The importance of planning for life for people with autistic spectrum disorders
Introduction

Autistic spectrum disorders
Autistic spectrum disorders (ASD) are social and communication disorders that impact on the ability of an individual to function in society. At all life stages, individuals with ASD will struggle to comprehend what is expected of them in social situations – whether at school, in peer relationships or in the workplace. Autism has no cure, and the vast majority of people with ASD will continue to struggle with social interaction throughout their lives.

Growing up
Writing in 1998, Patricia Howlin stated that ‘few families know what to expect as their children grow older. Many parents dread the onset of adolescence, fearing that this is certain to bring increased difficulties.’

To counter this fear, agencies need to work together with families to plan a positive future for people with ASD, covering aspects of life as varied as education and lifelong learning, relationships, sexuality, careers, housing options and living independently.

Planning for life - difficulties
To highlight the lifelong difficulties experienced by people with ASD and those who care for them, The National Autistic Society has chosen the theme of ‘planning for life’ for Autism Awareness Week 2004. This report pulls together evidence on current outcomes for people with ASD, using real life examples to illustrate the particular difficulties in planning for life created by the social and communication impairments associated with autism. While a statutory framework exists in all the UK nations for transition planning after compulsory education, its implementation is at best patchy.

Reality
An NAS survey in 2001 found that only 53% of people with ASD who should have had a transition plan had some form of plan in place, and only 16% had their identified needs met in full.2 Evidence collected from the NAS help! parent support programme suggests that more than half of parents of 11-16 year olds are not aware of the 14+ transition review and what that review should mean for their child. Where reviews had taken place, adult and children’s social services officers frequently failed to attend.

An NAS survey in 2001 found that the local health authority was involved in only 11% of transition plans, with social services involved in just a third.3 In another survey of 272 young people with disabilities, for those with transitions plans there was a ‘stark mismatch’ between the topics that families wanted to cover and those addressed by the professionals involved.4 The involvement of parents and young people themselves in the planning process was also far from satisfactory across the sample.

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No adult statutory requirements
Moreover, the statutory entitlements that are at least theoretically available to children and young people with ASD disappear in adulthood, with entitlement to services typically dependent on an individual’s presenting needs. For adults there is no equivalent of the raft of current policy initiatives designed to join up children’s services (see pp 7-8 Policy developments).

Lack of support
Even more problematic is the continuing reluctance of many local authorities to reorganise their administrative structures to better support people with ASD. People with ASD continue to fall through the gaps between mental health and learning disability services; an NAS survey found that 66% of adults with ASD who had received a community care assessment had no lead agency responsible for planning their care.5

Misconception reinforced
The recent Fair Access to Care Services guidelines for England reinforce the misconception that the support needs of people with ASD pose a minimal threat to their ability to live independently, through a case study featuring a person with Asperger syndrome under the heading ‘low risks to independence’.6

Person-centred planning essential
Despite this, the importance of person-centred planning for disabled people is enshrined in recent policy development across the UK.7 Ensuring that serious consideration is given to every aspect of a person’s future life at the earliest possible age is particularly important when an ASD is involved. This is because positive outcomes for adults with ASD are likely to require involvement from many different agencies, all of whom will need to be aware of a person’s likely future needs.

In addition, as recent good practice guidelines state, people with ASD ‘are often at their most vulnerable to mental health difficulties when they are insufficiently prepared for change.’8 A new report on housing options for people with ASD reinforces the message that ‘we should be planning ahead for the next stages in life – a lifetime plan including where and how people will live’.9

However, all too often, adults with ASD only appear on the services ‘radar’ when they reach crisis point. With no opportunity to plan effective services, families are left in the dark about support options that may be available, and left with stark choices – for instance, between an inappropriate residential service and keeping their adult child in the family home.

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Current outcomes
Current outcomes for many people with an ASD are poor. Autistic spectrum disorders have only been widely recognised relatively recently, and Asperger syndrome was only entered into diagnostic manuals in 1994. Society’s awareness of autism is still fairly low, particularly of adults with autism, and the nature of the disability is extremely complex. This makes genuine ‘inclusion’ hard to achieve as adjustments from others are often required if people with ASD are to be able to participate fully in society. The following section identifies outcomes for children and adults with ASD at different life stages, and examines how failures in statutory planning mechanisms impact on carers.

Diagnosis
Diagnosis, although improving in many areas, remains far from perfect. Many children with ASD are only diagnosed once at school age, and adults who suspect that they are on the autistic spectrum struggle to access specialists with expertise in autism. A study in 1999 identified the average age at diagnosis of children with classic autism as 5.5 and 11 for children with Asperger syndrome.10

Awareness of autism amongst primary health professionals remains a barrier to diagnosis; the NAS found that four in ten GPs do not have enough information about autism to make an informed assessment.11 Services, too, in many areas continue to be diagnosis-led rather than needs-led, despite Government guidance to the contrary. The later a child’s needs are identified, the less time is available for effective future planning.

Exclusion
Research by the NAS found that 21% of children with autism have been excluded from school at some time, the most common reason given being that the school was unable to cope with the child.12 Children with ASD therefore contribute heavily to the 2001 Social Exclusion Unit statistic that children with special educational needs (SEN) are seven times more likely to be excluded from school than other children.

In Scotland, figures for school exclusions in 2002-2003 found that, compared with the overall school population, ‘pupils entitled to free school meals, pupils with a Record of Needs, or pupils looked after by the local authority, all had higher exclusion rates than other pupils’.13 A child excluded from school and the consequent interruption in learning will inevitably see the child face disruption to ongoing planning processes.

Living at home
A survey by the NAS found that 49% of adults with ASD are still living at home with their parents.14 Although 70% of parents felt that their son or daughter would be unable to live independently without support, 65% of these adults had not had a community care assessment and are therefore unlikely to be known to the statutory agencies that should be supporting them.

Employment statistics
Only 6% of adults with an autistic spectrum disorder are in full-time paid employment, and more able adults cite employment as the biggest single issue or barrier facing them.15 However, many people with ASD are capable of work if they receive sufficient support. An independent evaluation of the NAS Prospects supported employment consultancy concluded that: ‘Failure to transfer the skills acquired through education to the workplace is a clear waste of resources. Continuing and unnecessary reliance

on state benefits is also extremely expensive, as are the costs of treating psychiatric disorders relating to long term unemployment'.

Criminal justice system
People with learning disabilities are over-represented amongst victims of crime. In 1999, Mencap reported that 21% of the people with learning disabilities whom they surveyed had been subject to physical attacks in the past year.

Although research in this field is limited, naivety and a lack of social understanding are likely to increase the vulnerability of people with ASD to crime. Those who do come forward as victims or witnesses are often confused and distressed by the criminal justice system. Exposure to different social situations should be an important part of life planning processes for people with ASD.

There is no data on the proportion of people with autism in the prison population. The NAS is aware of reports from families of distressing encounters with the police where an individual’s condition has not been recognised, or where their needs are not properly understood in prison. Without an informed and flexible approach to management custodial sentences can be highly punitive and completely unproductive for a person with autism, and it is important that their increased vulnerability to abuse is recognised.

Advocacy
Advocacy services are a good example of cost-effective, low-level support that can facilitate independent living. Access to an independent advocate should be built into planning processes. Yet a survey by the NAS found that many adults with ASD wanted to access independent advocacy, but few had been able to do so.

Only 11% of carers stated that the adult they cared for had used an independent advocate, and this fell to only 6% for households with an income below £12,000. Another survey of a sample of 55 advocacy services found only one service that listed people with ASD as a primary client group.

Carers
The lack of effective planning for adulthood places an ongoing burden on carers of people with ASD. Over 50% of NAS carer members surveyed in 2002 were not aware of their entitlement to a carers assessment, and only 22% had ever received any support from social services in their caring role.

Carers faced major barriers to finding and sustaining employment, the most significant being the lack of alternative appropriate care facilities. Many carers report frustration with being forced to act as a keyworker, co-ordinating support from different agencies for the child or adult in their care.

Planning vacuum as families age
As families grow older, the impact on both carers and disabled people of the planning vacuum becomes even more significant. Mencap found recently that only half of local authorities are aware of how many older parents are living in their area. Only one in four local authorities are investing sufficient time or money into meeting their needs or have planned alternative housing provision before parents die or become too frail to care for their son or daughter. Mencap estimates that statutory agencies will take 30 years to deal with the increasing backlog of provision. The complexity of these cases will be increased when the adult in question has an autistic spectrum disorder in addition to a learning disability.

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All the people* featured here have experienced significant difficulties in their everyday lives that could have been avoided with effective multi-agency planning.

**Rodney - 15**
Rodney comes from a large family, and his brothers and sisters all have communication disorders. Rodney has a diagnosis of Kanner autism. His mum had to fight for Rodney to get a transition plan when he was 14. The Connexions advisor was shocked that he wanted to stay in the school into sixth form, and was unable to recommend appropriate support for Rodney in either further education or employment. The befrienders provided by social services to support Rodney and his brothers are fading away as the boys get older. Rodney’s mum is very worried about whether Rodney will be able to find a job. Although he enjoyed his work experience, he found that travelling on public transport was extremely stressful.

**Lucy - 23**
Lucy was diagnosed with Asperger syndrome at 16, just before she sat her GCSEs. Her careers advisor had never heard of autism and didn’t know anything about the condition. She suggested that Lucy’s mum should ring local further education colleges to find suitable support and a life skills course. Lucy’s mum did eventually find a suitable college after phoning literally all the local colleges in the Yellow Pages. The college she identified had a lecturer who was sympathetic to Lucy’s diagnosis, rather than being a college with expertise in supporting students with ASD. Lucy and her mum are angry that there was no advice available at this critical stage of Lucy’s life; they felt isolated and had to find out all the possible opportunities themselves.

**Anna - 28**
Anna got a diagnosis of Asperger syndrome at 24. She hoped that this would give the mental health services she was in contact with a better understanding of her difficulties but unfortunately this was not the case. Anna excelled academically at school, but was the victim of emotional and physical bullying. Aside from one session with an educational psychologist, she received no additional support. No planning was put into Anna’s transition to university. She was criticised by her director of studies for being a loner, and although she joined a few groups she could not see how social activity might arise from this.

Her academic performance suffered, as she was not able to understand the style or method of answering the type of questions set and was not able to plan her work adequately. Anna became pregnant unintentionally during her final year at university due to her lack of awareness about safe contraceptives and lack of knowledge about how to encourage men to use contraceptives.

Following the birth of her daughter, she experienced problems in organising herself, in having social contact with other parents and in adapting to frequent changes in her daughter’s behaviour. After finally getting her diagnosis, Anna moved home and started an MSc course where staff and students are more tolerant and friendly. However, she still receives no support from services either in planning her life or in her role as a parent.

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* All names in these examples have been changed to preserve individuals’ anonymity.
**Lee - 19**

Lee was diagnosed with an autistic spectrum disorder relatively early at six. His Local Education Authority responded swiftly to his needs and issued a statement, firstly naming a mainstream school with 1:1 support, and later a boarding special school for pupils with Asperger syndrome where Lee remained until he was 18. Throughout his childhood Lee’s development has been aided by specialist support, but he is now not considered ‘disabled’ enough for support as an adult from his Community Learning Disability Team, and has been referred to a general social services team with no autism-specific expertise. The planned services put in place during his childhood are unravelling in adulthood.

**Martin - 30**

Martin is now 30. At 15, he experienced problems at school and was referred to his local authority Mental Health Team. He did not receive a diagnosis of autism until he was 27. At one stage, Martin was sectioned in a secure hospital, which heightened his anxiety and depression. He was desperate to leave and after six months was finally released into the care of his parents. Martin accesses support from an autism-specific service for three days a week and lives in his own flat. He remains angry at his treatment in a secure unit but is now looking for a befriender who will help him participate in his interests: mountain-biking, walking and running. No inter-agency planning has ever helped support Martin.

**Dave - 34**

Dave is extremely academically able. He has three A-levels, a law degree and was able to pass the Law Society’s Final Examination for Solicitors. Between 1993 and 1999, Dave struggled to sustain employment, with many temporary jobs that ended when he no longer found himself able to work with his colleagues. Dave was diagnosed with Asperger syndrome in 1999. He told his line manager of his diagnosis, and his line manager implemented a series of weekly three-way meetings involving the organisation’s Occupational Health Officer, which Dave found extremely supportive. However, Dave changed jobs within the organisation and found that, although his new line manager knew of his diagnosis, she did not support him and shouted at him in front of colleagues. Dave eventually resigned, but the involvement of his union representative led to his re-instatement, although no disciplinary action was taken against his line manager.

**John - 50s**

John was diagnosed with high-functioning autism in his late 40s. In the past, John had regularly experienced difficulties in holding down a job. Having told his Disability Employment Advisor of his diagnosis, John was referred to the NAS Prospects supported employment service. During a four-week Personal Development programme, John was taught coping skills to manage his difficulties with reading body language, particularly in an interview context. With the support of his DEA and a Prospects support worker, John found a permanent position as a filing clerk with a firm of building consultants.
Policy developments

Transition planning
The transition planning framework for England and Wales was established by the Education Act 1996, as amended by the Special Educational Needs and Disability Act 2001. The SEN Code of Practice (sections 9:51 to 9:67) makes clear that there is a statutory obligation to prepare a multi-agency transition plan from Year 9 for pupils with statements. The Connexions Service is responsible for overseeing the delivery of the Transition Plan, and the Connexions Personal Advisor should co-ordinate its delivery.

However, for those young people with Special Educational Needs but without a statement there is no statutory planning duty. As the Government’s SEN Strategy, Removing Barriers to Achievement, promotes a reduced statementing approach, it is likely that fewer young people with ASD in England and Wales will have a statutory entitlement to transition planning. In response, Connexions has interpreted its duty to prepare a needs and provision assessment under Section 140 of the Learning and Skills Act as applying to all young people with SEN. This will however place more pressure on Connexions, a universal service, to co-ordinate appropriate specialist support without the ability to insist that different agencies, in particular adult social services, should co-operate.

A parallel transition planning process exists for all young people who qualify as disabled under the Disabled Persons Act 1986. Education departments are required to notify social services of all young people aged 13 - 14 who are considered disabled. Social services are then required to co-ordinate a multi-agency assessment of the young person, which must be completed no later than three months before the young person is leaving school or college.22

This assessment should link to both the transition planning process and care planning for adults under the NHS and Community Care Act 1990. However, the experience of many families is that these processes are not integrated, that organisational structures prevent the transfer of important information and that eligibility criteria for adult social services exclude many people with ASD. The need for better multi-agency co-ordination of transition planning is recognised in the Children’s Green Paper Every Child Matters, the SEN Strategy Removing Barriers to Achievement and the forthcoming Children’s National Service Framework (NSF). The SEN Strategy commits the Department for Education and Skills (DfES) to producing national transition standards, and promises that the DfES will work with Connexions and the Learning and Skills Council to improve the quality of transition planning. Similarly, the Children’s NSF disabled children’s module has a transition theme. This is committed to ensuring that ‘high quality transition services should be delivered in a multi-agency context’.23

Scotland
For Scotland, under the Education (Scotland) Act 1980, all children and young people with a Record of Needs have their transition planned under the mandatory Future Needs Assessment which should take place two years before the young person leaves school. For children with special educational needs but without a Record of Needs, there is no compulsory mechanism for transition planning. As the Government’s SEN Strategy, Removing Barriers to Achievement, promotes a reduced statementing approach, it is likely that fewer young people with ASD in England and Wales will have a statutory entitlement to transition planning. In response, Connexions has interpreted its duty to prepare a needs and provision assessment under Section 140 of the Learning and Skills Act as applying to all young people with SEN. This will however place more pressure on Connexions, a universal service, to co-ordinate appropriate specialist support without the ability to insist that different agencies, in particular adult social services, should co-operate. A parallel transition planning process exists for all young people who qualify as disabled under the Disabled Persons Act 1986. Education departments are required to notify social services of all young people aged 13 - 14 who are considered disabled. Social services are then required to co-ordinate a multi-agency assessment of the young person, which must be completed no later than three months before the young person is leaving school or college.22

As well as this, the Scottish Executive will be publishing guidelines on supporting students with additional support needs in Further Education.24 The guidelines aim to bring various policy and

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23 Taken from Department of Health website http://dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformation/Articles/en?CONTENT_ID=4049345&chk=ngSysyJ
significant protection for people with ASD across the UK. The focus on adjustments to policies, procedures and practices in the DDA reflects the attitudinal rather than physical barriers to inclusion that primarily affect people with ASD. Yet autism is a hidden disability, and discrimination against people with an ASD may often appear reasonable – for instance, in the case of a child with autism who is excluded from school after hitting his teacher.

A key barrier to effective planning for adults with ASD is the lack of a comprehensive legal framework for decision-making in England and Wales. The absence of legislation has meant a variation in practice in the treatment of adults with ASD who are thought to be unable to make decisions for themselves. At one extreme, the NAS is aware of cases where important medical treatment has been postponed because no party was thought to have authority to give consent. Alternatively, adults with Asperger syndrome are currently vulnerable to assumptions from carers and professionals about their inability to decide for themselves. The Government has promised to introduce mental capacity legislation to tighten up the law, based on the principle of maximum autonomy for people whose ability to make decisions is impaired.

The All-Party Parliamentary Group on Autism (APPGA) Manifesto sets out 15 principles and objectives that form a ten-year plan for autism. The Manifesto states that ‘the APPGA believes that agencies have a responsibility to work together to make a reality of social inclusion and person-centred planning’ for people with ASD. The Manifesto has now been endorsed by over 200 parliamentarians from all political parties, and this Autism Awareness Week will see the APPGA reporting on progress towards these objectives one year on from its launch.

since the Disabled Persons Act 1986 and the NHS and Community Care Act 1990 are UK-wide, the transition planning process should be similar in Scotland to that of England and Wales. Nevertheless, the transition from one service to another is still problematic which is why the Public Health Institute of Scotland recommended that there should be ‘systems and funding mechanisms that ease the transition between services for individuals with ASD’. The Same As You? White Paper recommends that anyone with a learning disability, including people with ASD, should be able to have a ‘personal life plan’. The plan should detail how the person, their family and professionals should work together in order to help that person lead a fuller life. This would include assessments for community care, health, children’s services and transition from school to post-school life. Local area co-ordinators whose role is to support people with learning disabilities in the community will help people devise an appropriate plan. Information on take-up of personal life plans and how well they are working is unavailable at the moment as local co-ordinators are still being appointed across Scotland.

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Good practice needed

This report shows the costs of failing to help people with ASD plan their future effectively are felt by individuals with ASD, their carers and society in general. All people with ASD should have the right to ongoing support to help them achieve their full potential and live as independently as possible. To make this happen, we need to mainstream local examples of good practice, such as the project funded by the Greater Glasgow Health Board to identify the current and future service needs of adolescents and young adults with ASD, an essential prerequisite for effective life planning at an individual level.30 Programmes that address the social deficits inherent in autism will improve the opportunities in life for people with diagnoses on the autistic spectrum. More fundamentally, Government and the devolved administrations of the UK have a responsibility to ensure that key professional groups such as teachers, police officers and medical professionals are sufficiently informed about autism to meet the needs of people with ASD.

Too often, effective planning currently only takes place when parents act as advocates for young people with ASD. This perpetuates inequalities that begin to emerge as soon as a child gets a diagnosis, when the level of support they receive frequently depends not on their needs, but on the ability of their parents to ‘fight’ local authorities who feel compelled to protect their budgets. Families must have support from all relevant agencies to begin the daunting task of planning a future with their child with ASD at the earliest possible age.

When parents were asked what changes could be made to transition planning mechanisms, Ward et al concluded that ‘many of the changes they (parents) proposed were precisely what the statutory guidance says should happen already, or what would normally constitute good practice.’30 Young people with learning disabilities are now supposed to be a priority for both person-centred planning and health action planning.31 To ensure that all agencies understand the needs of people with ASD and adhere to their responsibilities, we recommend the following:

Young people

- Connexions, Careers Scotland and all other relevant local agencies should be given training in an understanding of autism, with sufficient staff and financial resources to support planning for all people with ASD in their area.

- In England and Wales, Connexions regional partnerships should identify a second tier of specialist advisors with expertise in ASD who can support individual Personal Advisors in their ASD casework.

- Keyworkers established by new legislation and guidance should support Personal Advisors to co-ordinate transition planning.

- Schools should develop a curriculum for transition, identifying essential life skills that will help young people with ASD plan future choices.

- Local agencies should ensure that families and people with ASD are aware of their rights to engage in planning processes, including transition planning.

- Local authorities in England and Wales should establish transition planning groups for ASD, ensuring effective transition planning for young people on the autistic spectrum without a Statement.

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Local authorities in Scotland should establish transition planning groups for ASD, ensuring effective transition planning for young people with ASD without a Record of Needs. This will prepare authorities for new legislation which will open up transition planning to all young people with additional support needs.

Transition reviews should consider the full range of needs experienced by young people with ASD, including identity needs, social relationship needs, social presentation needs and self care needs.\(^{32}\)

Inspection agencies, such as the new Commission for Social Care Inspection in England, should investigate why social services departments do not participate effectively in transition reviews.

### Adult services

- Psychiatrists should ensure that they are aware of the diagnostic indicators of ASD so that they can refer adult patients presenting with mental health problems who may have an underlying ASD for specialist assessment.

- Department of Health should revise the *Fair Access to Care Services* guidelines on eligibility for social care services in England, removing the case study that depicts Asperger syndrome as posing a low risk to independence.

- Colleges and universities should establish effective links with local schools to anticipate potential applications from young people with ASD who have sufficient academic ability to join the institution but may struggle with the social dimensions of their course.

- Colleges and universities should have discrete sections on ASD, and their approach to students with ASD, within their disability policy.

- Local authorities, housing associations and other agencies should collaborate on regional strategies to meet the current and anticipated housing needs of people with ASD.

- Central and devolved funding streams for independent advocacy should prioritise advocacy organisations working with people with ASD who find themselves excluded from the remit of many existing advocacy services.

### General

- All public agencies should receive training in the implications of the *Disability Discrimination Act* for their relationship to people with ASD.

- Local multi-agency databases accessible to children and adult services should be established to track numbers of cases of ASD in a population, identify service need and plan effective services.

- The Scottish Executive should implement the PHIS report recommendation calling for the establishment of a database for people with ASD in Scotland.

- Government should introduce mental capacity legislation for England and Wales to ensure that arrangements can be made for effective decision-making when people with ASD reach the age of 16.

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The National Autistic Society (NAS) was founded in 1962 by a group of parents who were later joined by people with a professional interest in autism. Today, the Society has become the UK's foremost charity for people with autism and Asperger syndrome, and for their parents and carers. The NAS leads national and international initiatives, providing a strong voice for autism. The organisation works in many areas to help people with an autistic spectrum disorder live their lives with as much independence as possible.

The NAS

- runs schools and adult centres
- supports local authorities in the development of their own specialist services
- maintains a library available to parents and researchers by appointment
- publishes a range of books and leaflets
- runs the Autism Helpline for parents and carers and people with autistic spectrum disorders
- organises conferences and training programmes
- offers specialist diagnosis and assessment services
- supports local groups and families around the country
- organises parent workshops
- encourages research into the causes of autism
- offers advice and advocacy for special educational needs
- raises awareness and creates a better understanding of autism
- organises volunteering schemes
- provides information and consultancy to professionals and organisations working in the field of autism
- offers an accreditation programme for autism-specific education and care services
- runs Prospects, a supported employment service, for adults with autistic spectrum disorders
- campaigns to improve services for autism in Westminster, the Scottish Parliament and the Welsh Assembly.