



Commissioning Services for People on the Autism Spectrum

Policy and Practice Guidance



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Commissioning Services for People on the Autism Spectrum

Policy and Practice Guidance

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Contents

	Page
Purpose	1
Background	1
Definition and prevalence of autism spectrum disorder	2
Service framework	3
Commissioning person-centred services for people with autism spectrum disorder	4
Outcomes	5
Action	8
Annexes	
Annex A: National diagnostic standard	9
Annex B: Tools to inform commissioning	10
Annex C: Service accreditation	11
Annex D: Models of support	12
Annex E: Estimated prevalence figures by local authority area	24
Annex F: National developments in autism spectrum disorder services	25
Annex G: Useful references and contacts	40
Annex H: Ideas for the whole system	42

HEALTH AND SOCIAL CARE SERVICES FOR PEOPLE ON THE AUTISM SPECTRUM – POLICY AND PRACTICE GUIDANCE

Purpose

This policy and practice guidance is issued to inform the commissioning of health and social care services for people with autism spectrum disorders in Scotland.

Background

*The same as you?*¹ review of services for people with learning disabilities was the first policy document to address the needs of people with autism spectrum disorder in Scotland. For the purposes of that review, learning disability was defined so as to include people with autism spectrum disorder, whether or not they also have a degree of learning disability. Whilst there have been positive service developments for people with autism spectrum disorder since then, there is still a lack of clear ownership for service development across health and social care to meet the needs of this group.

In 2002, the Public Health Institute of Scotland (PHIS) published the Autistic Spectrum Disorders Needs Assessment Report², which set out priorities for multi-agency service planning and delivery. The Scottish Government subsequently set up a national autism spectrum disorder Reference Group to inform a programme of work to support and encourage the development of good practice. Progress with the PHIS recommendations was reported in a 2006 Scottish Executive Report on Implementation³. As part of its work, the Group sought to build on a number of positive developments and focused on action to put policy into practice. This guidance has been developed for that purpose.

More recently, a national clinical guideline on assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorder has been published by the SIGN Council (<http://www.sign.ac.uk/pdf/sign98.pdf>). Whilst it relates to the needs of children and young people up to 18 years of age, those with a responsibility for providing services for people with autism spectrum disorder of all ages may find it helpful in developing local strategies.

In recognition of the role that services wider than health and social care have in the wellbeing and inclusion of this population, Annex H sets out actions that other areas of the local authority can take forward. These have been included as stand alone pages that can be distributed to relevant areas to inform their own service developments.

¹ <http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

² <http://www.scotland.gov.uk/Publications/2006/02/28094616/0>

³ <http://www.scotland.gov.uk/Topics/Health/care/VASUnit/PHIS2>

Definition and prevalence of autism spectrum disorder

Within this document the term “autism spectrum disorder” (ASD) is used as it is the most common term in use today. Some people may refer to autism spectrum conditions, however autism spectrum disorder is used and recognised in current practice when considering diagnostic issues. In this sense it should be seen as relating to experiences outwith the normal sequence rather than a pejorative term implying “defect”. This guidance aims to promote the development of services for all people on the autism spectrum, this includes higher functioning people with a diagnosis of autism and those with Asperger Syndrome, based on individual need and not on the basis of a specific diagnosed condition.

Autism and its related conditions are defined as “Pervasive Developmental Disorders” as the typical features appear during an individual’s period of growth and development. These conditions are assumed to be life-long but there is considerable variation in both how individuals present over their own lifetime and in comparison to one another. It is therefore important to consistently identify and assess an individual’s experiences and this is usually provided as a formal diagnosis.

A formal diagnosis should **not** be about just attaching a “label” to a person. The national Diagnostic Guidelines in Annex A highlight that this should be a participative process that consolidates knowledge and understanding of an individual’s needs, and generates options for change and future support.

The SIGN Guideline describes the two internationally accepted diagnostic classification systems: ICD-10 and DSM-IV. The criteria in both are based on the Triad of Impairments which means that an individual demonstrates problems in *socialisation* skills, abnormal *language and communication* development, and *rigidity of thought and behaviour*.

Prevalence studies at the time of publication of the PHIS Report resulted in estimates of 7714 children under 19 in Scotland. More recent studies suggest that a rate of around 1 in 100 is currently the best estimate of the prevalence in children, suggesting over 50,000 people in Scotland⁴. Within this population possibly up to 40% may be considered to have a diagnosed learning disability but many of the others will have difficulties in aspects of learning and acquiring information even though they may possess very superior cognitive levels. The focus on intellectual functioning is due to the current diagnostic standards where typically, individuals with a learning disability have been diagnosed with “Autism” while more able people have been described as fulfilling the criteria for “Asperger Syndrome”.

Prevalence studies have not been carried out on adults and would be difficult to do well. Information from services across Scotland suggests that an increasing number of more able adults are seeking and receiving a primary diagnosis. It is also evident that in many cases this is sought following an individual’s increased awareness of autism spectrum disorder as a consequence of a diagnosis given to a school-age relative.

The economic consequences of autism in the UK have been outlined in a recent report which can be accessed at the following link. <http://www.learningdisabilities.org.uk/publications?EntryId=28948>.

⁴ An Office of National Statistics survey of the mental health of children and young people in Britain found a prevalence rate of 0.9% for autism spectrum disorders or 90 in 10,000 (Green *et al*, 2005).

Service framework

People with autism spectrum disorder have a right to the information, equipment, assistance and support services necessary to live a fully productive life with dignity and independence. This requires a range of services beyond health and social care to take account of the needs of this group. This guidance however, seeks a specific response from commissioners of health and social care services.

Many adults with autism find that the way local services are structured and organised discriminates against them. This can result in their near exclusion from services, particularly if they have Asperger Syndrome or high-functioning autism.

Community care services for people with autism spectrum disorder should be embedded within joint partnership service planning, commissioning and delivery, including implementation of Single Shared Assessment (SSA). The development and implementation of Single Outcome Agreements provides an opportunity for performance measures and targets to be developed locally for people with autism spectrum disorder.

Community Health Partnerships (CHPs) and their partners should ensure integration between primary care and specialist services and with social care. These partnerships also have a role in reducing inequalities in access to information by providing targeted and coherent health messages particularly aimed at excluded or disadvantaged groups, including people with autism spectrum disorder. Guidance on the development of CHPs was issued in 2004.

There are a number of legislative and policy requirements which either have a specific focus or are applicable to people with autism spectrum disorder. Action to meet these existing requirements should mean that local authorities identify people with autism spectrum disorder who require support, and provide appropriate services:

- Integrated Children's Service Planning, which should assist in identifying those young people with additional support needs who have an ASD. Planning for transition between children's and adult services should ensure local authorities have a record of those who are likely to need community care services. Approaches to transition should be individualised and advance planning is crucial.
- The Education (Additional Support for Learning) (Scotland) Act 2004 places duties on education authorities to make adequate and efficient provisions for the additional support needs of every child and young person for whom they are responsible and who requires additional support for learning. Education authorities must identify, support and review the needs of all children with additional support needs including ASD. The 2004 Act places a greater emphasis on much better multi-agency working.
- More Choices More Chances is an action plan to reduce the proportion of young people not in education employment or training in Scotland. The Scottish Government believes in a partnership approach in aiding the transition of all young people from school, recognising that it often takes a wide range of support to enable some young people to progress. Opportunities are to be delivered in a way that makes them accessible to all young people, including those hardest to engage.
- The Community Care & Health (Scotland) Act 2002 significantly extends the rights of many carers in Scotland to have their needs as a carer assessed. The Act also requires local authorities and the NHS to advise carers of their rights. Local authorities are also required to recognise the care being provided by a

carer and to take into account the views of a carer in deciding what services to offer to the person they care for. This requirement seeks to ensure that carers are regarded and treated as key partners in the provision of care.

- NHS Quality Improvement Scotland's Learning Disability Quality Indicators set out criteria to evidence assessment and monitoring of specific health needs.
- Delivering for Mental Health aims to raise awareness of mental health and to support mainstream services to be aware of the needs of their clients with mental health problems and provide interventions that address these specific needs.
- The Disability Equality Duty, which from December 2006 places a duty on public authorities to promote equality and demonstrate involvement of disabled people.
- National Care Standards have been developed and published by Scottish Ministers for a range of care services. The standards aim to improve quality of life by raising the level of care and support provided.
- The Scottish Social Services Council Codes of Practice set out the standard of conduct and practice for social service workers and their employers. Everyone who registers will have to agree to abide by the codes. The codes are intended to reflect existing good practice and it is anticipated that workers and employers will recognise in the codes the shared standards to which they already aspire.
- Changing Lives, the 21st Century Social Work review reinforced the need for a preventative approach to delivering social work services.

This guidance sets out the key outcomes for people with autism spectrum disorder. People with autism spectrum disorder may also have a learning disability or other co-morbid conditions. It is important that services and support take account and consider suitable arrangements for those with autism spectrum disorder and dual diagnosis/multiple impairment, including those with mental health issues or learning disability. Equally, people with autism spectrum disorder sometimes have health care needs that are not addressed. Health care services need to identify and treat the conditions which are often associated with autism spectrum disorder appropriately and address the wide range of health needs of people on the autism spectrum. To support this, NHS Education for Scotland have developed an autism spectrum disorder learning resource for GPs and primary care practitioners www.nes.scot.nhs.uk/autism_spectrum_disorder.

Commissioning person-centred services for people with autism spectrum disorder

Commissioners need good quality, shared information about current and future demand for support across the wide range of abilities in the autism spectrum. Following the national audit of services for people with autism spectrum disorder in 2003, localities should have robust systems for the collection and dissemination of information about the needs of people with autism spectrum disorder.

Any good commissioning process should understand the needs of service users as well as their carers in identifying gaps in services and trying to fill them. A good way of doing this is through aggregating person centred plans to reveal any key or recurring themes. In this way, even people with the most profound disabilities can be included.

All council services, not just social work should be accessible to the general public as a whole. This is a central tenet of the Disability Discrimination Act and disability equality duty. Commissioning needs to include low level preventative services and support to reduce the need for expensive crisis services.

Joint working with Health and the independent sector will ensure that service provision leaves no gaps and avoids duplication. Health authorities and other partners can pool resources to work across geographical boundaries to create local and affordable autism-specific services, where these are required.

Joint commissioning and influencing across council departments and good prevention or early intervention work, especially with NHS partners, may mean that those on the autism spectrum need fewer specialist services and so will be better socially included. The cost burden of providing these is spread more evenly and each department can record meaningful results on inclusiveness. An example where this works well is in the provision of changing facilities for profoundly disabled people in town centres through planning and building departments, on the advice of social work. The result is that people can remain in the community for longer, rather than having to return to segregated or clinical settings for personal care.

Self-directed support allows for individual need be targeted in a way that block purchasing could seldom achieve. The government intend to increase the uptake of self-directed support and to look at a framework for enabling its development across Scotland. Evidence from England currently suggests that the aggregate costs to local authorities of providing services in this way has fallen by around 18% (source: 'In Control England').

A range of tools and guidelines to support commissioners in identifying appropriate services are set out in Annex B.

Services should be based on full citizenship rights, enable people to make choices about their lives and lifestyles and promote independence and inclusion in ways that are important to them. A number of examples of models of support from across Scotland are outlined in Annex D.

Outcomes

Services for people with autism spectrum disorder should be based on the principles of:

- **Dignity:** people should be given the care and support they need in a way which promotes their independence, emotional well-being and respects their dignity
- **Privacy:** people should be supported to have choice and control over their lives
- **Choice:** care should be based on identified needs and wishes of the individual
- **Safety:** people should be supported to feel safe and secure without being over-protected
- **Realising potential:** People should have the opportunity to achieve all they can and to make full use of available resources
- **Equality and diversity:** People should have equal access to information assessment and services. Health and social care agencies should work to redress inequalities and challenge discrimination

The new concordat between national government and local government heralds a new outcome-focused era for public services in Scotland. It sets out the overarching strategic objectives, 15 national outcomes and 45 national indicators. Local Government is in the process of agreeing a set of local indicators to fit with this framework, and local outcomes will also be developed in each of the 32 local authority areas.

Recently a broad community of people who use community care services, their carers, and agencies from all sectors across Scotland drew up 16 initial measures to determine how local partnerships (and indirectly national government and other bodies) are improving outcomes for people who use community care services. The measures are based on extensive research into the experience and aspirations of people who use services, and their carers.

The suite of 16 community care measures will be promoted as the recommended set of performance management indicators that partnerships can use to evidence achievement of the single community care outcome.

Whilst the national outcomes and community care measures are not generally focussed on particular client groups, all are applicable to people with autism spectrum disorder, and people on the autism spectrum should be included in the measurement and reporting of partnerships progress in improving performance across all measures.

The following illustrates how developing outcomes may be evidenced for people with learning disability.

Outcome 1:

People with ASD and parents/carers access information about available services.

Information is publicly available, in a range of formats that allows people to identify routes to assessment and services.

There is a clear point of contact for individuals enquiring about services.

Outcome 2:

People with ASD are satisfied with their involvement in the design of their support or care package.

Individuals who want them have access to self-directed support and receive support to manage their own care package.

People with ASD have support to communicate in the way most appropriate to them.

People with ASD have access to trained and experienced advocacy support.

People with ASD participating in consultations about the development of autism services.

Outcome 3:

People with ASD are assessed by appropriately trained staff following a diagnosis or becoming known to services.

Specialist assessments are carried out where ASD is first identified in single shared assessment.

Specialist assessment is done by a person trained in ASD.

Assessment addresses social, physical, language and emotional needs.

Local training strategies include awareness-raising for all staff, further training for some staff and a third tier of specialist training as required.

Outcome 4:**People with ASD and parents/carers receive services that address their specific needs.**

A multi agency approach is provided to young people with ASD from school to adulthood.

People with ASD are fully involved in the development of their own services using a person centred planning approach.

All services commissioned are accredited to the standards detailed in Annex C.

There are a range of low level, preventative services such as social groups, relationship counselling and befriending to avoid people getting into crisis.

Parents and carers are involved in the initial assessment of needs and are regularly involved in the review of the services received and planned outcomes.

People with ASD gain self-understanding.

Parents/carers are offered training to increase understanding and knowledge of ASD and tools to increase confidence and family capacity.

Parents/carers are offered a Carers Assessment, and have access to information i.e. benefits and support services.

Services build on an individuals assets to develop communication, behaviour support, skills acquisition, skills maintenance and growth in the ability to function independently.

Service design incorporates lifelong learning approaches that seek to continue personal progress and achievement for each individual, not just containment.

Outcome 5:**People with ASD are satisfied with opportunities for social interaction.**

Individuals with ASD are encouraged and supported to maximise their potential and have purposeful lifestyles by learning life skills to enable them to participate in further education and employment/ occupational activities.

Community capacity building supports people with ASD to participate in the local community.

Individuals are given the opportunity to look at self employment as an option.

Individuals are linked into work experience with employers.

People with ASD who are at risk of offending should be identified and preventative supports should be commissioned to minimise the risk.

Action

The following action points build on the above and will deliver improved outcomes for people with autism spectrum disorder. Local authorities and health boards should work in partnership to:

- 1) Be clear what outcomes are to be delivered for people with ASD. These should set the context and drive the specific actions taken by partners at all levels.
- 2) **Identify** and keep a record of people with ASD in their area. An audit of local needs should be carried out to identify service gaps building on the 2003 audit of services for people with autism spectrum disorders. Information about the number of children with autism spectrum disorder in education is available for each local authority and should be used to plan future demand on services.
- 3) Ensure that **diagnosis and assessments** are carried out by specially trained and qualified workers equipped to understand and assess the needs of people with ASD with reference to the diagnostic standard in Annex A.
- 4) Ensure that **services** provided are appropriate to meet the identified needs of people with ASD. A set of suggested outcomes is set out in the guidance.
- 5) Ensure the **involvement** of people with ASD in planning services.
- 6) Promote the **inclusion** of people with ASD through the provision of information in accessible formats and methods. Information about routes to services should be widely available.
- 7) Provide **awareness training** in the requirements of people with ASD for staff. Training should be accredited.
- 8) Appoint an ASD co-ordinator in the local partnership, to take **responsibility** for implementation, monitoring, quality assurance and reporting.

A senior officer should take the lead in the approaches to be adopted to ensure compliance with the Disability Discrimination Act 1995 and other relevant legislation in relation to the access and care needs of this group.

Summary

The following annexes provide material to inform and support action in developing services for people with autism spectrum disorder.

ANNEX A: National diagnostic standard

A quality standard for ASD diagnostic services is outlined which offers people with ASD and family carers a clear indication of what can be expected from a diagnostic service and provides a checklist for multi-disciplinary teams providing the service.

A quality service should:

1. Take place within the context of a multi-disciplinary AND multi-agency service involving professionals with ASD training.
2. Understand that diagnosis ought to be a process which supports the development and progress of an individual.
3. Be aware of the need to involve both the person with ASD, and parent/carer/partner/independent advocate if applicable, in the assessment and explanations.
4. Recognise and acknowledge cultural differences of all individuals and families.
5. Dedicate sufficient time for assessment in keeping with consensus timeframes.
6. Allow individuals of all ages access to a service appropriate to their needs in their locality.
7. Make a diagnosis if appropriate regardless of whether there are statutory services available.
8. Use internationally recognised diagnostic criteria and specify which criteria have been used.
9. Make a full diagnostic assessment including developmental history. In adults the developmental history is not always available but every effort should be made to ascertain it.
10. Use information drawn from observation, standardised interview and clinical experience in a variety of contexts such as home, school, workplace and the community.
11. Identify psychological, physical, social and other needs of the individual as well as making practical suggestions through joint planning of health, education, social work and the voluntary sector, to ameliorate any particular difficulties the individual is facing.
12. Produce a document to state diagnosis, which criteria and tools were used to assess, and describe any co-morbid conditions.
13. Give clear sensitive verbal explanations of the syndrome and provide quality written information.
14. Refer on for any medical or other assessment as appropriate or relevant genetic counselling.
15. Offer a follow-up appointment, preferably face to face, for the individual to ask further questions.
16. Offer clear explanations if a diagnosis of autism is not made (and any differential diagnosis) and offer second opinion as appropriate.
17. Provide information about post diagnostic services such as support groups.

ANNEX B: Tools to inform commissioning

A range of tools and guidelines have been developed which can support commissioners in identifying appropriate services for people with autism spectrum disorder.

1. The Joint Improvement Team (JIT) have developed a [commissioning toolkit](#)⁵ for learning disability services, designed to help commissioners use existing evidence and good practice when developing and evaluating individual service plans for people with learning disabilities, including those with ASD. JIT have also developed a capacity planning toolkit, which is currently being piloted, to support local authorities in identifying current and future need.
2. The Scottish Intercollegiate Guidelines Network (SIGN) has published a [clinical guideline](#)⁶ on the management of children and young people (up to the age of 18) with autism spectrum disorders (ASD).
3. The Scottish Government has produced a diagnostic standard outlining the level of service people should receive in assessment and diagnosis of ASD. The standard is in Annex A
4. The [National Autism Plan for Children](#)⁷ sets out an ideal model for service delivery for 0-11 year olds. It sets out a plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary aged children with ASD.
5. Health care services need to identify and treat the conditions which are often associated with ASD appropriately and address the wide range of health needs of people on the autism spectrum. To support this, NHS Education for Scotland have developed an ASD learning resource for GPs and primary care practitioners www.nes.scot.nhs.uk/autism_spectrum_disorder.
6. The ASD Education Working Group is taking forward the recommendations from Her Majesty's Inspectorate of Education's "Education for Pupils with Autism Spectrum Disorders" report and the National Autistic Society Scotland's "make school make sense" report. The intended outcome of this group is the production of a resource pack for education authorities which will include: strategic planning for future service provision; guidance on the information they should be providing for parents; and guidance to schools.
7. The Scottish Autism Service Network hosts a number of professional networks, including a commissioner's network which offers peer support and the opportunity to share learning and good practice around commissioning services for people with ASD. Details can be found at www.scottishautismnetwork.org.uk.
8. A National Training Framework for ASD has been developed, which audited existing training arrangements, provided a template of training needs, identified gaps in provision and provided recommendations for the implementing of a training framework. <http://www.nas.org.uk/content/1/c4/52/58/ASDReportText.pdf>

⁵ <http://www.jitScotland.org.uk/knowledge-bank/improving-outcomes.html>

⁶ <http://www.sign.ac.uk/pdf/sign98.pdf>

⁷ <http://www.nas.org.uk/content/1/c4/34/54/NIASARep.pdf>

ANNEX C: Service accreditation

The National Autistic Society provides an autism accreditation services based on the following criteria, which should be fundamental to the development of any service for people with ASD.

Criteria for Accreditation

- The service possesses Autism specialist knowledge
- This specialist knowledge consistently informs the way in which the service is organised and delivered
- The specialist knowledge consistently informs the work of the individual members of staff
- The service effectively identifies and responds to the individual needs of each person using the service

Benefits to the Person with Autism

- Effective approaches, based upon established methodology
- Best practice through continual research
- Consistent service
- Experienced and trained staff
- Shown respect and understanding and their individuality is valued

Benefits to Families

- Knowledge that their family member is receiving education and care of the highest quality
- Re-assurance that there is objective and credible monitoring of the establishment in relation to its policies and practices
- Ongoing involvement
- Support and Empathy through experienced and trained staff

Benefits to Service Providers

- Base-line standard
- Compatibility with other standards
- Acknowledgement of existing good practice
- Working towards excellence
- Management and Staff Team working towards common and shared goals
- Credibility in relation to the quality of service being provided
- Marketing

ANNEX D: Models of support

Research highlights the need to consider models of support specifically for people with autism spectrum disorder.

A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder (Janet Robertson and Eric Emerson, Institute for Health Research, Lancaster University) states that, in contrast to the considerable body of knowledge that exists regarding the comparative quality of life related outcomes and comprehensive costs of models of residential supports for people with intellectual disabilities, almost nothing is known about the comparability of residential supports for people with autism spectrum disorder. The results of earlier studies suggest that people with autism spectrum disorder require somewhat different vocational supports to those currently recommended for people with other types of developmental disabilities.

This list of examples of models of support is not designed to be all inclusive and there will be many other models of good practice throughout Scotland. However these examples have been selected to demonstrate:

- Support for different age groups
- Support for people across the autism spectrum
- Support throughout Scotland including support available in more rural areas
- Support that changes as levels of need change
- The range of support required from low level “light touch” to intensive support

Whilst the majority of models here outline specialist services, it is hoped that support for people on the autism spectrum will also develop across more generic services.

ADULT SERVICES

LOCAL AREA COORDINATION

Local Area Coordinators have been employed in 26 local authorities in Scotland to work with people with learning disabilities and autism spectrum disorders and their families. They work on the principle that people with disabilities have the same rights and responsibilities as all other people to participate in and contribute to the life of the community.

Their primary function is to support self-assessment, establish personal life plans and support people to implement those plans. They contribute to a whole system approach and aim to tie people into community services and networks. In this way they can help people to access low cost and no cost services and reduce the need for formal services.

National guidance on the implementation of local area coordination is currently being developed.

SELF-DIRECTED SUPPORT

Self-directed support (direct payments) in Scotland is part of the mainstream of social care delivery, targeted at empowering people and putting the principles of independent living into practice. It enables individuals to direct the care or support they need to live more independently at home and can be instead of, or in addition to, services that might be arranged by their local authority. These might be community care and children's services, housing support services and equipment and temporary adaptations.

Through self-directed support, users are able to take responsibility for their own lives, from deciding who comes into their houses to provide support, to the priority given to different tasks in any given day, like when they get up in the morning. This can be particularly important for people with autism spectrum disorders. Self-directed support helps increase the flexibility, choice and control people have over their lives, so that they can live more independently. The flexibility achieved is such that even those with the most complex and multiple needs can have self-directed support, using the Adults with Incapacity (Scotland) Act 2000 to safeguard their interests.

Guidance on self-directed support can be found at the following link
<http://www.scotland.gov.uk/Publications/2007/07/04093127/0>.

ONE STOP SHOP ADVICE AND INFORMATION SERVICE

Number 6, Melville Crescent, Edinburgh

This service for adults with Asperger Syndrome and High Functioning Autism in Lothians, originally funded by the Scottish Executive via Lothian Health, provides a wide range of low level supports (drop-in, social groups, advice, information, volunteer support), aiming to prevent the need for more intensive, costly interventions. The tender was awarded to Autism Initiatives UK in 2005 who are prioritising a funding strategy to ensure its continuation. (Appendix D)

Further information contact: www.number6.org.uk

AUTISM SPECTRUM DISORDER COORDINATOR

Autism Coordinator, Scottish Borders

The Adult ASD Coordinator post was funded from November 2005-November 2006 by the Scottish Executive. The remit of the Coordinator was to be a 'change agent' in the lives of adults with ASD, their families, friends, carers and the services that support them in the Scottish Borders. It provided a planning role for NHS Borders and Scottish Borders Council services for adults with ASD and their families, that has driven forward the ASD agenda in the area.

Further information contact: Scottish Borders local authority

SUPPORTED LIVING

Peterhead service, National Autistic Society Scotland

Recently opened nine “autism friendly” flats where individuals take out their own tenancy. Support is provided by NAS care staff tailored to individual need. The new buildings were a partnership approach by Aberdeenshire Housing Partnership, National Autistic Society and Aberdeenshire Council with a key funder being Communities Scotland.

Further information contact: Carol Evans 0141 221 8090 carol.evans@nas.org.uk

Outreach, National Autistic Society Scotland

This is an individually tailored support package for people with autism of any age across Scotland. The individual is matched with appropriate support staff who can support them at; home, in further education, employment, school, with social skills and life skills. It can range from a few hours a week to 24 hours a day.

Further information contact: Willie Gilmour on 0141 221 8090, willie.gilmour@nas.org.uk

VOCATIONAL TRAINING AND SUPPORT

Café Kudos Carluke, South Lanarkshire

Developed by the Scottish Society for Autism, Café Kudos involves people with Autism and Aspergers delivering a quality café service on a local high street to local people. The café offers both vocational experience and training for formal qualifications in partnership with the local FE College. The café has strong community connections and a broad customer base. It is intended to promote inclusion for individuals living with autism by building key skills that support independent living. The café builds on individual's skills and assets and addresses development needs through individually focussed programmes of support.

Kudos Crafts offers individuals with autism the opportunity to develop skills and experience through delivering a service to local people through a high street shop, providing a crafts and gifts service to customers. Individuals are supported to develop skills in card and gift production as well as retail skills. Individuals are encouraged through person centred programmes to build on their skills and assets and to acquire new skills that support independence.

Further information can be obtained from Kenny.Bryce@autism-in-scotland.org.uk Tel. 01259 728361

Gratwinny Horticultural Unit Coalsnaughton Alloa

Developed by The Scottish Society for Autism, The Unit offers stimulating and age appropriate activities in a real work setting that encourage adults with autism towards a more independent lifestyle and improved quality of life. The Unit is a horticultural nursery open to the public offering a range of bedding plants and herbaceous plants for sale. Service users are involved in all activities and also offer a wholesale service to local Garden centre outlets. Social skills are built into each programme and taught in the real work setting. In addition to practical skills in horticulture, non-specific work skills such as being on time, teamwork, having a break, health and safety etc are also integrated into the programme.

Further information on both services is available from autism@autism-in-scotland.org.uk

DAY/ACTIVITY SERVICES**Inverleith Activity Centre, Edinburgh**

Recently established in Edinburgh by Autism Initiatives UK, this service provides individualised programmes of activities for up to 9 adults per day. The service is available throughout the day including evening and weekends. It offers a range of community activities which are delivered from the security and consistency of a small service base.

Further information contact: inverleithday@autisminitiatives.org

The Abbie Resource Glasgow

Operating 7 days a week throughout the year, the Abbie Resource is an innovative and individualised service for adults with autism, which can accommodate individuals with a wide a range of needs. Staff build individual strategies which maximise each service users potential.

Further information on both services is available from autism@autism-in-scotland.org.uk

Joint Autism Service – Branchline and Day Services with Turning Point Scotland and Building Healthy Communities

Building on joint work undertaken throughout 2005-07, Dumfries and Galloway have launched a twelve month pilot project sharing a base and resources. As a local autism information point, work experience base, support planning and drop-in support facility, it will also offer opportunities for users, carers and workers across agencies to work and learn together to increase knowledge and opportunities for adults with autism or Asperger Syndrome. Open one day per week initially, it will promote active involvement of those on the autistic spectrum in the delivery of the project. For details contact Dumfries and Galloway.

DEVELOPING EMPLOYMENT OPPORTUNITIES

ASD Social Firms Project

In Summer 2007 Autism Initiatives UK appointed on behalf of a group of ASD agencies a Social Firms Coordinator with the remit of supporting agencies to develop Social Firms for people with ASD and to support generic Social Firms to become more accessible to people with ASD. The post is funded by the Scottish Government for 2 years and a network of ASD Social Firms will be developed to sustain the project in the long term. A Social Firm is a "business that has been set up specifically to create employment opportunities for people with a disability or disadvantage" and can be beneficial to people with ASD in that employment can be created around the known skills and interests of individuals.

Further information contact: Susan Astwood (ASD Social Firms Coordinator) 0131 240 2370
sfc@autisminitiatives.org

ASPIRE Employment Project

This project was specifically developed to help individuals with high functioning autism and Asperger Syndrome access and sustain employment. The project also provides a 12 week training programme – SUSS (Support and Understanding of Social Skills). The aim of the course is to assess and identify individual social skill deficits and address through the use of appropriate intervention, that will equip project participants with the necessary tools and techniques to facilitate development of existing and new social skills. SUSS encourages individuals to become more self-aware, increase participants confidence and help achieve their employment aspirations.

Further information contact: Jill Morris Tel: 08451 55 55 55 446008
E-mail: jill.morris@fife.gov.uk

Employment Development Worker

This worker supports individuals on the autism spectrum in Moray. She works with each individual according to their particular need, spending time working with each person on a one to one basis, building up a rapport with the person. A multi-disciplinary approach is important, to ensure continuity and stability for the individual, this also ensures that the support each person gets is Person Centred and tailored to their specific needs. The work is in accordance with the blueprint for supported employment as advocated by the Scottish Union of Supported Employment and the Scottish Government. For further information contact Moray Council.

Prospects, National Autistic Society Scotland

This service runs from Glasgow, Inverness and Aberdeen matching clients to jobs and taking clients through the process of becoming job ready. It offers training and support to employers and ongoing support to the clients.

Further information contact: Robin Walker on 0141 221 8090, robin.walker@nas.org.uk

PEER SUPPORT AND SOCIAL GROUPS

Aspie Solidarity Group (age 25+)

This is a self-help group in Fife where members talk of their positive experiences, discuss issues of concern and the way forward. Life experiences are also shared, developing self-understanding and acceptance. This group intends to create a series of Social Workshops, where members may learn how to deal with difficult situations. Outings are organised to assist in developing friendships and confidence in accessing leisure pursuits.

Further information contact: Stella Macdonald on 01383 623567. phad-fife.org.uk

WISE (Welcoming, Interaction, Supportive and Educational) group (14-25 yrs old)

In this group members reflect on positive experiences, and celebrate successes. Much discussion involves solution finding for individual challenges, encouraging the development of coping strategies and self-understanding. Friendships are encouraged.

Further information contact: Stella Macdonald on 01383 623567. phad-fife.org.uk

Befriending Services, National Autistic Society Scotland

These services run in most cities in Scotland offering opportunities for individuals to improve their lifestyles with one to one support in befriending and in group settings with social groups.

Further information contact Robert Moffat on 0141 221 8090, robert.moffat@nas.org.uk

RESPIRE AND SHORT BREAKS

The Asperger Support Project, Fife

This group meet fortnightly in different areas of Fife providing social activity clubs for adults and adolescents with an autistic spectrum condition to encourage the development of social skills improving their self esteem and confidence by providing leisure opportunities, and short breaks. Through the Asperger project Family/Carers benefit from the respite in their caring responsibilities. This service has proven to be extremely beneficial to the members and their families.

Further information contact fifeactiononautism@hotmail.co.uk

Clannalba – Respite and Transitional Assessment Centre Lamington by Biggar, Scottish Society for Autism

Clannalba combines residential respite care and family support to create a unique integrated service. It offers flexible, individual support to children and adults with autism and their families. Clannalba provides a level of support to enable people with autism to live in the community with minimal impact on family life and maximum contribution to personal enhancement.

Preparing for a New Life supports young and mature adults to prepare them for living more independently in their own community. Team Weekends offer Teenagers or young adults with Asperger Syndrome a range of personal and social skills development opportunities over a programmed series of breaks. Activity Breaks are also available to support Adults and children develop recreational and social skills.

Further information contact Adam Brodie 0845 3009272 Fax: (01899) 850330

Email: clannalba@autism-in-scotland.org.uk

Auchenhuive Respite Centre, Whiterashes, Aberdeenshire

Opened in early 2008 by Autism Initiatives UK, Auchenhuive is a 5 person residential respite and short break service for adults and children over 12 with autism spectrum disorder. The service is set in 8 acres of gardens and pastureland and was developed in response to the acknowledged need for additional autism specific respite services. Referrals are taken from all over Scotland and guests benefit from a high quality environment and individualised packages of respite support.

Further information contact: 01651 882278 auchnenhive@autisminitiatives.org

CHILDRENS SERVICES

SPECIAL SCHOOL

Daldorch House School and Continuing Education Centre, East Ayrshire. National Autistic Society Scotland.

A 52 week residential school for 59 pupils and 12 day pupils. A senior campus was opened in late 2007 where individuals have their own purpose built flats with their own tenancy to ease them from school life into adulthood up to the age of 21. The school offers outreach which includes training, assessment, consultancy and direct support to clients. A family support programme facilitates the transition of pupils to adult settings.

Further information contact: Shona Pinkerton on 01290 551666, shona.pinkerton@nas.org.uk

New Struan – A Centre for Autism, Scottish Society for Autism, Alloa

New Struan School demonstrates that children with ASD benefit from education approaches and programmes that specifically target the challenges of autism. Staff, parents and pupils work together to create highly individualised plans that aim to improve the child's social understanding, communication and ability to adapt and solve problems. This specially designed school enables children with ASD who have complex and intensive educational support needs, to achieve their maximum potential and a greater level of social inclusion.

Further information is available from Jim Taylor Tel: 0845 300 9281 or 01259 222000, Fax: (01259) 724239 newstruan@autism-in-scotland.org.uk

TRANSITION SERVICES

New Ridgepark – A Centre for Transition, Lanark

Focusing on the person with autism's journey through life, New Ridgepark offers placements for individuals who require a transition service from school, college or home as well as for anyone going through a significant life event who requires a period of intense support or crisis intervention.

The aim of this service is to evaluate and appraise the person's needs, identifying their strengths and limitations within all areas of their life, to provide strategies that enable them to cope with their limitations and to offer opportunities that will enhance and develop their strengths. The service offers intensive support and intervention at the right time that has proved to be successful and cost effective, thus avoiding the need for higher levels of support later in life.

Further information from: Elaine Hislop, 01259 728400 ridgepark@autism-in-scotland.org.uk

FAMILY SUPPORT SERVICES

Autism Spectrum Disorders Integrated Network (ASDIN)

This is a project that has been funded by the Scottish Government through Changing Children's Services Funding. ASDIN is a multi agency group including a parent and staff from health, education and social services with training and experience in autism. They work across Dumfries and Galloway providing information, training, advice and support for parents/carers, families and staff from public, private or voluntary agencies who have contact with or work directly with children and young people with Autism Spectrum Disorders and Social Communication Difficulties.

ASDIN focuses on building capacity by developing an understanding of autism, stressing the importance of developing understanding and skills within families and people who work directly with children and young people, encouraging a focus on progressing independent skills, developing strategies and targets which relate to social communication and interaction difficulties and sexual health and relationship education. For further information contact Dumfries and Galloway Council.

Help! National Autistic Society Scotland

A programme of support for one to three days for a small group of parents to learn about ASD and how it affects their child, information about what is available in their area, legislation and benefits. This is for parents whose child has recently been diagnosed and runs across Scotland for groups up to approximately 10 families.

For information contact: Barrie Cooper 0141 221 8090, barrie.cooper@nas.org.uk

DIAGNOSTIC SERVICES

The development of ASD diagnosis for adults in the Managed Care Network Area – Lothian, Fife, Forth Valley and Borders.

The Regional ASD Consultancy Service is a Tertiary level multi disciplinary team with staff from each of the four Health Board Areas in South East Scotland. It is a “virtual” team with one full time member and the others giving time in special interest sessions or by arrangement with their managers.

In October 2007 there were:

- 4 Consultant Psychiatrists (2 LD and 2 Gen Ad Psych, one specialises in Schizotypy one in Affective Disorders)
- 2 Consultant Clinical Psychologists
- 1 Consultant Speech and Language Therapist (who is co-ordinator)
- 4 Specialist Nurses (Community & inpatient)
- 3 Specialist Registrars (1 LD and 2 Gen Ad Psych)
- 1 Clinical Psychology trainees.

The team receives referrals from the age of 18. Average age of referral is 38. These people are usually very complex and several members of the team may see them to give different perspectives. No one test is appropriate for all and each individual referral may be assessed using a different combination of tools. ADI-R is used where appropriate. DISCO, AQ, EQ, SQ, KADI, SCQ and a range of neuropsychological assessments, language assessments etc may also be used. Psychiatrists carry out psychiatric interviews. Early developmental history is gathered by whatever means possible (interviews with parent if available, partner, family member, early medical records, school reports etc). There is a clear Diagnostic Care Pathway document which is adhered to and audited regularly so there is a consistent method of addressing an inconsistent type of referral. Evaluation forms are completed by the referrer and the clients themselves in order to maintain quality and improve it where necessary.

Training

ADI-R: the team did a days training to enable the clinical use of ADI-R. In addition three SPRs also attended the full course in Cambridge. After that it was used where appropriate. It was found by the team that it was sometimes difficult to do, as parents were having to cast their minds back many years to when their child was aged between 4-5. eg an 89 year old mother about her 56-year-old daughter. It was found to be extremely time consuming but valuable with some cases.

It was found not to be so useful for adults with average or above average IQs. In practice the majority of our referrals. (July 2007: 245 non LD referrals, 32 LD referrals)

The ADI-R clinical use courses for Fife, Forth Valley and Borders are still running.

ASD “awareness” courses for Psychiatrists and Clinical Psychologists have been run in Forth Valley and Borders. The next step is planned for March 08 in the Borders. However, significant progress has been made.

A new programme is just starting for SPRs wanting to gain knowledge and experience in ASD. They will be offered 6 month supervised placements. A document with further information is available.

Other Diagnostic progress

An ASD diagnostic care pathway for Community Learning Disability Teams (CLDT) is being piloted in Lothian. This is in an attempt to address the apparently large number of people with a Learning Disability who may be on the spectrum but who may have been missed over the years. This project is being audited and after the 3 month pilot should be rolled out to all the 8 CLDTs in Lothian. Forth Valley and Borders are likely to implement it too if it proves useful.

Other Training

The one day “Understanding and working with adults with Asperger Syndrome” courses run at Number 6 have become very popular with General Adult Psychiatrists in Lothian. It is gratifying to see that many of the Consultants have now attended. Junior Medical staff also attend as well as GPs and Social Workers. Many Clinical Psychologists have attended. Following these courses there tends to be an upsurge in referrals.

Summary

Training in all aspects of ASD seems to be more useful than just using a tick box tool. If people are more knowledgeable about the Spectrum as a whole it can help to make more useful diagnoses with more practical recommendations. Availability of knowledgeable Medics and Clinical Psychologists is extremely helpful. The absence of diagnostic instruments for adults is a concern. Most seem to be for children.

CASE STUDY – SOMEBODY WITH ASPERGER SYNDROME

Questions, questions, incessant questions.....

- What is the world all about? What are relationships all about? Why are tasks carried out? Why in a particular way? What may be gained? What's the point? Am I of any value? How can I fit in? What are people doing and why? How do people know what to do? What does this mean? What does that mean? Who exactly, and of what use, am I? Why, why, why, what, why.....?

I am an observer, existing at the edge of other people's experiences. A 'nobody': detached, living in my own world. I want to belong, but how do I slot in? What should I be doing? Who should I copy? How will I cope? I don't understand.

My world is an infinite world of sense, sensation, and facts. A world with no boundaries – whether experience or thought. A sensory-crowded, literal and unpredictable existence. Thoughts overloaded with processing, reasoning, rationalising and actioning – in a state of high-anxiety. I have an IQ of 155, and ability to multi-think in a visual and multi-dimensional way, but difficulty with everyday tasks and living as 'part of the crowd'. I feel clumsy and awkward. Daily life is intense and serious, with all matters demanding urgent attention. I live very much in the present moment, with each moment bringing with it pressure to perform and 'get it right', but all too often failing. Actively reflecting on, and utilising, social rules prove problematic. Leaving me permanently challenged.

WHAT HAS HELPED?

- 1) Pre- and post-diagnostic support, including advocacy and counselling.
- 2) Appropriate delivery of support and care, by professionals (including GPs, dentists, opticians etc.) who understand.
- 3) Timely support and advice, together with access to information on local and national services that cater for the needs of families and those diagnosed. Information packs handed out at time of diagnosis.
- 4) Local access to a well equipped collection of books relating to ASDs.
- 5) Parents who understand and have gained knowledge about the condition and tools/aids that may be used. Additionally, that sibling needs are recognised and addressed.
- 6) To be able to integrate: becoming active participants and contributors. Offered 'taster' opportunities to experience possibilities and allow discussion.
- 7) Through learning, developing and using independence skills: social, life, living, housing, employment and vocational. Group-work has been beneficial.
- 8) A number of services that have greatly assisted an increase in capacity building include: training for parents; respite; befriending; support groups; direct payments; after-school clubs; leisure and recreational opportunities, and play schemes.
- 9) Self-help groups for those diagnosed to share and learn from each other's experiences and coping strategies. Gaining self-understanding and companionship of likeminded people.

ANNEX E: Estimated prevalence figures by local authority area

The prevalence figures outlined in the table are estimates of the total number of people with autism spectrum disorder by local authority area, based on the prevalence rate of 90 in 10,000 people from the Office of National Statistics survey of the mental health of children and young people in Britain (2005). The ratio of males to females was found to be 4:1. Not all of this population will need formal community care services. However, it is clear from the figures that general community services, such as housing, transport, sport and leisure, should be taking account of the range of needs of this population.

Location (CAPS= city status)	Population 2006	Estimated ASD 90/10,000	Age Demographics												Total								
			ASD male/female/sum (assumes 4/1 male female ratio)																				
			0 to 4		5 to 9		10 to 14		15 to 19		20 to 29		30 to 65			65 plus							
M	F	Total	M	F	Total	M	F	Total	M	F	Total	M	F	Total	M	F	Total						
Aberdeen	206880	1862	90	23	113	94	24	118	97	24	121	95	24	119	197	49	246	696	174	870	225	56	281
Aberdeenshire	236260	2126	103	26	129	108	27	135	110	28	138	109	27	136	225	56	281	794	199	993	257	64	321
Angus	109320	984	48	12	60	50	13	63	51	13	64	50	13	63	104	26	130	368	92	459	119	30	149
Argyll & Bute	91390	823	40	10	50	42	10	52	43	11	53	42	11	53	87	22	109	307	77	384	99	25	124
Ciannmannanshire	48900	440	21	5	27	22	6	28	23	6	29	23	6	28	46	12	58	164	41	206	53	13	66
Dumfries & Galloway	148030	1332	64	16	81	68	17	85	68	17	86	68	17	85	141	35	176	498	124	622	161	40	201
Dumfries	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	478	120	598	155	39	193
Dumfries & Galloway	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	478	120	598	155	39	193
Dumfries & Galloway	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	478	120	598	155	39	193
Dumfries & Galloway	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	478	120	598	155	39	193
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Dumfries & Galloway	142170	1280	62	15	77	65	16	81	66	17	83	66	16	82	135	34	169	4					

ANNEX F: National developments in autism spectrum disorder services

In consultation with the national Autism Spectrum Disorder Reference (ASD) Group the Scottish Government has funded a number of innovative projects and pilots to inform service development across Scotland. These developments and a number of additional national models are detailed in this Annex.

Project 1: Scottish Autism Service Network (SASN)

Aims of project:

The Scottish Autism Network aims to provide the following:

- collation and provision of information on good practice and resources
- a structure for sharing advice and receiving support
- sourcing and making available links to good autism spectrum disorders materials, events and training, information and publications
- dissemination and publication of impartial autism spectrum disorders related information
- communicating information regarding related research
- conferences and the dissemination of regular newsletters
- routing and referring queries to local professionals, organisations and services
- facilitating autism networks and supporting those that already exist
- developing on-line forums for networking and sharing information about autism spectrum disorders

Delivery of project:

The National Centre for Autism Studies (NCAS) at the University of Strathclyde were granted funding from the then Scottish Executive in September 2005 to develop SASN. SASN will continue from January 2008 with funding from other sources. The SASN office is based in Glasgow but covers the whole of Scotland.

The original remit of the project was to develop a Scottish Autism Service Network to provide:

- a hub of direction to services to people affected by Autism Spectrum Disorders (ASD),
- a structure for sharing advice and receiving emotional support
- an internet presence for information provision
- consultation with users, families and professionals towards responsive development of the network to meet what the ASDcommunity in Scotland needs.

Outcomes for people with ASD:

The primary outcome for individuals on the autism spectrum and their family members would be the increased capacity of practitioners, organisations and services in their knowledge, awareness and understanding of professional practice, local and national contacts, and most specifically increased collaborative working.

The Network provides a multi-agency and cross-professional approach in improving services to people with ASD and their families across Scotland and has been successful in establishing a number of networks across Scotland on a cross-cutting basis involving disciplines in education, health, social work and the third sector. The increased capacity of these professionals increases the likelihood of successful inclusion (educationally and lifelong) and provision of appropriate and good practice for children and adults with ASD into mainstream services.

Outcomes for local authorities and health boards:

The Scottish Autism Service Network is seen to be unique and at the leading edge of inter-professional development in this field as there is no known similar national autism specific network within Europe. Its unique, inclusive, innovative and cross cutting approach is an enormous strength, and feeds its capacity to support a wide range of professionals across all local authorities and health boards in Scotland and reduce the isolation of those who are geographically constrained.

The Network provides practitioners within local authorities and health boards an opportunity to tap into a wide ranging yet specialist source of knowledge and information that is not commonly otherwise readily available within local authorities. Sector and geographically specific networking opportunities are available to those working in local authorities and health boards, both physically and virtually. The benefits of this and the hub of information provided are on two levels. Firstly, practitioners are informed in their professional understanding, practice, and knowledge and secondly the capacity of services is increased and work toward strategic objectives is supported.

Project 2: Autism Resource Centre (ARC), Glasgow

Aims of project:

The ARC has been set up with two broad aims:

- 1) To provide expertise, information and training in order to build capacity within mainstream agencies and with families and carers, so as to enable them to provide effective support and service provision for individuals with ASD.
- 2) To improve the social, physical and emotional well being of adults with ASD and build their capacity to live full and independent lives in the community.

Delivery of Project:

Adult Autism Service – diagnosis and assessment (via weekly clinics); individual and group interventions; support and linking to services; drop-in facility; user-led interest groups and involvement in service.

Training – training to all individuals e.g. professionals, carers and clients; a wide range of training options are provided from one day autism awareness training to high level diagnostic training. Training is currently free and also available on an outreach basis.

Information Service – advice and information in person, over the phone or through various media, via the information officer; library of current books, articles and service information; computer access to a range of online resources; operation of a duty system so that visitors have access to further specialist support and/or advice.

Development Team – strategic planning for autism services; partnership working with mainstream services and care groups; ensuring standards of service delivery for all individuals with ASDs; helping Greater Glasgow Health Board and Glasgow City Council ensure that they meet national standards through involvement in a range of Parliament/Government led reference groups.

Finance

Funding from the then Scottish Executive (£250,000 per year) ended in March 2006. Currently the ARC receives funding from a number of sources:

1. Recurring revenue from Glasgow City Council of £189,900
2. Recurring revenue through Greater Glasgow NHS through releasing existing staff of £119,476

One-off payment for 2007/08 from Greater Glasgow NHS of £185,000.

Outputs (November 2004 to June 2007)

- 2245 completed general one-day autism awareness training
- 45 completed advanced autism training (8 half days)
- 11 link practitioners in Learning Disability Teams
- 36 completed DISCO diagnostic training
- 7004 visits to the Centre
- 1432 requests for information
- 525 referrals to the Autism Resource Centre

Outcomes for people with ASD:

- Attendance at a wide range of group activities
- Availability of one-to-one autism specific interventions, either on outreach basis or in the Centre
- Information base, including 4 public access computers
- 'Safe' environment to carry out coursework or interests
- Website available for individuals on the spectrum, aimed at mutual support and problem solving
- Coordinated and seamless approach to services for individuals
- Fast access to appropriate health, social care, employment and other services
- 87% of participants felt that their overall experience at the ARC was 'very positive' or 'positive' (Source: NCAS evaluation 2006)

Outcomes for local authorities and health boards:

- Specialist Tier 4 service providing ASD expertise to other services
- Access to autism training at a variety of levels to enable appropriate skilling-up and competency building of staff within services
- Extensive library and information services for professionals
- ASD knowledge to enable authorities and health boards to meet their statutory duties in the most effective way possible
- Assisting all services to meet the needs of individuals with ASD

Project 3: “Number 6” the One Stop Shop for adults with high functioning autism/Asperger syndrome

Aims of project:

To provide a venue for people with AS and their carers to access a range of services including social activities, specific advice information and support, support with employment, in education and housing as required. Outreach support is provided across the Lothians. There is a training programme for professionals, parents and carers and volunteers. There is an extensive volunteer programme. There are specific groups for women, men with co morbid mental health problems and/or offending behaviour and a social group for 16-19 year olds.

Delivery of project:

Autism Initiatives provide the service from a budget of £250,000 of which AI get £200,000 pa the other money spent on Into Work, Independent Evaluation and other AS related projects

Number registered to use the service: 233

Number of attendances for a variety of services: 7011

Number of training courses run: 95

Number of volunteers: 52

Outcomes for people with ASD:

- “There is calmness, actual acceptance, a welcoming feeling. You can come and know it's alright; it's ok to come here. Whatever is happening you can fit in, there is a structure but its not rigid”
- “Concerns have been absolutely listened to and taken into consideration. There has been no judgement; there is complete acceptance and help”
- “I didn't have enormous expectations, you get used to not having expectations, I try not to set my expectations too high but I am quite satisfied”
- 80% of service users felt positive or very positive about their overall experience of Number 6
- 100% of parents and carers felt that their family member has benefited from the service or support they received
- 85% of the parents felt that they themselves had benefited (Source NCAS Evaluation 2006)

Outcomes for local authorities and health boards:

- Pre and Post diagnostic support provided by Number 6 is greatly valued by the local NHS diagnostic service
- Training for staff from local authority and NHS and others including Vol Orgs and the Prison Service among others enables more effective ways of working leading to more appropriate care provision where required
- Access to extensive library and information resource for staff
- Record of people being successfully supported into employment
- Record of people being enabled to commence and remain in Further and Higher Education
- Record of tenancies being maintained
- Record of mental ill health being monitored and early referral made where necessary
- Record of potential offending behaviour being noted and managed. Number 6 is a remote reporting Police Station

Project 4: NHS Education for Scotland Autism Learning Resource for Primary Care Professionals

Aims of project:

- (a) To increase the understanding of key primary care practitioners of the needs of people with ASD when receiving routine patient care (not specific to their ASD condition)
- (b) To increase the understanding of key primary care practitioners of when and how to refer patients to a diagnostic team

Delivery of project:

The Autism Learning Resource for primary care professionals is a web based resource which meets the above aims.

Primary Care Professionals include GPs, District Nurses, Public Health Nurses, AHPs, Practice Nurses and Practice Managers. However this resource would be useful for any practitioners who are involved in caring for people with ASD when receiving routine care e.g dentists and staff in A&E. Staff in social care settings and the voluntary sector may also find aspects of the resource useful.

Outputs from the project are a web resource for longer term reference, and production and distribution of leaflets to give information and signpost the web resources. The website will be assessed annually in terms of any updates.

To date statistics gathered on the use of the website shows that people are accessing it from all over the world and that the case studies, scenario and reference pages being the most accessed pages.

Outcomes for people with ASD:

Improved support and care when accessing primary care services (or front-line services).

Outcomes for local authorities and health boards:

Improved understanding by primary care staff of the needs of people on the spectrum and therefore possibly less complaints and more efficient use of services with improved outcome.

Project 5: NHS Education for Scotland Autism Argyll Project. June 2004 – May 2006

Aims of project:

To produce an information resource for parents/carers of children receiving a diagnosis of ASD based on the Autism Argyll Information pack.

Delivery of project:

February 2006.

Directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland. Distributed widely within Primary Care and across Scotland (Print run 6500)

May 2006

Parent /Carer Booklet. (Print run 6000)

Two-year supply distributed to all known diagnostic teams/centres in Scotland.

June 2006

Parent Booklet and ASD Directory available as PDF Documents on the Scottish Autism Services Network website. www.scottishautismnetwork.org.uk

October 2006

Parent/Carer booklet (Second print run 6000)

Distributed as per requests across Scotland. Stock held at the Scottish Autism Service Network.

Scottishautismnetwork@strath.ac.uk or Telephone: 0141 950 3072

Total Cost: £110,000 + Staff Costs

Running in parallel with this project was the NES ASD Learning Resource for Primary Care Professionals and some of the development costs (design) were shared.

Outcomes for people with ASD:

Scotland wide provision of high quality basic information on ASD for parents and carers available at the time their child receives a diagnosis.

Sustainability achieved by Scottish Autism Services Network hosting materials (booklet and directory) on their website.

Outcomes for local authorities and health boards:

Scotland wide directory of where the diagnosis of ASD (both children and adult services) takes place and contact details of at least one professional involved in diagnosis in each Health Board area.

Links Professionals involved in ASD diagnosis.

Provides clear referral pathway for Primary Care.

Project 6: NHS Education for Scotland NES ASD Projects 2006-2007

Aims of project:

To build training capacity and capability within Scotland for professionals involved in the assessment and diagnosis of ASD.

Delivery of project:

November 2006

Autism Diagnostic Observation Schedule (ADOS) Scoping Exercise completed by Dr Anne Gilchrist, Professor Anne O'Hare & Mrs Ros McCaughey.

January 2007

Training in the Diagnostic Interview for Social & Communication Disorders (DISCO) The Autism Resource Centre (ARC) Glasgow. E-mail: infoarc@glasgow.gov.uk

Three-year training programme for 98 trainees based in Scotland with a nationwide remit.

Partnership start-up funding to:

- Acquire seven course worth of training materials
- Set-up the infrastructure to organise the training

January – March 2007

ASD Seminars. Three events with two held in at New Struan Campus and the third in Aberdeen. 97 delegates attended. Collated evaluations available.

February and April 2007

Training in the Developmental, Dimensional & Diagnostic Interview (3di) computerised assessment for ASD (Software included). Two two-day events held in Glasgow with 43 trainees attending. Evaluations available.

TOTAL COST: £88,600 + Staff Costs

Outcomes for people with ASD:

- Improved knowledge and understanding of assessment, diagnosis and clinical interventions in professionals dealing with the children and families.
- Increased reliability of diagnosis.
- Improved diagnostic services.

Outcomes for local authorities and health boards:

Provision of evidenced based assessment diagnosis and interventions as recommended by SIGN Guideline number 98.

Increased capacity and capability across Scotland in the use of specialist ASD structured instruments (interview schedules and observation schedules) in both children and adult services.

Project 7: Scottish Independent Advocacy Alliance – Autism Development Officer

Aims of the project:

- To raise awareness and build capacity amongst independent advocates supporting people affected by ASD.
- To raise the profile and promote independent advocacy amongst those providing services to people with ASD.
- To establish stronger links between Advocacy organisations and Autism service providers.
- Identify barriers and gaps in access to independent advocacy for people affected by ASD.

Delivery of Project:

- Deliver 10 “Introduction to ASD” training sessions to advocacy organisations throughout Scotland.
- Offer in house training to all advocacy organisations in Scotland on: Introduction to ASD.
- Offer in house training to all ASD service providers in Scotland; Introduction to Advocacy.
- Offer talks/presentations about independent advocacy to ASD service providers.
- Offer talks/ presentations on ASD to Independent advocacy organisations.
- Deliver 3 “Advocacy Awareness Training” sessions for autism service providers.
- Deliver 4 “Autism and Advocacy Dilemmas” workshops for advocates.
- Provide relevant information through the dissemination on newsletters and e-bulletins.
- Build links with advocacy organisations and ASD Service providers to ensure open and effective communication.

Outcomes for people with ASD:

- Improved access to independent advocacy.
- Increased awareness about the value of independent advocacy.
- Advocacy organisations are better equipped to support people with ASD and appropriately meet their needs.

Outcomes for local authorities and health boards:

- Increased awareness of the role and value of independent advocacy amongst ASD service providers.
- Potential to save resources in the long run by ensuring people with Autistic Spectrum Disorders get their needs met early (before crisis situations).
- Advocacy organisations that are better equipped to meet the needs of people with ASD.

Project 8: Develop 2 new awards: Professional Development Awards (PDAs)

Aims of project:

To equip professionals/employees/carers/parents/volunteers to meet needs of those with ASD, gain skills, improve standards of practice and assist employees to progress within specialism.

Delivery of project:

The national Autism Spectrum Disorder Reference Group identified the need for awards to recognise the specialist skill involved in working with people with autism spectrum disorders.

The Scottish Social Services Council with a working group appointed a consultant to develop 2 new awards for SQA Care Scotland 2004/5. The awards were completed at the end of 2005 and promoted from early 2006, by Care Scotland, via centres and at Falkirk (Airth Castle) event.

Developed Certificate in Supporting Individuals with Autistic Spectrum Disorders (SCQF level 7) and Certificate in Managing the Support of Individuals with Autistic Spectrum Disorders (SCQF level 8).

Outcomes for people with ASD:

The outcomes reflect the aims above. There is an increase in the number of people with the right skills and knowledge to work with people with ASD, improved referrals between services, improved information sharing and involvement of support services like advocacy.

Outcomes for local authorities and health boards:

Retention of skilled staff, improved referrals, increased information exchange and good practice.

Project 9: Transitions into Adulthood

Aims of project:

The aim of the project is to prepare young people approaching statutory school leaving age for the transition from school to other avenues of education, training or employment. There are two elements to the project, inschool support and out-of-school support. These two parts complement each other so that participants who are able to access both elements are able to put the theoretical skills learned in the classroom into practice in the out-of-school social groups.

Delivery of project (ie, who, where, how, costs):

- Two project officers (one for in-school support and one for social groups)
- Glasgow City; East and West Dunbartonshire; South Lanarkshire.
- The in-school support is delivered to small groups of young people (2-6 pupils) who attend mainstream schools or Communication Disorder Units attached to mainstream schools. The type and level of support is dependent on the needs of each group but tends to follow a format of one school period per week (55 minutes). The topics that the Transitions project delivers are broken down into modules which last between 6 and 12 weeks.
- The Out of School support is delivered to small groups of young people receiving in-school support. The groups tend to follow a format of one social evening (2 hours) per fortnight. The social groups incorporate a range of different activities aimed at developing skills covered during the in-school sessions, but also allowing the young people to take part in peer appropriate activities outside the family environment.
- Cost: £71K per annum

Outcomes for people with ASD:

To be able to plan for a successful transition to post-school opportunities. To apply for college/university place and acclimatise to new environment prior to start of course. To develop independent travel skills. To develop money management skill. In general, to equip young people with a range of skills that are essential for a successful transition towards college, university, employment or other future life opportunities.

Outcomes for local authorities and health boards:

- Access to experienced transitions staff
- Assistance re developing transitions protocols
- Encourages multi-agency working

Project 10: Post-Diagnostic Information Project (Next Steps)

Aims of project:

To develop an information resource for parents and educationalists that incorporates both generic autism information along with directories of autism services available locally within all 32 Scottish local authorities.

Delivery of project (ie, who, where, how, costs):

- One project officer (plus line management)
- Based in NAS Scotland office but liaising with all 32 local authorities
- To compile the generic autism information via research (especially regarding the NAS information base)
- To liaise with key local authority personnel in social work, education and health in order to compile the local service information
- Cost: £50K per annum (three year project)

Outcomes for people with ASD:

- Access to comprehensive generic autism information resource
- Access to information regarding availability of local autism services in 32 local authorities
- Ready access to information relieves the stress of searching for accurate autism information and information on services that are relevant to parents and carers on a local level

Outcomes for local authorities and health boards:

- Ownership of a significant autism information resource
- The ability to provide relevant generic and local information to parents and carers at, or shortly after, the point of diagnosis
- By accessing this information resource, local professionals become more informed and better skilled regarding their input to parents and carers
- Encourages multi-agency working

Project 11: Autism Spectrum Disorder (ASD) Assessment Project, NHS Argyll and Clyde, 2006

Aims of project:

To address the question as to whether or not waiting times for assessment of ASD can be reduced in a rural/urban area, by establishing local multi-agency ASD assessment teams (AATs). The *research hypothesis* of the pilot was that following an initial training input, local multi-agency assessment teams would perform as reliable and valid ASD assessments as a specialised team. This could therefore be one possible method of minimising current, increasing waiting lists for ASD assessment.

Delivery of project:

- Four local AATs (in Argyll and Bute and East Renfrewshire) were trained by members of the specialised AAT (based at Vale of Leven Hospital) in ASD assessment, including the use of ADOS, an ASD-specific assessment instrument.
- The 4 local AATs assessed 39 cases of suspected ASD in the 0-18 year old range, during February-August, 2006. The specialised AAT assessed the same cases in parallel, each team being blinded to the other's activity and findings.
- Quantitative data was gathered and the local AATs were also evaluated as regards their qualitative experience of the project.

Outcomes for people with ASD:

- 38 children and young people were assessed over 7.5 months (M31>F7; Age 44m to 176m). By comparison, during 2002-04, the specialised AAT (SAAT) assessed 57 'likely ASD' patients (ie the project assessed 38 cases in 7.5m (5 cases per month), compared with the SAAT assessing 57 cases in 24 months (2.4 cases per month); ie the pilot process appears to be over 100% more efficient.
- Local AATs took only 10 weeks, during the assessment phase of project, to reach diagnostic consensus with the SAAT.
- Diagnostic consensus between speciality and locality AATs can be reached after approximately 14 weeks (1 week training, 13 weeks mentoring) and using local AATs can substantially reduce waiting lists times, with minimal extra resources.

Outcomes for local authorities and health boards:

- Multi-agency working in local AATs can be achieved with minimal disruption to services, with minimal training, equipment and time resource.
- Waiting times for ASD assessment can be significantly reduced by means of creating local AATs within a context of having a specialised AAT for training, mentoring and peer supervision (CPD) on completion of a training and mentoring phase for the local teams.
- Local authorities and health boards who have significant ASD assessment waiting lists should investigate the applicability of this model to their area and implement similar initiatives so as to reduce ASD lists.

Project 12: Retrospective case note review of children with autism spectrum disorders: utilising clinical information to inform diagnostic boundaries and assessment

Aims of project:

1. To identify subgroups within children with Autism Spectrum Disorder (ASD)
2. To explore relationship between developmental history and symptom profile
3. To determine if case-note analysis can provide a robust baseline for a future follow up study of children with autism

Delivery of project:

A retrospective consecutive case note study of 280 children aged from three to eleven years was undertaken by the Scottish Centre for Autism, Royal Hospital for Sick Children, Glasgow. Items of information relating to reported and observed behaviours were identified and defined in a glossary. Latent class analysis was used to identify subgroups based on observed items of behaviour and these essentially reproduced the diagnostic categories. Information from the parent interview was sorted into three subscales. Summed scores on each subscale were significantly different for each of the diagnostic categories, but there was a large overlap. Case notes provided a rich account of symptomatology and history but lacked standard measurement of global functioning or IQ. While these were not necessary for diagnosis, this may limit the usefulness of the dataset for a future follow up study of developmental trajectories in ASD.

Outcomes for people with ASD:

The reliability of a specialist diagnostic service which does not rely on standardised instruments but instead uses a naturalistic play based assessment is demonstrated and results indicate the importance of both detailed parental account and direct observation of the child. Distinctive patterns of symptomatology between Asperger syndrome and autism were demonstrated. A cluster analysis of all those with Asperger Syndrome produced three clusters and description of these may alert clinicians to recognising more subtle presentations of ASD.

Outcomes for local authorities and health boards:

A specialist national second opinion service for ASD has a key role in identifying cases complicated by subtle or unusual presentation or comorbidity. While autism is everyone's business, it is likely that there will continue to be a need for tier four services for ASD.

Project 13: : Enhancement of Autism Services Directory on the internet

Aims of project:

The aim of the project is to develop and extend the information on services in Scotland for people with autism spectrum disorders and their parents/carers. The National Autistic Society and the Scottish Autism Service Network are linked and work collaboratively in this project to share information about services which is then validated, organised and published in the National Autistic Society's web-based database the Autism Services Directory, formerly known as PARIS, (the Public Autism Resource Information Service)
<http://www.info.autism.org.uk>

Delivery of project:

- One Autism Information Officer
- The postholder is an information professional who gathers, organises and maintains information in the Autism Services Directory relating to services relevant to people with autism.
- The postholder works in co-operation with the Scottish Autism Service Network (SASN), sourcing information from contacts they have, and ensuring information about services suitable for the Directory is validated and published. She has been involved in promoting information-sharing amongst professionals involved in autistic spectrum disorders.
- From October 2006 to March 2007 the details of 314 services have been updated. 143 new services have been validated and added to the Directory.

Outcomes for people with ASD and their families:

- Improved awareness of, and access to, up to date information about autism specific services, training and support groups in Scotland.
- A greater number of autism specific services included on the Directory.

Outcomes for local authorities and health boards:

- Improved awareness of, and access to, up to date information about autism specific services, training and support groups in Scotland.
- A greater number of autism specific services included on the Directory.

ANNEX G: Useful references and contacts

References

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MacKay, T. and Dunlop, A-W. (2004) *The development of a national training framework for autistic spectrum disorders*, Glasgow: NAS

National Autistic Society (2004) *Autism: improving understanding. A review of work undertaken by the National Autistic Society to provide basic autism awareness training to social work staff under section 9 of the Social Work (Scotland) Act 1968*, London: NAS

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Her Majesty's Inspectorate of Education (2006) *Education for pupils with autism spectrum disorder*, Edinburgh: HMIE

Batten, A. and Daly, J. (2006) *Make school make sense. Autism and education in Scotland: the reality for families today*, London: NAS

Powell A. (2002) *Taking Responsibility. Good Practice Guidelines for Adults with Asperger Syndrome*. National Autistic Society. London.

For housing support services, (ASD related services, if any, probably in "learning disabilities" category) access www.thehousekey.org.

Information on National Occupational Standards (NOS) for contracting, commissioning and procurement (CPC) for leadership and management for care (LMC) and sensory services (SS) are available at www.sssc.uk.com.

SSSC monthly eBulletin service has up-to-date news from SSSC and the social services sector.

Contact enquiries@SSSC.uk.com.

Contacts

Autism Initiatives
 Number 6
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 Edinburgh EH3 7JA
 T: 0131 240 2370
 Contact: Richard Ibbotson, Director

National Autistic Society Scotland
 Central Chambers, 1st Floor
 109 Hope Street
 Glasgow G2 6LL
 T: 0141 221 8090
 F: 0141 221 8118
 E:Scotland@nas.org.uk

Scottish Society for Autism
 Hilton House
 Alloa Business Park
 Whins Road
 Alloa FK10 3SA
 T: 01259 720044
 Contact: John Macdonald, Chief Executive

Scottish Autism Services Network
 University of Strathclyde
 Room D002, David Stow Building
 76 Southbrae Drive
 Glasgow G13 1PP
 T: 0141 950 3072
www.scottishautismnetwork.org.uk

Autism Resource Centre
 Unit 8b
 The Quadrangle
 59 Ruckhill Street
 Maryhill G20 9PX
 0141 201 6247
 Contact: Nigel Rooke, Director

Supporting People Enabling Unit – <http://www.ccpScotland.org/spunit/>
 Information on Scottish Government policies, contracts, housing support service delivery issues and registration/workforce development activities.

Local learning networks – www.learningnetworks.org.uk
 Four established in Scotland to assist social services and workforce development activities.

ANNEX H: Ideas for the whole system

This appendix sets out suggestions of actions that should be taken across a local authority to improve the opportunities and quality of life for people with autism spectrum disorder. The headings for each section also indicate who should be leading a review on that topic.

The action blocks are interdependent and of equal value. It is likely that each group leading a review would identify further actions relevant to their own local services.

There are a large number of suggestions made in these blocks. There may be too many to attempt at once. However this is intended as a resource to enable you to identify and prioritise the key issues that need to be addressed in your area.

It is clear from the prevalence figures in Appendix E, and the numbers known to community care services, that meeting the needs of the population of people with autism spectrum disorders has to be considered across all community services.

The action blocks and corresponding references have also been included as stand alone pages, in the pocket at the back of this document. These can be distributed to the relevant areas for their information and to inform the development of action plans.

Health Services

<p>Health services provided within the current legislative framework and in a way which upholds the principles of inclusion and respect, and conforms to professional standards</p>		<p>Children and adults with ASD and their family carers are involved in the planning and delivery of health services through self-representation and independent advocacy</p>	<p>Every effort is put into finding ways of assisting people in assessment and treatment beds or out of area placements to connect with and return to their community</p>
<p>Physical activity and healthy eating, smoking cessation and sensible drinking initiatives are accessible and connected so that people with ASD receive the messages and the opportunities</p>		<p>Health services identify and treat the conditions that are often associated with ASD appropriately</p>	<p>Primary care staff make use of NHS Education Scotland ASD learning resource for primary care practitioners www.nes.scot.nhs.uk/ASD</p>
<p>There is continued improvement in the quality of patient care for people with ASD through delivery of the NHS QIS learning disability quality indicators</p>	<p>At times when people are at risk of exclusion (i.e. hospital admission) special efforts are made to support the person to retain their connections. Service arrangements minimise disruption to ordinary living</p>	<p>Staff are appropriately trained to build the capacity of health workers to respond positively to people with ASD</p>	<p>Information about healthcare is available in accessible formats for everyone including people with ASD</p>
<p>A wide range of healthy living opportunities are available and in use, including options for people who are very unfit or lacking in confidence</p>	<p>A coordinated approach to finding out and applying what works for health staff supporting people with ASD</p>	<p>Buildings are pleasant, safe, accessible and well signed</p>	<p>GPs, dentists and other health professionals have the appropriate and relevant information and training to support people with ASD</p>

Additional resources on health

For information about work that is promoting wellbeing in Scotland, see www.wellscotland.info

Better Health Better Care, Edinburgh, Scottish Government (2007)

The same as you? review of services for people with learning disabilities, Scottish Executive (2000)

Autistic Spectrum Disorders Needs Assessment Report, Public Health Institute of Scotland (2001)

Sign Guidelines – Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders, NHS Quality Improvement Scotland (2007)

Independent Advocacy: A Guide for Commissioners, Scottish Executive (2001)

Health Needs Assessment Report – People with Learning Disabilities in Scotland, NHS Health Scotland (2004)

Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities or mental health problems, Disability Rights Commission (2006)

Promoting Health, Supporting Inclusion: The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities, Scottish Executive (2002)

Autism Spectrum Disorders: Identification, Education and Treatment, edited by Dianne Zager (2004) ISBN 080584578X

You can make a difference: Improving hospital services for disabled people, Equality & Human Rights Commission

The Pathway to Care for children with autism spectrum disorders (aged 0 to 12 years), C Brogan, National Autistic Society (2001)

MRC Review of Autism Research Epidemiology and Causes, MRC (2001)

Social Care Services



Additional resources on social care

For information about work that is promoting wellbeing in Scotland, see www.wellscotland.info

Better Health Better Care, Scottish Government (2007)

The same as you? review of services for people with learning disabilities, Scottish Executive (2000)

7 Step Individual Commissioning Pathway toolkit, Joint Improvement Team
<http://www.jitscotland.org.uk/knowledge-bank/toolkits/improving.html>

Relentless Optimism – Creative Commissioning for Personalised Care, Report of a seminar held by the Commission for Social Care Inspection on 18 May 2006. Commission for Social Care Inspection September 2006

Independent Advocacy: A Guide for Commissioners Scottish Executive (2001)

On the Borderline: People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings (Assessment of need and care planning) Scottish Executive (2004)

Housing



Additional resources on housing

Chartered Institute of Housing (1999) *Housing and services for people with support needs – good practice briefing*, Coventry: Chartered Institute of Housing

Harker, M. and King, N. (2004) *Tomorrow's big problem: housing options for people with autism. A guide for service commissioners, providers and families*, National Autistic Society
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Ignored or Ineligible? *The reality for adults with autism spectrum disorders*, NAS: London, 2001.

For housing support services access www.thehousekey.org.

On the Borderline: People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings (Assessment of need and care planning) Scottish Executive (2004)

Culture, Leisure and Recreation



Additional resources on cultural, leisure and recreational activities

Orsmond Gael, Krauss Marty, Seltzer Marsha (2004) *Peer relationships and social and recreational activities among adolescents and adults with autism*, Journal of Autism and Developmental Disorders, Vol 34, Number 3 – June 2004

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