCO) in each mainstream school whose role is to work with class teachers and parents in helping them meet the needs of children with special educational needs, including those with ASD.
SIGN	Scottish Intercollegiate Guidelines Network. This is the Scottish equivalent of NICE (National Institute for Clinical Excellence) in England & Wales. Both organisations evaluate medical treatments and offer clinical guidance to medical practitioners.
Social Stories	Developed in the USA as a tool to teach some aspects of social skills to individuals with ASD. It involves sitting with a child and working out scripts for particular social situations where the child is experiencing problems. It makes the social rules underlying such situations explicit and enables the child to develop some social scripts to guide actions. Needs a minimum level of understanding speech, although pictures can be used for children who cannot read.
Son Rise	A programme developed by the Kaufmans (1976; 1994), based on the Option philosophy that believes that an attitude of acceptance (and an intensive experience of being in control in a safe environment) can enable children with an ASD to develop social and emotional relationships and move towards 'recovery'
special	This means different to the typical and is generally applied to schools, units, resources or staff that deal exclusively with individuals with SEN or disabilities. There is an implication that there will be specialist resources and expertise in such establishments.
specialist	In the context of ASD, this implies schools, classes, units or staff that cater specifically for the needs of individuals with ASD, and are qualified to do so.
SPELL	Developed by the National Autistic Society (NAS) in the UK as an eclectic programme for use in its schools and adult establishments and as the basis of its training and consultancy to other schools and services. It stands for Structure/ Positive/ Empathy/ Low arousal & Links. In practice, very similar to TEACCH programmes. Used in NAS schools and some other, mostly special, schools.
TEACCH	This stands for Treatment & Education of Autistic & Communication Handicapped Children. It is a specialist programme for individuals with ASD and their families, developed in North Carolina but used internationally. It aims to provide a 'cradle to grave' service, although in the UK it is largely confined to

	<p>school practice. Two, 3, or 5 day training is given to staff and trainers need to take a 3-month internship in North Carolina. It uses structured teaching based on providing 'prosthetic' environments within which the child is trained to develop independent work skills. There are structured language programmes, special assessment tools, social skills and vocational training in natural contexts, with particular supports in managing time and transitions.</p>
Therapist Drift	<p>This is a term first used by Jordan and Powell to describe the process by which, over the course of an intervention, practitioners may begin to change what they do, or the way they do it, according to their own perceptions of themselves (e.g. as 'carer' or 'teacher') and its interaction with the role taken in the therapy. This is at the unconscious level so that there is an inconsistency with what practitioners 'think' they are doing and how they are actually behaving in practice.</p>
triad of impairments	<p>This refers to three areas of development that are affected in all autism spectrum disorders and which form the basis of both international diagnostic systems (ICD-10 &amp; DSM-IV). The triad was proposed by Wing in 1988, but is differently interpreted by different authors. Jordan suggests it should be represented as difficulties in:</p> <ul style="list-style-type: none"> <li>• social and emotional understanding</li> <li>• all aspects of communication</li> <li>• flexibility in thinking and behaviour</li> </ul> <p>There is current debate about the independence of these three areas and about the behavioural implications of these difficulties but they are generally accepted as a description of core difficulties across the spectrum.</p>
24 hour curriculum	<p>Used to describe a curriculum for educational input throughout the day and night to include daily living skills and leisure opportunities and to establish sleep patterns; it is to meet genuine educational needs rather than a need for social care or to provide respite for families.</p>
Verbal Behavior (Applied Verbal Behavior)	<p>An ABA programme based on Skinner's (1957) ideas about language acquisition (now largely discounted by linguists and child psychologists). Treats language as verbal behaviour, which the child can be trained to deliver in appropriate situations through the application of rewards. Uses discrete trials as in traditional ABA and teaches 'mands' (demands), 'tacts' (comments) and 'intraverbals' (use of 'closure' or answers to wh- questions). Almost unknown in UK schools but some training of parents and demand for pre-school programme support.</p>

