Better Services for People with an Autistic Spectrum Disorder

A Note Clarifying Current Government Policy and Describing Good Practice

16th November 2006

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Policy	Estates
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Document Purpose	For Information	
ROCR Ref:	**Gateway Ref:**	6868
Title	Better Services for People with An Autistic Spectrum Disorder- A Note Clarifying Current Government Policy and Describing Good Practice	
Author	Department of Health	
Publication Date	16th November 2006	
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT PEC Chairs, NHS Trust Board Chairs, Allied Health Professionals, GPs, Communications Leads, Directors of Children's SSs	
Circulation List		
Description	The document clarifies the nature and intent of existing government policy as it relates to adults with an Autistic Spectrum Disorder (ASD). It is intended to encourage people in the social care and health field to develop local agendas for action.	
Cross Ref	Valuing People: A New Strategy for Learning Disability in the 21st Century' White Paper HSC 2001/016: 'Valuing People: A New Strategy for Learning Disability for the 21st Century: Implementation	
Superseded Docs	N/A	
Action Required	N/A	
Timing	**N/A**	
Contact Details	OPD Enquiries (Policy Management Unit) Room 120 Wellington House 133-155 Waterloo Road London SE1 8UG OPDEnquiries@dh.gsi.gov.uk www.valuingpeople.gov.uk/dynamic/valuingpeople2.jsp	
For Recipient's Use		

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1. Introduction

1.1 Purpose of this document

This document clarifies the nature and intent of existing government policy in relation to adults with an Autistic Spectrum Disorder (ASD). It is intended to encourage people in the social care and health field to develop local agendas for action.

It does not develop new policy but explains what existing policies mean for local commissioners and providers in terms of government expectations for the delivery of public services for people with an ASD. In this context, the document describes good practice and identifies what existing policies ask local people to do. Legal and other absolute requirements are described as things people must do. Phrases such as 'need' and 'should' are used to describe action that would result in good practice and the delivery of existing policy.

It is about people aged 16+ who fit the definitions of 'Autism', 'High Functioning Autism' (HFA) and 'Asperger Syndrome' (AS) [1]. It does not cover children because there is work within the Children's National Service Framework (NSF) in the Autism exemplar and in the SEN Action Programme[2], 'Removing Barriers to Achievement' that covers this.

When describing both Asperger Syndrome and Autism together this paper uses the term *Autistic Spectrum Disorder* (ASD). There is a shift away from saying "ASD" to "Autistic Spectrum Conditions", but this is not yet in common use. Definitions of learning disability and mental health are given in appendix 4 because services for these groups often serve people with an ASD.

ASD is only one of many conditions that cross traditional service boundaries, Epilepsy and Cerebral Palsy are two others. This document does not try to make a special case for people with an ASD but aims to redress poor general understanding of the condition, clarify how national policy applies and to make clear what services people with an ASD can expect to have access to, regardless of how services are configured in their local area. Examples of current best practice are given to help local areas with implementation.

This document was jointly commissioned between the National Clinical Director for Mental Health, Louis Appleby, National Director for Learning Disabilities, Rob Greig, and National Clinical Director for Children, Shelia Shribman. It focuses on the six most relevant current adult national policies. There is a lot of consistency between these policies.

This document includes three main sections. The first part of the main document presents a policy wide summary of key themes and actions that need to be taken to meet Government expectations for people with an ASD. The second part (appendix 1) provides more detailed individual policy summaries and interpretation. The third part (appendix 2) provides best practice examples. Policies covered are:

- Fair Access to Care
- Valuing People
- National Service Framework for Mental Health
- Our Health, Our Care, Our Say: a New Direction for Community Services
- Improving the Life Chances of Disabled People
- NSF on Long Term (Neurological) Conditions

Policies for young people in transition are covered in a single, cross cutting, interpretation, called Growing into Adulthood.

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1 „Both people with HFA and AS are affected by the triad of impairments common to all people with autism. Both groups are likely to be of average or above average intelligence. The debate as to whether we need two diagnostic terms is ongoing. However, there may be features such as age of consent and motor skill deficits which differentiate the two conditions" NAS helpsheet. What is high functioning autism and Asperger Syndrome? http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=255&a=3337

2 Removing Barriers to Achievement, SEN Action Programme, January 2004, Department for Education & Skills, Chapter 5.

1.2 Acknowledgements

The paper was written by Judith North. Judith is a Director of Consultancy at Paradigm, a consultancy and training organisation working across the UK in the field of education, social and health care. Previously she was Chief Executive of Kingwood Trust, a specialist provider for people with an ASD in the Thames Valley area.

This paper was prepared with the help of a steering group of interested professionals, families and people with an ASD. Particular thanks to Mia Rosenblatt and Nic Rowland-Crosby for their efforts and to those who shared best practice examples.

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1.3 What is an ASD?[3]

ASD is a lifelong developmental disability that affects the way a person communicates, relates to people and to the world around them. Children and adults with an ASD often have difficulties with everyday social interaction, social relationships and understanding emotional expression.[4]

Asperger Syndrome (or "high functioning autism") usually describes those people with an ASD who have an average or above average IQ and relatively good spoken language but who also experience significant difficulties with social, occupational and other areas of their life (Powell 2002)[5].

People with an ASD can have accompanying learning disabilities or mental health needs, but not all do.

People with an ASD experience three main areas of difficulty known as "the triad of impairments". These areas of difficulties are social interaction, social communication and social imagination.

- **Social interaction** (difficulty with social relationships, for example appearing indifferent to other people)
- **Social communication** (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice)

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3 The Medical Research Council Definition of ASD is given in appendix 4

4 The main international diagnostic classifications are the International Classification of Diseases 10th Edition ICD-10 (World Health Organisation 1992) and the Diagnostic and Statistical Manual 4th Edition DSM-IV (American Psychiatric Association).There are many diagnostic tools. All are based on behavioural observation. See National Autistic Society Information Sheet "Diagnostic options in Autism, a guide for health professionals".

5 Taking Responsibility, good practice guidelines for services for people with Asperger Syndrome. 2002 Andrew Powell. National Autistic Society .

- **Social imagination** (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively).

People's experiences vary individually, so for example one person may not use spoken language whereas another may have a wide vocabulary but not know how to use language in different social situations. Understanding the condition is therefore no substitute for understanding a person.

Additionally someone might experience difficulties with change in routine, high levels of anxiety, problems with sensory processing, inflexibility of thought and difficulty understanding what other people think and feel. It is this 'jagged' profile of ability, combined with communication or processing difficulty that is unique to each person and core to what 'disable' them even when they have a high non-verbal IQ.

> "Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything."
>
> *A person with Autism*

2.   Key Headlines

Existing Government Policy makes the following clear in relation to services and support for people with an ASD:

The current position whereby some people with an ASD 'fall through' local services – in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy

Proper individual assessments, based on eligibility criteria as set down in 'Fair Access to Care' are the starting point for people getting the services they need. This should be supported by the use of person centred approaches

The services required to meet identified needs are best provided by local services that have the right skills and trained staff to provide what an individual requires. This 'most competent' approach is better than deciding that either mental health, learning disability or physical disability services should provide all ASD related services as a matter of principle.

Services and supports should focus on supporting each person's inclusion in society on their own terms, rather than being based on assumptions relating to a diagnostic label

New approaches to funding and support such as direct payments and individual budgets should be made available to people with ASD in the same way as everyone else

Service provision should be determined and driven by a clear contractual framework and service specification with regard to ASD from PCTs and Local Authorities

This whole approach should be underpinned by effective planning partnerships, including not only the relevant service sectors but also local representatives of people with an ASD and their families.

3. Conclusions from Current Policy - key implementation issues for local areas – a best practice checklist.

This clarification note covers six national policies that obviously have themes in common. Consistency in the Government's policy agenda means that the implications for local organisations are clear. This section provides a summary of actions implied across the six policies. A more detailed explanation of how each of the six policies relate to the themes is in appendix 1.

3.1 Responsibility & Funding

Some people with an ASD who need services fall through the gaps created by traditional service boundaries. There are a number of ways to prevent this and joint working protocols provide some of the strongest examples. Strong protocols cover assessment, diagnosis, joint working arrangements, care pathways and decision making based on 'best interest' principles. They give clarity about how people get access to a service.

3.2 Commissioning

Policy requires public bodies to identify, assess and meet the needs of the local adult population and this should include people with an ASD. This overall responsibility falls to the Director of Adult Social Services (DASS)[6] and/or the Director of Public Health. They should ensure there is local data about local people, know what services are available to them and what the gaps are. There are a small number of good examples of this happening, supported by local planning groups that take the work forward.

Good local services only exist where local people work well together. This includes those with a role in: learning disability, mental health, primary care, adult services, services for young people, housing, support providers, treatment services, along with people with an ASD and families. An effective service system is likely to have pooled resources, joint working protocols, joint training and ways of sharing expertise. Different areas have used different arrangements to achieve this to good effect.

Person centred commissioning strategies treat people with an ASD and their families as 'experts' and can consistently evidence, in line with policy, direct payments being offered to them.

An effective commissioning strategy will build the local infrastructure and capacity of local providers. This will help to stop over-reliance on single, specialist providers and/or sending people to services a long way away from their homes. Commissioners taking a proactive approach to commissioning services for people with ASD say that it is important to:

- Have a person centred commissioning strategy that create support solutions for each individual person
- Use this individual information to build a picture of the total local population of people with ASD.
- Actively develop local providers so that they know how to provide individualised services.
- Set an expectation that providers work in partnership with both other providers and other agencies.

The logical conclusion from the six policies is that it is important to have either (i) specific commissioning contracts with key providers that cover service delivery for people with an ASD or (ii) existing commissioning contracts with key providers that say how ASD services will be provided, the desired outcomes and the funding and resources to be applied. For example, the Mental Health NSF

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6 See statutory and best practice guidance on the new role for ADSS:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4134800&chk=3ri7eW (statutory)

http://www.dh.gov.uk/assetRoot/04/13/49/44/04134944.pdf (best practice).

talks about specific funding and contracting responsibilities. Funding can come from a combination of learning disability, mental health and physical disability sources, or from specific additional allocations.

Having a clear, locality wide structure through which ASD is championed has been shown to help. Some of the best examples are currently in the form of a managed network (see footnote 25 for a definition of a managed network).

3.3 Assessment & Review

Where services are effective, assessments are fully coordinated. Each person eligible for services has a written plan that refer to what services they will get, who will provide it, their wishes and needs, needs related to their condition and crisis arrangements. Localities doing this well clarify what different disciplines do and how their work is coordinated. Strong protocols ensure assessors are trained in ASD and they prevent people being delayed or denied access to services as a consequence of secondary assessment (e.g. IQ testing).

National policy also places emphasis on using family carers and users' expertise in assessment, arranging services and service monitoring. Services may need to be imaginative in creating ways to engage people with an ASD in these processes.

3.4 Monitoring & Regulation

Monitoring systems, standards and practice should be adapted to ensure they are responsive to the needs of diverse groups of people. Presently, only a few extend to monitor things that matter to people with an ASD.

3.5 Service Provision

People with ASD are entitled to receive direct payments and individual budgets in the same way as everyone else. It is thus expected that there will be a growing number of people with ASD who will take up this option and purchase their own services provision.

From 2007, following implementation of the Mental Capacity Act, people must be assumed to have capacity to make decisions about the services provided or offered to them unless it has been demonstrated otherwise. This includes people with an ASD and those who may not find it easy to express their choice in words. This will provide people with an ASD much greater freedom to direct their own support. Use of "best interest principles" (i.e. decisions guided by what would be in a person's best interest) should guide decision making for the few people for whom choice is very difficult to ascertain.

Existing policy would not support the exclusion of people from services based on their 'label' alone. This implies that people with an ASD should be able to access the same services as anyone else. Some of the policies explicitly say that the statement of purpose and operational policies of services like respite, day services etc. must show the service can meet diverse needs. People with an ASD are citizens in the local population and so most general services ought to be considering how to serve this group of people.

In order to help ensure that providers are competent in working with people with ASD, competent commissioners are including expectations about person centred approaches, person centred planning and working with ASD as part of their commissioning requirements.

Providers that state that they provide services to people with an ASD may want to consider whether it is appropriate, in terms of equality, to set arbitrary cut offs in terms of which of the ASD population they will and will not serve (e.g. IQ).

3.6 Community Integration and Employment Support

Policy emphasises the importance of community participation and employment. Some of the strongest efforts to build inclusion focus on people's gifts, talents, interests and preferences. This requires organisations to support people to manage their anxiety in social situations, build opportunities around individuals' special areas of interest and support other people to understand how to help someone with an ASD to fit in.

Local supported employment and other specialist employment services should have the competence to support people with ASD into paid work. Some people with an ASD and their families, particularly those with complex needs and Asperger Syndrome, report being excluded from existing mainstream and specialist employment services. It is incumbent upon providers to develop the necessary knowledge and competencies. Commissioners need to produce information that helps people to understand their options and entitlements.

The Disability Discrimination Act and the new Disability Equality Duty underline the need for all services to understand, and respond to, the needs of disabled people. This means that day, employment, leisure and education services (as well as all other public services) <u>must</u> make reasonable adjustments to facilitate the inclusion of people with an ASD.

3.7 Family Carers

Existing policy requires that the following are in place for family carers;

- The right to an assessment
- Expert carers programmes
- Respite
- Information about services (including diagnostic services) and support.

These expectations for family carers apply to family carers of people with ASD exactly as much as they do to other family carers.

3.8 Health & Specialist Services

There are some obvious starting points where specialist skills and knowledge about ASD should be developed - namely primary health care, mental health worker roles and health facilitation roles. Specialist workers need to be clearly identified in the local system and their role described in joint working protocols. Their role should be to help general workers by providing diagnostic services, advice, support and training. These roles are also used, in some areas, to disseminate information & knowledge to the wider health and social care community.

The Mental Health NSF and Our health, Our Care, Our Say, place emphasis on local provision of specialist services. In the context of ASD, "specialist" services could mean crisis outreach, diagnostic or treatment services. Where specialist services are deemed to be unnecessary commissioners are expected to show that the needs of local people can be met by mainstream services. Due to the level of local variation in services and numbers of people with an ASD, the size volume and type of services need to be locally determined. Commissioners also need to be clear about which service will meet what need.

People with an ASD and their families say diagnostic services are important. Knowing where to get diagnostic help, getting help in a timely way and receiving post-diagnostic support and information are all important. The policies place this responsibility with health commissioners.

Mental ill health can result from feeling isolated and not getting timely support. Projects like social and education groups appear to help people get connected and stay well.

People with an ASD have a greater risk of some health conditions. Health Action Plans or care plans help to address these especially when help is given by Health Facilitators (or other specialist health staff) that understand the associated health issues.

The lack of evidence on effective service and treatment interventions for people with an ASD is beyond the scope of this document to comment.

3.9 Workforce Development

Policy requires that local workforce development plans include reference to people with a broad range of needs – this will include staff to support people with an ASD.

Commissioners of staff training and education should contract so that an appropriate level and type of training is provided for all relevant staff. Families believe it is important that Autism awareness training is a minimum requirement for all staff in contact with people with an ASD. Staff in regular contact with people with ASD need more than awareness training and should fully understand an individual's support needs and issues relating to diversity. Organisations should be able to evidence that training results in person centred practice.

Currently there are a small number of examples of ASD training being taught in a person centred way. Not all organisations understand that person centred approaches and ASD go together. Training Officers should be competent in assessing the curriculum of all training courses, including mandatory training (e.g. NVQ) to ensure that they focus on person centred approaches to ASD. There are some excellent examples of people with an ASD teaching from their own experience.

Assessors, care managers and senior staff should understand the needs of people with ASD. For example, assessors should understand that someone may be able to carry out a task in one environment but not in another, care coordinators should understand that someone may have difficulty understanding the implications of decisions they make. In practice this generally means commissioning specialist training for designated specialist workers.

An implied expectation of the policies is that workforce development plans should focus on ensuring staff are being selected on the basis of the right human qualities. The training strategy needs to develop an emerging workforce that will work with people under direct payments and individualised budgets.

Continuity is vital for people with ASD. Thus, workforce development plans need to support staff retention through career development initiatives and flexible remuneration packages. Commissioning practice should support these themes rather than inadvertently create discontinuity of support (e.g. automatically timetabled re-tendering).

Local commissioners report that workforce development initiatives benefit when organisations pool and share training resources and expertise. Training consortia and managed networks are two possible ways of handling this.

3.10 Transition & Emergencies

To meet the needs of young people in transition the policies state that health and social care commissioners should:
- Ensure each young person and their family/carers are supported by a single 'trusted adult' contact who will liaise with services, support, the young person and their family/carers.
- Have early access information about what the future may hold such as learning and employment, support services and opportunities for participation.
- Respect an individual young person's preferences for daily structure, support and communication.
- Ensure that a consistent and skilled approach is taken across all services and support is offered as the young person grows into adulthood.
- Meet the statutory requirement to commence transition planning from the age of 14.

Approved Social Workers, assertive outreach teams, challenging behaviour teams and psychiatrists will be more confident and deliver better solutions if they understand the impact of major transition, crisis and change on people with an ASD.

3.11 Involving People with ASD. Decision Making, Consultation and Advocacy

Policies emphasise the importance of involving people and their families in planning. This works best when planning processes are adapted to help people get and stay involved. Plans should describe how people with an ASD want to live and how they will be supported to do that. Good practice examples readily demonstrate that a person's views can still be held central to the planning process whether or not they are able to use words to express themselves or make clear decisions and choices.

A number of policies stress the importance of advocacy. People with an ASD sometimes get excluded from advocacy initiatives. Advocacy support services have to understand some of the specific issues people face. Where advocacy support services are unable to embrace the needs of people with ASD, localities may need to consider setting up ASD specific advocacy services.

3.12 Equality (all policies)

Understanding ASD as an equality issue is vital. Equally, all equality issues affecting the general population apply to people with an ASD. ASD needs to be understood as a difference (in this case neurological, biological, processing and sensory) rather than as a "disorder".

There is very little research identifying the needs of people from black and ethnic minority communities with an ASD. However, the available research, along with the data about other minority groups, emphasises the importance of understanding and responding to diversity.

Respect for an individual's cultural and other differences is an especially important element in providing continuity and developing a sense of self worth and self identity.

Appendix 1
Policy Summaries

LAC (2002)13: Fair access to care services: guidance on eligibility criteria for adult social care 2002[7]

Summary of the LAC (2002) 13

"Fair access to care" (FAC) sets out how social services should identify which people are eligible for social care. It says how councils should carry out assessments and reviews. It provides a Framework designed to create a more consistent approach to determining eligibility across England

Assessment

The process for deciding whether a person will get services is in two steps. Firstly a simple "access" assessment is made based on someone's presenting needs that is used to decide whether a person needs a full assessment. The full assessment decides what a person is eligible for. A statement of eligible needs must be produced after the assessment. FAC says that in deciding eligibility no further or alternative assessment processes are necessary.

Assessment and reviews should be co-ordinated by competent professionals in a position to decide on and plan services. Plans should be developed in partnership between people who need support and the council. They should include eligible needs, risks, required outcomes, emergency contingency plans, details of services provided, charges, family and friends and a review date. If support needs to be changed this can only be done after another assessment.

Reviews have to be conducted independently by a professional who is not providing care to someone. They should be person centred and involve providers, carers, representatives of the service user and the person themselves.

Councils should monitor what groups are referred, which get an assessment and which go on to get services. They should monitor the quality of assessments, the eligibility decisions taken, which presenting needs turn out to be eligible.

Eligibility

People who get help should be those in the greatest need. Eligibility criteria are made up of four bands defined by amount of risk to a person's independence were their needs not met. When deciding what band a person comes into, help they get from family etc. is taken into account. Services can not be provided to meet needs that family etc. will. When people are ineligible, councils should risk assess their situation to help with planning and developing preventative services.

Commissioning

Councils have to commission services to meet the needs of people who meet the criteria. They should do this even if it means moving money around budget headings. If there are gaps in services they should be filled. Services should each individual's and justification should be given for commissioning or separating services for one group of people from another. Direct payments should be offered to everyone.

Managing change

When big things change in a person's life or if services are going to be reduced or withdrawn people should be helped to understand what is happening. Interpreters, translators, advocates and/or supporters should be available if needed.

Councils should respond immediately to people who need social care support in a crisis going back to complete a full eligibility assessment once a person has been made safe.

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7 http://www.dh.gov.uk/assetRoot/04/01/96/41/04019641.pdf

How policy applies to people with an ASD

Assessment

The concepts of presenting needs and eligibility need to be understood in the context of ASD. With regard to presenting need, assessors need to be aware that the uneven or 'jagged' profiles of ability can be common in people with an ASD. These will affect the assessment process. What someone can do today they may not be able to do tomorrow and so needs may be more easily overlooked by assessors.

With regard to eligibility a diagnosis of ASD does not justify access to services. Equally, a label can not be used to deny access. Instead the focus for assessment and decision making should be the associated difficulties such as vulnerability, mental health needs, social skills and activities of daily living.

Assessment, care planning and review processes will need to be explained and may need to be adapted to include features ("things") that matter to the person being assessed. Assessors will need training to do this.

When someone is not eligible for services they may require help to understand the practical implication of this and should still get clear information about where else to get help to address the difficulties they do have.

Councils should monitor the number of people being referred with a diagnosis of ASD and which services they receive.

Responsibility

Adults with an ASD who also have learning disabilities are funded and learning disability services.[8] People with Asperger Syndrome are sometimes served by learning disabilities and sometimes by mental health services. Many report falling into the gap between the two, unable to obtain assessments or support regardless of eligibility. Reasons given by service are a person's IQ or that the "pot" of money from which they would be funded is for different groups of people. FAC explicitly states authorities must focus on "presenting need" and "eligibility" and not on where the money comes from. Further assessment processes, like IQ, may be used to better understand how to support someone but not to decide on eligibility. The relevant questions in deciding responsibility are:

Does the person have:

- An eligible need for support?
- A diagnosed, or undiagnosed, mental health need?[9] (Mental health services should take financial responsibility)?
- A learning disability? (Learning disability services should take financial responsibility).
- A physical disability or sensory impairment? (Physical disability services should take financial responsibility)?

Or do they:

Not obviously meet any of the above and but still have a presenting or eligible need. (A locally agreed joint working protocol allocates responsibility to local professionals with most experience in diagnosis, assessment and arranging services for people with ASD. Funding for these individuals can be made available from a pooled fund, or similar arrangement, and the lead consistently given to the team with most experience in ASD).

Assessors in all areas of responsibility need training on ASD and the locally developed protocol if they are to make adequate and timely judgements on this.

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8 The historical basis for this is generally a tested adult IQ of <70

9 NB: ASD is not in itself a mental health need

For those people who are not eligible for services but require preventative input there are a wide range of supports that could be made available such as continuing education, social, discussion and special interests groups. [See best practice example 18 in appendix 2].

Commissioning

People with an ASD can find every day interactions with other people difficult and anxiety provoking. Some commissioning strategies create situations where groups are placed together based on diagnosis or label. This can lead to poor outcomes for people who experience difficulty in adapting to other people or dealing with the sensory demands in shared surroundings. Individualised approaches are needed that make sure both the relevant skills and the right environment are identified for each person.

Crisis & emergencies

Major life transitions can be distressing. Crises happen most often in services because something is not right for someone and not enough is understood or done quickly enough to put it right. Sometimes changes are made without adequate thought or understanding for the person's needs. Person centred transition plans are essential to manage change effectively. Change should happen at the persons', and not the systems', pace. Professionals most often involved in making crisis arrangements need to ensure they are sensitively planned. Advocacy services can help in these situations.

Crisis arrangements need to be thought through in advance in the care plan. Commissioning resources need to be directed to local services such as outreach that help people to stay at home in familiar surroundings. The Mental Incapacity Bill provides a statutory framework to protect vulnerable people, carers and professionals. It clarifies who can take decisions in which situations and how. The Bill assumes people have capacity and says that all practical steps must be taken to help the person make a decision.[10] Given what is know about ASD it is important that people are not placed out of area in unfamiliar surroundings unless unavoidable.

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10 Mental Incapacity Bill (now renamed Mental Capacity Bill) Fact-sheet, April 2004, Department for Constitutional Affairs
http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm

Valuing People: A New Strategy for Learning Disability for the 21st Century. 2001

Summary of Valuing People White Paper

The Valuing People White Paper focuses on achieving full lives for people with learning disabilities. It aims to stop the inequalities in how people with learning disabilities live their lives. It lists things not working in the current system like; support for carers, services for young people becoming adults, the lack of choice and control experienced by many people, unmet health needs, limited housing choice, institutionalised group day opportunities, that fact so few people have jobs; the needs of people from minority ethnic communities being overlooked; inconsistency in services and poor partnership working. It commits to tackling these things.

Valuing people is underpinned by four principles; Rights, Independence, Choice, and Inclusion. It sets eleven objectives to deliver these principles. Ten of them are relevant to this paper (for transition issues see Growing into Adulthood section):

> Objective 3: Enabling People to Have More Control Over Their Own Lives
> Enabling people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approaches.

> Objective 4: Supporting Carers
> Increasing the help and support carers get.

> Objective 5: Good Health
> Enabling people with learning disabilities use a health service designed around their individual needs.

> Objective 6: Housing
> Enabling people with learning disabilities and their families to have greater choice and control over where and how they live.

> Objective 7: Fulfilling Lives
> Enabling people with learning disabilities to lead full and purposeful lives in their communities; to have friends, interesting things to do and real relationships.

> Objective 8: Moving into Employment
> Enabling more people with learning disabilities to get a paid job.

> Objective 9: Quality
> Ensuring that all agencies commission and provide high quality, evidence based services that deliver good outcomes and best value.

> Objective 10: Workforce Training and Planning
> Ensuring that social and health care staff are appropriately skilled, trained and qualified.

> Objective 11: Partnership Working
> Promoting services that help people with learning disabilities, by working together.

How policy applies to people with an ASD

The Valuing People White Paper applies to everyone with a learning disability. This means that if someone with ASD also has a learning disability as defined in Valuing People, then they should have access to the same services and supports as any other learning disabled person.

Person centred approaches & planning

Person Centred Planning is used to put each person (with the help of family and friends) in control of their life. It focuses on what people can do. Difficulties with planning, imagining the future and making choices are common for people with an ASD. This has implications for how PCP is carried out but not

whether. Some forms of Person Centred Planning (for example Essential Lifestyle Planning) are important in helping someone to communicate things that are important to them on a day today basis e.g. routines and rituals. [See Best Practice Example 13 in Appendix 2]

Person centred approaches are important in providing services. People with an ASD have as many aspirations as other people although learning what they are can sometimes be difficult. Information about a condition may give information about the types of supports a person needs but it does not 'define' who a person is or what they want from life. [See Best Practice Examples 22 and 23 in appendix 2]. Individualised living arrangements, such as supported living are working well for people who find it difficult being around other people. Individualised budgets[11] and direct payments[12] are working really well for families who have been unable to get what they need from traditional services.

Advocacy

Advocacy services that work with people with an ASD should understand the difficulties people with an ASD face in making themselves heard. For example, some people with an ASD find it difficult to figure out what other people already know and what they need to be told.[13] Other people have unusual priorities and personal preferences meaning they often need support to assert their personal point of view. People with an ASD can be excluded by advocacy services set up for other groups (mental health and learning disability) which means advocacy services, as with other services, need access to specialist advice and support.

Health

People with an ASD seem to have greater health needs than the rest of the population. Some health needs are specifically related to ASD (e.g. gastro-intestinal problems) and some are due to difficulties with finding and receiving treatment. The Health Facilitator role is an obvious target for the development of ASD support. They should ensure everyone known to services is registered with a GP. Each person should have a health action plan (LD) or care plan (MH). The health facilitator role is an example where pooled mental health and learning disability resources could make sense. Other opportunities are specialist facilitator/coordinator roles and joint training initiatives. Health and social care commissioners should ensure strong working links exist between mental health coordinators [mental health], specialist "mental health workers" [primary care], Health Action Plan facilitators [learning disability] and GPs with special interests [primary care] as well as those interfaces already identified in the White Paper. It is more important that the links exist than the precise nature of the arrangements. [See best practice example 3 in appendix 2]

Housing

People with learning disabilities should be living in all types of housing. They can cope with a full range of tenures and no housing solution should be routinely disregarded as a matter of deliberate policy. Options that create lower demands in terms of social interaction and those that adapt environments to suit individual needs are likely to improve life outcomes for many. The selection and adaptation accommodation is important and care should be taken to minimise the negative impact of sensory hypersensitivities, manage particular fascinations (e.g. plumbing and electrics) and maximise lifestyle opportunities (maintaining important relationships). Partnership Boards developing housing strategies need to understand these issues and to identifying responsive housing providers. [See best practice example 19 in appendix 2]

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11 For more information on individualised budgets see http://www.in-control.org.uk

12 For more information on Direct Payments see:

http:www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en or ask your local council for a leaflet

13 See literature on theory of mind such as Dr. Simon Baron-Cohen, Mindblindness, Cambridge, Mass: The MIT Press

<u>Fulfilling Lives and Employment</u>

Some people with an ASD are excluded from mainstream day service provision because the service can not meet their needs. Attendance at large day centres or participating in group activities will often be challenging.

Research shows that "supported employment for more able people with autistic spectrum disorders results in significantly higher rates of employment, more appropriate employment, greater job satisfaction and higher employer satisfaction when compared to generic disability employment services, and that such gains are maintained over a significant period of time".[14]

Some people with an ASD have what are sometimes termed "restricted interests", "passions" and "obsessions" – i.e. topics or activities that take up much of their attention. To achieve community integration services can utilise people's passions and interests and provide help with developing and managing social contacts and relationships. Services need to know how to manage the social and physical environment to maximise success.

<u>Workforce Development</u>

Effective partnership working is a cross cutting theme throughout this paper so many of the issues on workforce development are picked up in other sections. Learning Disability Partnership Boards (or Local Implementation Teams in Mental Health) can take a role in developing groups of local champions from different parts of the service system that have an impact on people's lives. [See best practice examples 5, 8 and 20 to 23 in appendix 2]

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14 Janet Robertson and Eric Emerson, 2006, Institute for Health Research, Lancaster University.

http://www.autism.org.uk/content/1/c6/01/06/11/review.pdf

The National Service Framework for Mental Health, 1999 and the National Service Framework for Mental Health – Five Years On, 2004

Summary of the National Service Framework for Mental Health 1999

The National Service Framework for Mental Health sets out seven national standards. It lays out an expectation that most mental health needs will be tackled locally, by general practice and primary care supported where necessary by local and other specialist mental health services. The framework says that health and social care organisations should work in partnership and create single processes in support of:

- Promoting mental health and reducing discrimination and social exclusion associated with mental health problems.
- Improving primary mental health care so people, including those with severe mental illness, get consistent advice and help
- Ensuring people with severe mental illness get the services they need; that crises are anticipated or prevented; that effective help is provided quickly and as close to home as possible.
- Ensuring carers for those with severe mental illness get assessments and the help they need.

Summary of the National Service Framework for Mental Health – Five Years On, 2004

The NSF for Mental Health – Five Years On reviews the impact of the strategy set out in 1999 and plans for the following five years. It highlights key policy aims including:

- Continued work to tackle social exclusion and improve employment prospects.
- Improving services for people from ethnic minorities, abolishing inequalities and earning the confidence of minority groups.
- Improving the care of long term mental disorders, the availability of psychological therapies, and information.
- Workforce redesign

Information to support the specialist commissioning of services for people with Aspergers will be published in final form in autumn 2006.

How policy applies to people with an ASD

The NSF in mental health applies to everyone with mental health needs, regardless of additional or underlying conditions. This means that someone with ASD should have access to the same mental health care as anyone else.

Mental health needs are common in people with ASD,[15] who may suffer from depression, anxiety and obsessive compulsive disorder. ASD can sometimes be mistaken for schizophrenia.[16] There are, however, no data on the number of people with ASD using mental health services.

Assessment and care planning

The NSF emphasises the importance of primary care as the gateway to specialist assessment of mental health. Local care pathways and case management arrangements should be agreed, covering primary care, community mental health teams and specialist services, social services, community learning

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15 "Clinical experience suggests that over their lifetime about 60 – 80% of patients with [ASD] receive psychotropic medication" (p.28), "No systematic epidemiological studies have been performed [but]… reports suggest at least 10% of children and adolescent seem… to suffer from psychiatric disorders… In an outpatient example we found that out of 68 children and adolescents 9% suffered from other psychiatric disorders. This sample consisted mostly of persons with mental retardation [sic]", (p.99) Ghaziuddin, M. (2005). Mental health aspects of Autism and Asperger Syndrome. London: Jessica Kingsley Publishers

16 Deudney C. and Shah, A. (2005) Mental and Asperger Syndrome. London: The National Autistic Society (Information sheet available from the NAS Information Centre)

disability teams and specialists such as ASD specialist nurses. [See best practice example 4 which emerged from a mental health service].

Following assessment people should get written care plans that name a care co-ordinator, say where specialist advice will come from and describe how crises will be managed. Equally important is that written care plans describe a person's ASD-related support needs.

Many people with an ASD need sameness, routine and continuity. Poorly planned attendance at health care services can cause distress and adversely affect their mental health. It is also helpful if specialist services (such as community mental health teams and community learning disability teams) provide support to mainstream clinicians when they are in contact with people with an ASD.

The care coordinator should be known to the person with ASD. Individuals who may need to be admitted should be helped to become familiar with services they may need in future. Families can play an important part in this if the care plan sets out clearly the information they need.

People with ASD who have an IQ of less than 70 and significant mental health needs will almost certainly require enhanced CPA (the most intensive level of mental health service provision). Case management and CPA should be fully integrated and used consistently. The Mental Health NSF 5 Years On notes that 92% of Local Implementation Teams confirm progress on agreeing roles and responsibilities between mental health and learning disabilities. ASD should be referred to in these agreements.[17]

Diagnosis

Many people with ASD and their families report the diagnosis of ASD as having been helpful in understanding the kind of supports an individual needs. However, diagnosis and the availability of diagnostic services are frequently problematic. Primary care services may not feel competent to diagnose ASD. Clinicians in mental health services may find it difficult to distinguish ASD from other conditions, including schizophrenia. Clinical staff often lack experience of how a person with ASD communicates verbally and non-verbally. A recent report from the Royal College of Psychiatrists suggests that all psychiatrists should be able to diagnose obvious ASD.[18]

Commissioning

The most successful services seem to be built around a professional with an interest in ASD, drawing on their expertise to build local competence. Commissioners in the early stages of developing capacity should therefore identify such a practitioner and develop a working protocol for both specialist assessments of individuals and to support other professionals in developing appropriate skills.

People with ASD may need to use specialist mental health services and staff in a range of care settings will need to be aware of ASD and have access to specialist advice. For example, crisis resolution/home treatment teams may be the best way of providing acute mental health care - treatment at home preserves routine, sameness and predictability in a way that an admission can not. Assertive outreach teams provide intensive community support to people with complex needs and may be the first port of call for people with ASD who are in crisis.

Carers

47% of adults with ASD live at home with parents.[19] Parents often understand what care is needed better than professionals can. They are an invaluable source of advice and support.

Local health and social care commissioners should be clear about the main source of carer support which may include an expert carer's programme. Other services that may be needed are home- based respite and crisis support. Services that support carers need to understand how living with someone with ASD can affect carers. For example, some of the features of ASD - sleep disorders, eating disorders,

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17 See the National Service Framework for Mental Health pages 90 – 95 for a definition of 'Local Implementation Team'

18 http://www.rcpsych.ac.uk/publications/collegereports/cr/cr136.aspx

19 Barnard et al, 2001 Ignored or ineligible? The reality of adults with autism spectrum disorders, London: National Autistic Society, p.5

behavioural difficulties, violence and self harm – leave families feeling exhausted and desperate by the time they first seek help.

In accordance with the Carers Recognition & Services Act 1995 carers should be made aware of their right to request an assessment. Social services should draw up a care plan for a carer in need of support and communicate it to their GP and primary care team. They should make sure that carers can make use of carers' groups and networks, information services and help-lines.[20] The NSF 5 Years On says that 90% of areas now have a comprehensive directory services. These directories should also cover services for people with ASD.

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20 The NAS Information Centre runs an enquiry service for professionals: Email: info@nas.org.uk and a helpline for families
http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=617 NAS also provides Autism Data, a bibliographic database of books and journal articles on
Autism is searchable on the NAS website http://www.autism.org.uk/autismdata

Our Health, Our Care, Our Say: A New Direction for Community Services (2006)

Policy Summary

The vision set out in Our Health, Our Care, Our Say is to make services more responsive, focus on people with complex needs and shift care & supports closer to home. It seeks to give people choice and control over their life and the health and social care services they get. Some of the ways set out to achieve this are:

- Giving patients real choice and influence over services like which Doctor (General Practitioner) they see and what services they use.
- Emphasis is put on direct payments (money paid to a person so they can purchase their own support) and individual budgets as key to choice and control.[21]
- Joining up health and social care responsibilities like care planning and record keeping.
- Creating single Personal Health and Social Care Plans i.e. one document describing people's needs, the support and treatment they require and who will help them.
- GP practice based commissioning focussed on developing health services close to home & communities.
- Social care commissioning based on population needs assessment and understanding of what people want.
- Increased use of health act flexibilities so that people with "particular" needs get the help they need.
- The introduction of support models such as extra care housing and intensive support at home.
- Monitoring, regulatory, contractual and financial focus on outcomes and help avert avoidable crises.
- Skilled and competent case managers for people with complex needs who can work across organisational boundaries.
- Using new information, assistive and systems technology to focus on health prevention.
- Joint workforce investment in training.

How policy applies to people with an ASD

Primary Care

People should be encouraged to choose their GP. For people with an ASD problems are reported with finding a sympathetic GP who understands the issues. Support services can act as a bridge by identifying services that will meet needs such as those willing to undertake home visits or set longer appointment times. Health practitioners need to be aware of health needs that affect people with an ASD.[22] There are such a wide range of treatments and approaches for people with an ASD that it is difficult to keep up. Also there is little evidence base as to what treatment is actually effective. PCTs and GP practices need access to specialist advice. The National Autistic Society provides a good range of information sheets[23] which could be used in the context of information prescriptions.[24] The new developments proposed in primary care (i.e. "mental health worker" roles and GPs with special interests) as well as primary care support provided through learning disability or mental health teams are good starting place for focussing advice to general health care, and other, staff.

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21 Individual budgets bring together several income streams from social care, community equipment, access to work, independent living funds, disability facilities grants and supporting people

22 People with an ASD are more likely to have some of the following conditions: epilepsy, attention deficit hyperactivity disorder, Tourette's syndrome, mental health needs (e.g. depression and anxiety) particularly when ASD has been undiagnosed, dyslexia, dyspraxia, visual, auditory and gastrointestinal problems

23 e.g. "Patients with an ASD, Information for Health Professionals",& "Mental health and Asperger Syndrome"

24 24 PARIS (Public Autism resource and information service) http://www.info.Autism.org.uk

Commissioning

Due to the relatively low local population numbers of people with ASD (see appendix 3) it helps when resources for advice are pooled between health, social care, mental health and learning disability. This can be managed differently in each locality. Liverpool has set up a specialist team [See best practice example 4 in appendix 2], the London Borough of Newham has appointed a specific care manager for people with an ASD [See best practice example 5 in appendix 2] and Somerset has set up an Asperger service supported by an operational policy [See best practice example 3 in appendix 2]. Learning from these suggests key work for professionals in an advisory role are accessing and supporting mainstream practitioners, clarifying the source of advice and how to get it and developing champions with specialist ASD knowledge in the local system [See best practice examples 6 and 11 in appendix 2]. In some areas advisory staff are working with families to support them to make their own arrangements [See best practice example 12 in appendix 2]

Community needs assessment is the basis of good strategic planning. In social care it is the responsibility of the Director of Adult Social Services (DASS) and, for health services, the Director of Public Health. Where information about people with an ASD is not very good they should make sure the information is made available. Organisations that support people with complex needs do best when housing, clinical and support providers work together to create a good system. [See best practice example 5 in appendix 2]. Managed networks[25] can have an impact. There are some great examples of groups of champions working together to create ASD friendly service solutions (e.g. well planned housing design, use of assistive technology and person centred support) [See best practice examples 6, 7, 8, 11 and 19 in appendix 2]

Direct Payments & Individualised Budgets

The expectation that everyone eligible for support should be offered direct payments clearly applies to people with an ASD. The importance of getting support right for people with an ASD combined with the poor performance of some traditional services means an increasing number of people are using direct payments and individualised budgets. People with an ASD may need specific support with managing some of the implications of new ways of working for example the social issues in managing staff and the systems developing around individualised budgets are developing to accommodate this.[26] [See best practice example 12 in appendix 2]. New services are being established that offer families and people with an ASD, alternatives to statutory or traditional approaches. [See best practice example 14 in appendix 2].

Staff development

Training in person centred approaches to ASD is essential. As important as training are the right human qualities such as understanding diversity, willingness to learn, empathy and compassion. The issue for services is how to develop and maintain these in the context of other workforce training priorities. This could be one of the functions local specialists (e.g. community nurses or clinical psychologists) help with. It also raises issues regarding the basic knowledge of ASD needed by staff in ancillary and administrative roles (e.g. training and human resources departments).

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25 Network means a group of interested people from different organisations (e.g. including professionals, specialists, families, carers support organisations etc) that come together in a common interest, common purpose and a commitment to act. A managed network is when the group is provided with a person's time or resources to administrate and help direct the business of the group.

26 See http://www.in-control.org.uk

Improving the Life Chances of Disabled People 2005

Policy Summary

'By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society'[27]

Improving the Life Chances of Disabled People outlines a twenty year strategy focused to markedly improve the life chances of disabled people in Britain. It focuses on four key areas and gives commitment to supporting delivery. Most notable is the setting up of the Office for Disability Issues based within the Department for Work Pensions which reports directly to the Minister for Disabled People. The four key areas of work are:

1. Independent Living – introducing individual budgets for disabled people, enabling people to have control over how they are supported, who supports them and what they do.
2. Families and young disabled children – ensuring early education and support for all family members. Working to ensure that services and supports are centred on children and their families and not on funding systems.
3. Transition in to Adulthood – putting in place improved mechanisms for transition planning in to adulthood and the support needed to go with this. Working to ensure that young disabled people have access to more opportunities and choices.
4. Support and incentives for getting and staying in employment – combining support for benefits claims; the provision of work-based training, and reforming Access to Work and in-work support, thus contributing to the governments overall employment targets.

The Office for Disability Issues will produce annual reports detailing the work being undertaken to deliver the vision. The report makes six recommendations on moving towards delivery:

- The strategy for improving the life chances of disabled people should be developed fully and progressive reform to 2025.
- Provision for disabled people should be reviewed and a new mix of mainstream, specialist and integrated provision derived from it.
- More coherent and explicit standards should be developed that bring legislation and rights in to a consistent framework.
- Government focus will ensure that priority is given to disability issues and reform is in line with the public service agenda.
- New arrangements will be established for securing participation of disabled people in policy design and delivery at all levels.[28]

How policy applies to people with an ASD

Independent living: Finding appropriate housing that fits how someone wants to live is a challenge for local authorities and housing providers. Housing scarcity, the acceptance of local communities and the accessibility of leisure and employment options mean there are real barriers to independence. Commissioning strategies need to consider the multilayered needs of people with an ASD if they are to ensure these issues are addressed.

The Disability Discrimination Act[29] requires organisations to make reasonable adjustments to accommodate the needs of disabled people

From January 2006 the Disability Equality Duty means public organisations need to understand how their services are experienced differently by people with ASD.

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27 Executive Summary, Improving the Life Chances of Disabled People, PMSU 2005

28 Chapter 8, Improving the Life Chances of Disabled People, PMSU 2005

29 http://www.opsi.gov.uk/acts/acts1995/1995050.htm

Parts 2-4 of the Disability Discrimination Act give a disabled person a right of redress for unjustified less favourable treatment or failure to make reasonable adjustments in a number of areas.[30] It places public authorities in a position where they need to take sufficient action to avoid being sued.

The new Disability Equality Duty shifts the burden of thinking about discrimination or less favourable outcomes from the individual to the public sector by requiring all public authorities to carry out their functions with 'due regard' to the need to eliminate discrimination and harassment, promote equality of opportunity and positive attitudes towards disabled people, and encourage disabled people to participate in public life. This means that the authorities covered by this document should be thinking about questions like:

- What do we know about the access people with an ASD get to services?
- What outcomes do they achieve?
- What do we need to do to promote equality for them?
- How do our activities promote positive attitudes to people with an ASD?
- How are we encouraging and enabling people with an ASD to participate in public life?

The Disability Equality Scheme that all NHS trusts and principal local authorities need to publish by 4 December 2006 should set out authorities' answers to these questions, amongst others. Involving disabled people in the development of the scheme is mandatory.

Families and young disabled children - caring can be a full time commitment. Families need access to flexible and skilled support from people who know their son or daughter well, understand their diagnosis and are able to work co-operatively with the family. Families need to take a break. Familiar and consistent respite that can maintain people's everyday routines is important. Preparation for the use of respite is vital. Some families find that one or both of the 'earners' have to give up work to care for their child – and so family support needs to extend to supporting families in maintaining their income and employment.

Transition into Adulthood – this is one of the complex changes that happens in a person's life. The issues are the same at this time as at others. Transition issues are covered more in the section on growing into adulthood and crisis and emergency arrangements in the section on Fair Access to Care.

Employment – only 6 % of people with an ASD are in paid employment. Finding work when noise is difficult, crowds are stressful, or sudden changes in routine are upsetting is difficult. Many people with an ASD need support in ordinary community environments. The issues for people with an ASD who want to find work are numerous and people will require skilled and understanding support. Some people will need the working environment managed or adapted to reduce the impact of things like sensory hypersensitivities or social demands. Successes have come from matching people's particular skills with a job and offering ongoing support to the employer and members of the workforce as well as supporting an individual. Lack of training or learning opportunity can make it seem as if people with ASD have fewer skills to offer. The truth is in the right job many people with an ASD have more to offer. The complexity of the benefits system, tax credits and concerns around 'means testing' may create more difficulties in getting into work. Vocational schemes will fall separately under the responsibilities of mental health, learning disability etc. Commissioners therefore need to be clear about the main source of employment support for people with an ASD in their locality.

Workforce: The introduction of individual budgets will require workforce skilled in supporting people with an ASD and their families directing their own support. Workforce development plans can be expanded to ensure the needs of the whole workforce are appropriately considered and developed.

Growing into Adulthood

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[30] (part 2 covers employment; part 3 the provision of goods and services, including public services and functions like the NHS; part 4 covers education).

Transition means the process of supporting a disabled young person through a move between school, college and into the adult world. For young people with complex support needs this includes the move from children's services to adult services. Transition in this document covers ages 14 to 25 years. This section covers policy and legislation relevant to transition and highlights the central themes.

The central objective of all the government legislation is summarised in Valuing People:

Objective 2
As young people with learning disabilities move in to adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.[31]

The National Service Framework for Children, Young People and Maternity Services further outlines this vision:

- Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.
- Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development; and health and well being both now and in the future.
- Services and staff who are able to respond in a sensitive way which encourages engagement and provides high quality support for young people.

Standard

- All young people have access to age-appropriate services which are responsive to their specific needs as they grow in to adulthood.[32]

Key Components
There are three key components of effective support at transition age;

- Planning focused on individual needs
- Continuous service provision
- Access to a more transparent and appropriate menu of opportunities and choices[33]

The Code of Practice for Special Educational Needs highlights the following values as central to transition support and planning:

Participative, Holistic, Supportive, Evolving, Inclusive, Collaborative[34]

These values highlight the importance of participation of young people and their families. The recent pilot and roll out of Person Centred Transition Reviews (Jointly funded by the Dept of Health and Dept of Education and Skills) offers a model of involvement where the young person participates in creating a person centred transition plan. This is in line with the SEN Code of Practice that says work undertaken with a young person should evidence their involvement and participation in the reviewing of support or making plans for the future.[35]

Under Section 140 of the Learning and Skills Act 2000, the Connexions Service, on behalf of the Secretary of State for Education, must carry out needs assessments of people with SEN statements in the last year of school who want to go on to further education and training so that provision is developed that meet those needs. This is particularly important when choices are being made that will impact on adult life.

31 Valuing people, DH, 2001

32 Standard 4 'Growing up into Adulthood' – NSF for Children, Young People and Maternity Services, DH 2004

33 Chapter 4 – Growing into Adulthood, Improving the Life Chances of Disabled People, Prime Ministers Strategy Unit, January 2005

34 Paragraph 9:52, Special Educational Needs Code of Practice, DfES, 2001" - the Code was published in 2001 and became effective from January 2002)

35 Every Child Matters, DfES, 2003

The role of the specialist (SEN) Personal Adviser in the Connexions Services is to ensure that young people with learning difficulties and/or disabilities are heard.[36] The 'Youth Matters' paper has set out new 'quality standards' that ensure young people receive impartial advice that raises their expectation of what the future may hold.[37]

Individual Budgets – Personalised Learning

In education there is increasing emphasis on 'personalised learning' where a curriculum is constructed that matches the learning needs and aspirations of individual young people. The 'Further Education: Raising Skills, Improving Life Chances' white paper states clearly that the Learning and Skills Council is committed to the continuing development of personalised learning opportunities for learners with learning difficulties and/or disabilities; and that they will do this by "supporting collaborative working between agencies".[38]

Transition – Working together

Transition is a time where services should be working closely together focusing on the individual and how they can support the young person in their move in to the adult world. Central to this are the outcomes set out in Every Child Matters:

> *Being healthy, Stay Safe, Enjoy and achieve, Make a positive contribution, Achieve economic well being*

These describe the aspirations of disabled young people and are the foundation for all work being undertaken across children's services.[39] For a disabled young person they are the markers of a successful transition in to the adult world the first step in which is meeting the statutory requirement for transition planning to commence at 14 years of age.

How policy applies to people with an ASD

Transition is anxiety provoking for young people on the autistic spectrum and their family. Families and schools need to work closely together, maintaining open and honest communication.

Planning for transition based on individual needs

Multi-agency transition planning, starting at age 14, means that young people and their families are prepared for future changes and that they can participate in planning how those changes should be made. Maintaining a person's special interests, for example, may help a person feel secure. Transition Plans can includes these features and reduce anxiety.

Workforce

It is not possible to deliver fully continuous service provision across the ages of 14-25 years. Where workers are organised to support the young person in a variety of settings then the potential for successful transition is increased. Maintaining continuity for people with ASD has implications for both commissioning practice and workforce development initiatives to improve staff retention.

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36 Guidance for Connexions Partnerships and Personal Advisers supporting young people with learning difficulties and/or disabilities, DfES, October 2002

37 Youth Matters: The Next Steps, DfES, February 2006

38 Further Education: Raising Skills, Improving Life Chances, DfES April 2006

39 Every Child Matters, DfES, 2003

Access to a more transparent and appropriate menu of opportunities and choices

Young people with an ASD need very individual support and often very individual opportunities. As good practice example 17 illustrates, delivering a variety of opportunities requires multi-agency working, flexible funding and skilled support. Choice and opportunity requires decision making and can mean instability, insecurity and change all of which can cause stress and anxiety. Transition planning and preparation can forestall this.

National Service Framework for Long Term (Neurological) Conditions 2005

Summary of the National Service Framework

The NSF for long term neurological conditions sets out quality requirements and evidence base for services for people with long term neurological conditions resulting from disease of, injury or damage to the body's nervous system. It applies to health and social care services working alongside other key agencies such as providers of transport, housing, employment, education, benefits and pensions.

Individual neurological conditions are not separately addressed in the NSF. It states "that although the NSF focuses on improving services for people with neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition. Commissioners are therefore encouraged to use this NSF in planning service developments for people with other long-term conditions".

The NSF sets out eleven quality requirements that include:

> The need for person centred services. This requirement underpins the NSF. It emphasises the need for good service coordination, provision of information and for a holistic, integrated, interdisciplinary approach to care planning.

> Prompt diagnosis, appropriate referral and treatment. These requirements focus on ensuring people with long-term neurological conditions are referred to appropriate specialist healthcare services as quickly as possible and that:

> a. Primary care and acute hospitals are skilled in recognising different neurological conditions.
> b. People with neurological symptoms get referred to specialist services quickly in accordance with locally agreed protocols;
> c. People get prompt diagnosis;
> d. People get emergency care from staff with appropriate skills and facilities;
> e. Appropriate treatment is jointly agreed with people
> f. People receive safe and effective medicines, the use of which has been jointly agreed between healthcare professionals and the person.

Opportunities for rehabilitation, adjustment and social integration

This requirement ensures people are appropriately supported to make major physical, emotional, social and environmental adjustments. It emphasises support in appropriate settings. It covers support provided to people as they adjust to change and take part in leisure and other social activities. It also addresses work, vocational rehabilitation and supporting people to return to employment.

Multi and inter - disciplinary working

This requirement reemphasises the importance of different professionals working together to a common goal in an integrated way.

Lifelong care and support for people with long-term neurological conditions, families and carers
The five requirements under this heading underline the importance of; well coordinated, long-term support, maintaining independence, social and psychological well and providing personal care, support, equipment and accommodation planned around individuals needs in their own homes. They emphasise the benefits of assistive technology, information advice and support to families and the management of care in other settings (e.g. support for neurological difficulties during everyday health care intervention e.g. dentistry and screening clinics).

The importance of providing good information about a person's condition and sources of support and help is a recurrent theme throughout the NSF.

How policy applies to people with an ASD

The NSF for Long term (Neurological) Conditions sets out quality requirements and evidence base for services for people with long term neurological conditions resulting from disease of, injury or damage to the body's nervous system and their carers. It states "that although the NSF focuses on improving services for people with neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition. Commissioners are therefore encouraged to use this NSF in planning service developments for people with other long-term conditions". These other long-term conditions could include people with ASD who often have a broad spectrum of needs (e.g. physical, motor, sensory, cognitive, behavioural, communication, psychosocial and emotional difficulties).

The issues covered in the NSF for Long Term (Neurological) Conditions are covered elsewhere in this paper and are therefore signposted, rather than repeated, below:

- The need for person centred services applies to people with an ASD. More detail on PCP and people with an ASD can be found in the Valuing People section
- The NSF for Long Term Conditions builds on previous policy by emphasising the importance of person centred practice. The need for holistic, integrated working a way to achieving this for people with ASD is covered in other relevant policy and in this paper the Mental Health and Our Health sections.
- The NSF for long term conditions alongside the NSF for Mental Health make the strongest case of all national policy documentation for early and robust diagnostic services. This really matters to people with ASD. Diagnosis and diagnostic services are covered in the mental health section.
- Emergency and acute management for people with ASD are covered in sections on Fair Access to Care and Our Health.
- Community participation, vocational and educational opportunities are important and often overlook for people with ASD. Reference is made to these in Valuing people and Improving Life Chances sections.
- The benefits of assistive technology and housing are covered in Valuing People and Our Health sections.
- Providing personal care and support for people with an ASD is covered in the Valuing People section.
- Supporting family and carers of people with ASD is covered in the Mental Health and Improving Life Chances sections.
- Supporting people with an ASD in hospital or other health and social care settings is covered in Our Health and Valuing People sections.
- There is a greater emphasis on the need for good accessible information both about neurological conditions, services and how to get help in the NSF for long terms conditions than in other policy. This stresses how important it is for commissioners to identify the primary sources for the production and supply of information. Clarity about this in locally developed joint working protocols and care pathways would go a long way to meeting the needs of families and people with an ASD.

Appendix 2
Best Practice Examples

Commissioning & joint working

1. Suffolk Mental Health Partnership NHS Trust

Learning Disability clinical psychologists undertake assessments and consultancy work for people referred from by adult mental health (AMH) practitioners e.g. psychiatrists, occupational therapists, community psychiatric nurses and social workers. They undertake diagnostic work and follow this up by working with AMH staff. This might mean training, attending review meetings, working with staff groups etc. The Learning Disability Directorate has moved away from purely using an IQ below 70 as a cut off for access to specialists who work in the Directorate. It has meant cross service working i.e. between AMH and LD and skills and interest are slowly building in the AMH service. The approach benefits all concerned.

A group of specialist clinical psychologists meet regularly to discuss ways of moving services in the Trust forward for people who have AS who live in Suffolk. In a related piece of work, one psychologist is undertaking a project to explore what role Suffolk Mental Health Partnership NHS Trust should have in provision for people with AS. This project is under the guidance of the Director of Learning Disabilities and the Trust Chief Executive. It has involved talking to different stakeholders who have an interest in AS and a survey of staff in AMH about the difficulties they have in providing services. As a result, AMH staff have identified training needs that have been raised with the Workforce Development Manager. Part of the project will explore the costs of Extra Contractual Referrals (people placed out of area) compared to developing local services and what services people with AS who become involved with the Forensic Service need.

Contact: Dr Fiona Hay fiona.hay@smhp.nhs.uk

2. Leicestershire, Multi-agency Approach

In recognition of people falling between services and insufficient appropriate services for people with Asperger Syndrome, an Asperger Syndrome Planning group was established in November 2003. It consists of multi-agency representatives including family carers, Leicestershire Partnership Trust, Leicestershire and Leicester City Council Authorities, Primary Care Trust, Learning Disability Services, Child and Adolescents Services.

The group reports directly to the LIT (Local Implementation Team) for Mental Health and links with Learning Disability Partnership Boards, Counties and City Local Authorities, including Children's Services such as CAMH'S and Transition Services.

The group focuses on strategic planning to enable people with ASD/Asperger Syndrome fair access to assessment and services, within the framework of Local Authorities Statutory Duties and Local Health and Social Care Policy and Practice Guidance.

Regular meetings take place to discuss and action planning specific issues such as: diagnosis, education, carers' needs, transition, Fair Access to Care, review and commissioning. Other professionals are invited to the meetings to contribute expertise in specific areas.

Members of the group have established clear pathways and responsibility for Community Care Assessments and care packages. There is a Pathway Protocol for Community Care Assessments for people with an ASD. For the Pathway Protocol to be applied, staff who first come in contact with people with Asperger Syndrome, commissioning staff and support workers get guidance about the protocol and awareness about Asperger Syndrome to identify and refer people to the relevant services.

A multi-agency training programme was established. A series of training sessions on basic Asperger Syndrome awareness and the local protocol were provided to social & health care staff as well as social the independent/voluntary sector. The training was delivered by core group members (leading mental health and disability practitioners, and carers) over 7days and attended by 210 multi-agency professionals. The attendees included carers, Social Workers, Psychiatrists, Nurses, occupational Therapists and Health Visitors. Due to the success of the training, a further two sessions and one more advanced session will be provided in 2006. There has also been a request for further training sessions and due to resource implications future training will need to be provided through an alternative route.

Adults with Asperger Syndrome and carers were consulted about their views about services to inform service development in this area.

Two sub-groups were also formed to develop a longer term training strategy and to map services to people with ASD/Asperger Syndrome. Both sub-groups reported back to Asperger Planning group.

Contact: Pratima Patel, pratima.patel@leicester.gov.uk, Planning and Service Development Officer Adult Planning and Service Development Team Adult and Community Services Leicester City Council 2nd Floor, Town Hall, Town Hall Square, Leicester, LE1 9BG. Tel: 0116 225 4774

3. Somerset Asperger Syndrome Consultancy Service

The Asperger Syndrome Consultancy Service (ACS) was set up in January 2005. They provide a diagnostic service and post diagnostic support as well as advice, consultancy, co-working, support and training both for carers/users and those working with people with Asperger Syndrome (AS). The team is part of Somerset Partnership which is an integrated Mental Health and Social Care Trust

ACS provides services for people aged 18+. A transitions assessment is made when there is uncertainty which adult service should take responsibility for the person with AS.

The team was created after Approved Social Workers and Learning Disabilities specialists recognised a high volume of referrals during liaison work between MH and LD services.

The Team consists of Team Leader for the ACS, who is an ASW another specialist Approved Social Worker for Learning Disability a specialist Occupational Therapist 1 day of clinical psychology. Service capacity is being increased to cover 12 diagnostic Psychiatry Assessments annually and 12 annual sessions of Speech and Language Therapy. There is administrative support of 2.5 days a week.

The team has a comprehensive operational policy. Referrals come from an identified care co-ordinator and the team is piloting a diagnostic pathway. They have devised a basic awareness training which is being followed up by an enhanced training for Link workers focussing on management strategies. There is planned to be a Link worker in every mental health team plus representatives from connexions, mind, education and support time and recovery workers. They will carry a maximum of 3/4 cases and will act as a source of knowledge and support for their teams. The ACS will in turn provide the Link workers with support further training and expert supervision.

ACS has a close relationship with carers, learning disability services and voluntary organisations through an Autism interest group that meets four monthly. They support and closely liaise with the preferred provider of specialist supported living resources within the county and also other housing providers across the County.

The service has made a significant impact on the way people with AS and their carers experience services and are becoming increasingly contacted by other Trusts/Authorities wanting to both learn from our experience and build on their own.

Contact: Pat O'Connell, Peter Webb and Lisa Masters. Contact: Pat O'Connell, Team Coordinator, Asperger Syndrome Consultancy Team, Southwood House, Southgate Park, 2/4 Taunton Road, Bridgewater, TA6 3LG. Tel: 01278 426 203.

4. Liverpool Asperger Team & Managed Care Pathway

In 2003 an innovative service was set up in Liverpool to provide services to people who have Asperger Syndrome to ensure that people who fell through the gap in service provision would have specialist support and a direct route into multi-disciplinary services. The team is commissioned by Central Liverpool PCT with a contribution in terms of a half time social work post from Liverpool Social Services. The team consists of a Team Manager who is also a Head Speech and Language Therapist, two community nurses, a psychologist, a social worker and a support worker. There have 283 referrals in 3 years and 90 people are actively supported. The referral process is open and designed to be as person centred as possible. Referrals must be over 16 and a resident of Liverpool or have a Liverpool GP. The only other criterion is that the individual is in agreement with the referral being made or has self referred. People do not have to have a formal diagnosis of Asperger Syndrome as the team carry out the diagnostic work. Sometimes people come to the team specifically for a diagnosis and return a couple of months later to talk through what the diagnosis has meant and continues to mean for the future.

The Liverpool Asperger Team provide a person centred approach to assessment and diagnosis, and to the support and inputs offered to people when they are accessing the team's services.

The team use the Managed Care Pathway approach to co-ordinating services. Acting as a central point of access from assessment and diagnosis, the team also have a co-ordination role within a whole network of services.

The Team acts as a bridge to services, both in terms of the person being supported to acquire other services and to other agencies and in terms of helping services to understand what makes sense for the individual who has Asperger Syndrome.

In terms of services such as employment support, education, and other statutory and non statutory services, the care management role is usually undertaken by a member of the Asperger Team. The pathway also includes an active group of people who use the service which is autonomously run, and a carers group.

Services in the Managed Care Pathway include specialist services in the criminal justice system, mental health services and alcohol and substance misuse services. Where people using the service have been regularly admitted to in patient services it is likely that the care management role will be with this service, as the Asperger Team do not have a Registered Medical Officer. They do have some psychiatry input mostly for second opinion. In this situation the focus is firmly on joint working.

The team supports people in accessing and using a whole range of co-ordinated services. From supporting people in prison to helping women on the maternity wards write their birth plan, they offer a person centred approach and support designed to meet individuals' needs.

Contact: Liverpool Asperger Team, Chris Austin. chris.austin@merseycare.nhs.uk Tel: 0151 737 4805

5. Newham, Rehabilitation and Continuing Care Team

Newham Adult Services, in partnership with ELCMHT (East London & City Mental Health Trust), have launched a project to coordinate services for adults with Asperger Syndrome (AS) or High Functioning Autism (HFA). An initial report found that people who receive a diagnosis of AS / HFA were receiving ineffective and costly services, such as crisis management. There were no specific services for this group. Demographics for Newham suggest that over 650 adults would meet the diagnostic criteria, however, only a small number are known to services. In developing a service Newham will enable those people to access appropriate support.

The new service aims to:

- Provide easier access to assessment;
- Provide individual assessments to those who meet the criteria to determine the impact of AS/ HFA;
- Signpost to provider agencies, services and advice;
- Provide a specialist service to support the most complex needs.

The project offers training to partnership agencies, including colleges, voluntary groups and community groups to raise awareness of AS/ HFA. It aims to improve the accessibility of community services to adults who have AS/ HFA that will hopefully include education and employment opportunities. The project plans ongoing development work with involvement from service users and carers and will be consulting on a long-term strategy to ensure that the needs of this group are properly recognised and supported. Partnerships are an integral part of the way the independent and voluntary sector works in Newham. There has been close consultation with the National Autistic Society.

Contact: Melissa Balik, Recovery and Rehabilitation Team, Warton House, 150 Stratford High Street, London, E15 2NE or melissa.balik@elcmht.nhs.uk

6. C-Change, Interagency working

C-Change for Inclusion is a supported living organisation in the Greater Glasgow area. They are small, providing individually designed services for about forty people. They are an organisation that successfully supports adults with learning difficulties who, due to their reputation for challenging services would most likely remain in segregated settings. They are not a specialist organisation and believe that their success in keeping people in their own homes is based upon collaborative working with the people they support and all those involved in their wider network of support such as family, advocates and professionals (care managers, community nurses, psychiatrists and psychologists).

Albert spent most of his adult life in secure institutional settings. He has had a number of labels assigned to him including "being on the autistic spectrum". He's had two independent living services fail him resulting in his return to hospital. He's made it clear that these readmissions were against his will. Albert challenged his support in ways that posed considerable risk to himself, his support team and the wider community. C-Change knew that they wanted to support Albert to remain in his home and not to have to go back to hospital. They have created a dynamic process for agreeing risk management strategies that involves 2 weekly risk management and planning meetings attended by the Community Nurse and the Practice Team Leader both from the Learning Disability Team, his Psychiatrist, his Psychologist, the Behaviour Nurse Therapist from the Learning Disability Partnerships Complex Needs Support Team and his Housing Officer. This bigger group have adopted creative risk management strategies focussed on preventing readmission to hospital. Albert spent a short time in prison and had to move home, but for the first time in his adult life he has now spent two years in his own home. C-Change is confident that he will continue to do so as long as he chooses to. By working together they broke the cycle that had dominated Albert's adult life.

Contact: sam.smith@c-change.org.uk

7. Mary's story

In 2002 Mary lived in residential accommodation with two other people having moved there from residential school. When asked she said she liked where she lived however she found living with other people difficult as there were features of the house which she did not want to share that were in communal use (e.g. light switches). She expressed regular frustration at having to share but was unable to articulate this other than by causing damage to the house or to other people. She asked to move regularly however this was interpreted both by professionals and staff that supported her as "typically autistic behaviour", "perseveration" and "repetitive use of language". It was assumed that because she expressed her frustration physically her aspiration to live in single accommodation (with staff support) was unrealistic. Professional advice given initially was to respond to her request with a set response ("no, you live here"), by reinforcing and encouraging her when she was not angry or with medication. These all increased her anger and frustration and episodes of challenge increased in both duration and intensity. Eventually the multidisciplinary team faced a choice. They could either admit Mary to an assessment and treatment unit, or take a risk and try to listen to and respond to her request. They did the latter and Mary has been living successfully, independently, in her own home. Within days after her move, Mary's 'challenging behaviour' disappeared almost entirely. Her support levels have reduced and she is engaging in activities in the community which she never would have coped with before.

Contact: Chief Executive, Kingwood Trust, 01491 410450

8. Surrey County Council

Surrey County Council recently produced a strategy that uses population needs assessment to plan future health and social care services for people with an ASD. Surrey's strategy outlines systems for allocating responsibility for new referrals and assessments ("the mental health and learning disability services protocol") and for local service development through a network of "Autism champions" drawn from key stakeholder groups such as housing, health, social services, independent sector providers, leisure and employment.

Contact: Thomas.moore@surreycc.gov.uk

9. North West Regional Autism Task Group

In the North West Region services are being developed through specialist providers and commissioners working together to develop Autism expertise in local services. The task group was established and coordinated by Brenda Nally, Regional Coordinator for the NAS and is chaired by Anne Williams. All the NW local authorities and all the ASD-specialist providers are members of the network. The North West Autism Task Group reported to commissioners in 2002 on the implementation of Valuing People. It recommended more regional strategic work and local collective work through multi-agency Autism Services Development Groups, comprised of statutory agencies working closely with parents/carers and independent sector agencies.

The best example of it is in Greater Manchester where the Autism Consortium has worked in this way since 1996. (See best practice example 13)This consortium has been promoting regional strategic commissioning, but recognised that the processes for its effective development need to be agreed as a first step.

A parallel development to the Greater Manchester Consortium was Partners in Autism. This is the group of ASD-specialist provider agencies in the region. They and the commissioners from Learning Disability and Childrens' Disability Services set up a working group to produce Commissioning Standards for services for people with an ASD. The commissioning standards will be available from 12th June 2006.

Contact: Brenda.Nally@nas.co.uk, Tel: 0161 998 7860, Mobile: 07766 311971

10. Greater Manchester Consortium

A consortium has been formed by the 10 Social Services Department in Greater Manchester. It funds and steers an NAS project that supports development of local services for people with an ASD. There is an Autism development group in each of the 10 local areas that comprises of families, providers, health education and social services. Social Services Managers from each locality form the consortium steering group The Consortium has formed a regional training strategy awareness-raising pack which is available to all within the consortium to deliver for free. A parent resource pack was produced in partnership with local Autism society and the consortium runs parent workshops.

The consortium holds an annual convention when good practice is shared. There has been discussion about joint commissioning across areas although this has not yet materialised. The project produces a regular newsletter and has modified an information booklet for adults with AS for use within Greater Manchester.

Contact: Mari Saeki and Debbie Waters, Project Officers, NAS, Tel: 0161 998 4667, E mail: mari.saeki@nas.org.uk, debbie.waters@nas.org.uk.

Individualised Services

11. Patrick's Story (Partners for Inclusion, Ayrshire)

Patrick is a man with an ASD and a severe visual impairment. For 18 years he lived in a long-stay institution developing a reputation for extreme challenging behaviour and causing people severe harm 7 or 8 times a week. When the hospital was closing Patrick was referred to a service provider (Inclusion Glasgow) who used the principles of self-directed support to design and deliver a support service to him. In practice this meant:

- Patrick was allocated an Individual Budget of £60,000 per year
- Patrick and his family were highly involved in designing his support service and supporting the management of the service
- Patrick was found his own home to meet his needs; this involved setting up a trust with family to buy a home that was paid for from Patrick's benefits
- Patrick had his own small support team, recruited just for him. Some of the team lived with him, some did not.
- Policies, procedures and working practices were designed around Patrick, to keep him and other people safe.

10 years later Patrick is thriving. His family play a real part in his life and he is happier and much less anxious. Although one can never say that his difficult behaviour has gone, the incidence of such behaviour has fallen dramatically. He lives in an environment that has been designed to meet his individual needs. He is no longer forced to live with people who are likely to attack him. Although he had flatmates they since moved out but continue to support him. He also no longer lives with people who are vulnerable. This means that everybody is much safer. In the last 7 years he has only hurt people twice.

Contact: doreen.kelly@partnersforinclusion.org

12. Story from a family that chose a Direct Payment.

"Our son has a diagnosis of Autism and severe / moderate learning difficulty. He lived at home until he was 23. No suitable day care could be found in his home town so he was moved to an Out of County Residential Service (Autistic Specific) which meant a loss of family and friends as well as living with other unpredictable people. He needed a single person service. The local authority refused to fund a provider to do this and so the provider served notice. The local authority made no provision for him; no one knew where he would be living. He was evicted 2 days before Christmas and moved to four different locations in one calendar year. Consequently he was suicidal and displaying challenging behaviour (not surprisingly). We did a Person Centred Plan (a PATH) to show us what to do quickly and well and also an Essential Lifestyle Plan to help my son recover control over his life. We took the plan to Service providers who were saying, the plan sounded good, but it wouldn't work. They couldn't deliver it because "corporate priorities were more important". They felt they could not alter how they did things e.g. shift patterns, pay structure, staff team, person specifications, team structure and where and who lives with who etc. We helped our son exercise his right to a Direct Payment to secure his way of life. We formed a Trust to help him manage his money. He now has his own home with a consistent staff team. He chooses who comes and goes and what he does. He is recovering and beginning to regain trust in people. There can be no more enforced evictions. He has a stable life. We are saving the Local Authority a fortune. It costs a fraction of what they were prepared to give a provider to go on providing the same kind of service that failed. We can act quickly so things don't get to crisis and all the money gets spent on HIS needs. We still have things to sort out, life is like that, but we are not going to bail out on him when things get difficult".

Contact: Jackie Clarke

Person Centred Planning & approaches

13. Health Farm – Person Centred Planning

A young man with an ASD lived in his own flat, had a job at a local supermarket and was in a relationship. When his relationship with his girlfriend broke down, he lost his job fell into despair and would not talk to anyone. His name was John.

John was placed in an Autism specific residential service. He talked at length about his future plans however when asked what he wanted and when, he became very anxious, abusive and uncooperative. He was asked if he would like a person centred plan. His support provider started by developing a circle of support.

Developing a circle of support/friends for John had benefits on many levels. It provided him with the opportunity to, have good role models, facilitate conversations, develop his specific interests, develop skills for social conversation and empathy.

John's circle of support got people together in a small discussion group and by using pictures/graphic facilitation they were able to bring his dreams to life. Part of this meant making the whole process more concrete. The visual planning helped with his lack of executive functioning. John now lives in his own flat and is employed as a kitchen assistant at a local care home for older people

The four homes on site at Health Farm now have over twenty people who have plans. Seven people have moved into their own homes, four people have obtained meaningful employment, many people have succeeding in fulfilling their dreams and aspirations for the future. This work demonstrates that Person Centred Planning with people with an ASD helps people to regain control over their own lives.

Contact: Maggie Sykes, maggie.sykes@autismcareuk.com . Tel: 01526 320312

14. A Provider of Choice.

The Missing Link Support Service, Ltd. (MLSS) was established by a former Consultant Psychologist, specialising in learning disabilities. MLSS aims to provide psychological support to people who feel they do not 'fit in' to society (getting around the need for an IQ test or a diagnosis).

The MLSS has received referrals from individuals from over 5 counties, mainly people with an ASD that need help with an 'official' diagnosis or in managing the anxiety associated with day to day living. Work is done with individuals, families, NHS, social services or private care staff, courts, prisons, probation and secure units.

The work is based on the principles of Solution Focused Brief Therapy which focuses on discovering existing strengths and working out how to use the things that already work to help the person achieve the goals they set for themselves. It is helpful in establishing respectful working relationships, even when relationships are usually difficult for the individual to make and using a person's own language rather than professional language of 'feelings', 'emotions' and thoughts. .

MLSS is founded on co-working with people who have an ASD, learning disabilities or mental health problems who co-present in training and conference speaking.

Practice Examples:

Andy was referred to the MLSS due to severe aggression culminating in a serious attempt to kill a family member. The referral came from the Community Mental Health Team (CMHT) where multiple members of the team were involved including psychiatry, nursing and occupational therapy. No inpatient bed could be found for Andy's level of communication and social skill. He had been removed from his home and placed with an extended family member who was unsuitable. The CMHT needed specialist input because they were unsure how to proceed. The entire family wanted Andy to return to his family home. Andy was an expert in knowing what things worked and didn't work for him and MLSS provided expertise in asking questions and noticing Andy's existing strengths and coping skills. By focussing on these Andy managed to carry on with his college course, start a weekend job, and organise his time between meeting various professionals. MLSS worked with

Andy's mother, father and sister to create a plan for Andy's return. MLSS was flexible, meeting with Andy in the evening or at weekends. Using this approach the solutions and plans were instrumental in his return to the family nonetheless.

Martin was referred for support by his mother because he had struggled to cope in his own flat. He became more and more isolated and less able to cope with the demands of daily life. Local Mental Health Services became involved and concluded he was psychotic. When he would not cooperate with the Mental Health Services they tried to section him under the Mental Health Act. He moved in with his mother and became house-bound not talking to anyone outside the family for two years. MLSS established an expert to expert relationship with Martin revealing his many strengths. Within 3 meetings however Martin was able to sustain a conversation about topics relevant to his situation. After 7 sessions he was able to go out and after 10 the Mental Health Service was reintroduced. The family coached the Mental Health professionals, (e.g. psychiatrist, social worker and psychologist as well as a new GP) in how to help Martin. MLSS involvement is being phased out as local services take over his care.

Contact: E. Veronica (Vicky) Bliss, Consultant Psychologist, The Missing Link Support Service. http://www.missinglinksupportservice.co.uk. Email: mailto:clarks@globlanet.co.uk. Tel: 07971 569042

Employment & Community Inclusion

15. Prospects Employment Support (National Autistic Society).

Prospects is a specialist employment consultancy for adults with an ASD. It is part of the National Autistic Society. They have five branches – in London, Glasgow, Sheffield, Leeds and Manchester.

Prospects provide work preparation training, assistance with job finding, and support in the workplace as well as training and consultancy to managers and their teams. They are job brokers for New Deal for Disabled People, working in partnership with Status and Breakaway. Two newer projects include an 'Access to employment' course, providing training and support primarily in the areas of social and communication skills. The other project is a 'Transitions' course aimed at final year university students or recent graduates living in London making a transition from university to employment. Prospects have successfully placed people with major investment banks, government departments such as the Foreign and Commonwealth Office, Cabinet Office, and National Audit Office as well as Local government.

Contact: Prospects – Studio 8 The Ivories, 6-8 Northampton Street, London, N1 2HY. Tel: 020 7704 7450.

16. Kingwood Trust Community Engagement Project

In 2002 The Kingwood trust was awarded funding for a 3 year project by the PPP Health Foundation. The objective was to identify innovative ways in which to support people with an ASD to participate in community activities. In the first year, 8 people with an ASD took part and a Community Development Coordinator was appointed. Each person's aspirations were identified and plans written to help achieve these. Some were very modest, for example one woman's aspiration was able to walk to the shop whilst coping with the noises of the environment, and others more challenging e.g. finding paid employment working in a hotel or to learn Japanese. Each year more people were included in the project and training courses were designed for support staff based upon the learning gained over the lifetime of the project. Community presence increased for those involved in the project, and there was general increase in community involvement across the organisation. Staff members are now more confident in taking risks as well thinking creatively in identifying ways in which to help people to achieve their aspirations in the community.

Contact: Chief Executive, Kingswood Trust, 01491 410450,

17. Improving Choice Transition Broker – Cambridgeshire and Peterborough Learning and Skills Council and Cambridgeshire and Peterborough Connexions Service

Through funding from the national Learning and Skills Council to the eastern region, Cambridgeshire Connexions Service were able to employ a transition broker whose role focuses on supporting the development of local post-16 and post-19 learning opportunities for young people who would have historically gone away to residential college or in to local day service.

Centred round the three colleges; Peterborough, Cambridge and Huntingdon he project has been running for a year. The project is due to end in July 2006. Fourteen young people including a number with an ASD spectrum have been supported in developing an individual/personalised learning package that has meant they can access local learning whilst living in their home community.

For a number of young people they have a direct payment from local social care services which is part of the funding for their support i.e. they receive support from a set group of people, part of which is funded via the local college with 'Improving Choice' funding and part of which is funded via direct payments. The package is informed by a multi-agency group of professionals including paediatricians, speech and language therapists, nurses, social workers and college staff. The broker acts as the person pulling together the different strands of funding and support and fulfils this role by being a bridge between professionals, college, independent providers and the young person and their family.

For one young man, aged 19, with Aspergers this means he attends a local mainstream college for three days a week, with support from familiar people, he has a work experience placement at a local garden centre (his choice) and he lives in supported living about a mile away from his parents. His parents speak of how relaxed he is and how happy they are for him.

This example highlights the three key components of transition: transition planning based on individual needs, continuous service provision and an appropriate menu of opportunities and choices.

Contact: Trish Bugg Learning and Quality Director Learning and Skills Council, Learning, Planning and Performance, Felaw Maltings, 42 Felaw Street, Ipswich, Suffolk, IP2 8SJ, Tel: 01473883076, Mobile: 07789 273 887, Email: trish.bugg@lsc.gov.uk

18. National Autistic Society Social Groups

The National Autistic Society runs social groups across the UK for people with Asperger Syndrome. Groups are supported by volunteers, meet monthly and agree their own activity programme. People using the groups and their families report improvements in mental well being and reduction in feelings of isolation.

Contact: socialprogrammes@nas.org.uk

Housing Design

19. Design matters
(Synopsis of findings from a Report by Housing Options for the Shirley Foundation)

Most architects and service commissioners have little experience in design for people with an ASD. Like service design, knowing about individuals is more important than following recipes. Some behaviour patterns, compulsions or aversions can be lessened and increased by an environment but it is a very individual matter.

Designing to accommodate every potential risk and contingency associated with an ASD can begin to look institutional. To learn living skills and independence people need to manage in as ordinary a world as possible. The usual criteria for good housing apply and what follows is a checklist of points for particular attention.

- Space standards: limited personal or communal space is unsatisfactory, especially if you have an ASD. If a building is generous with space people manage better
- Simple layout: a clear layout and organisation of spaces can help the use of a building, minimising confusion about location of rooms and their uses.
- Serviceable and hardwearing materials are available for any requirement. The priority is finding the right balance between necessarily special and ordinary domestic standards.
- Light, acoustics and noise is important in design. Some people can be very sensitive to noise. Layout, sound insulation, choice of materials and furnishings help.
- The choice of furniture, fittings equipment and furnishings all need thought. Understand and plan for the individual.
- Security and risk management should be part of the thinking in design but personal support is often more important than physical solutions to reduce risk.
- Assistive technology can help promote independence, improve safety and provide practical help with home life. A recent guide has good examples.

20. A housing story

During transition planning a number of young people attending a small post 16 college run by Hampshire Autistic Society identified the need for a place to live at the end of full time education. Social service authorities were informed and agreed in principle to fund support services.

The local autistic society was willing to provide the support meaning suitable accommodation was needed. A housing association agreed to the purchase of a house using Social Housing Grant towards the costs. The important criteria for the choice of housing were whether the young people wanted to share, location, space and amenities. The process for making choices was not straightforward as direct questions were difficult for some of the young people. Ideas were discussed with the group as plans progressed so that provisional assumptions could be tested. A key part of the decision making for the young people themselves is that they had their own ideas about growing up and independence and which could be discussed with them.

Because it was not possible to talk about options that might not be deliverable it took a lot of careful planning to make a choice of where and how the young people live possible.

The design choices that were difficult were affordability, the priorities of the housing association as owner and the priorities of the support organisation with which the residents all of which family advocates may not have agreed with. Issues such as who is in charge, whose standards apply, what are "enough" bath and washing facilities, what is "appropriate" space for staff all had to b worked out.

In the end was as delivered was an ordinary house, a semi, in a quiet street, better than the average student flat-share. As they get older they may want something else but for the time being it's proving a vital part of growing up.

Contact: Maurice Harker, Housing Options http://www.housingoptions.org.uk

Workforce Development

21. Gateshead Multi -Agency Training.

In Gateshead Social Workers wanted to respond positively to prevent service breakdown for people with an ASD and complex needs. After searching for support solutions the team decided to actively promote the development of services with an enhanced likelihood of success and commissioned training that combined:

- person centred approaches to working with people with an ASD
- general information about the support needs of people with an ASD and
- problem solving sessions tailored specifically to meet the needs of an individual.

Families, the provider organisation, representatives from the community learning disability team and the whole of the care management team were involved in the awareness training. People directly involved with specific individuals attended tailored sessions.

Contact: Sue Ashton, Social Worker Tel: 0191 278 8249 E-mail: susan.ashton@newcastle.gov.uk

22. Workforce Development - A brother's story

"For many years my sister was labelled as a person with challenging behaviour. My parents struggled with this all of their lives. Upon the death of my parents I took over the support of my sister totally. With this came all the difficulties that my parents had experienced.

I approached professional bodies to try and get an understanding as to why things were so difficult for my sister. I explained events and behaviour in graphic detail. This was the first time I began to hear the word "autistic."

I already understood my sister but to understand how I could help her I felt I needed to understand Autism. Knowing my sister, helped me to understand what life means for her and how she perceives people, approaches & relationships. Some of my understanding had developed from my sister's brutal experiences in the past. No-one ever understood that she was autistic she was labelled as someone with so called "challenging behaviour". This left her with a great deal of distrust in the motives of people she encountered.

Once I understood this, my challenge was to create a secure environment around my sister with a circle of support that understood her anxieties. This is very time consuming (which can be a barrier for business organisations) and it's the person that suffers. One needs to be very focussed on understanding the small things that give my sister the confidence to be able to begin to trust.

There are two things which work best for my sister. Firstly, the personal approach. This requires a very patient and finely tuned understanding of her. Secondly she needs a positive, trusting relationship. Get these two things right and we begin to understand what support really means for her".

Contact: Don Jones

23. Dimensions UK Ltd

In August 2005, Dimensions where given the opportunity to be involved in setting up a person-centred service for a woman with an ASD. As Dimensions are not considered to be autism specialists they decided on a person-centred approach. The direct support team was vital to success. Staff development needs were identified specifically in relation to the person needing a service by family, providers, commissioners and previous providers working together. The team's health and well-being is a vital component in supporting the individual with in their transition and future life. The key foundation for staff was their values. Thereafter person specific training was agreed and jointly funded by Dimensions and the commissioners. Commitment of all parties was paramount to success, and everyone involved in the life of this individual have been included. Team, managers and area managers attended to ensure the wider organisational team as well as the support circle think on the same lines.

The most important development areas for the team were;

- Understanding the person and not just "autism".
- Understanding the team's health and well-being as a significant part of the support they offer.
- Understanding the person's "world", how it differs from individual team members and how that can be used constructively to help the person.

The plan has resulted in a positive life experience and much more independence for the person, better confidence in the team and improved empathy for how others perceive their "world".

Contact: Jackie Skinner – Area Manager Dimensions UK Ltd. (North East Region) 0191 228 8167

24. Person Centred Approaches to Autism Courses.

Paradigm:
Paradigm has a wide range of ASD products and will be working hard of the coming year to develop further projects. Those currently available include one and two day person centred approaches to autism courses, developing advocacy, leading services for people with Autistic Spectrum Disorders, modernising services for people with an ASD, sexuality and various others. People with an ASD are co tutors on the courses. They draw on theory as well as focusing on the experiences and perspectives of people with an ASD. They seek to teach the key skills staff need to see people as people, "get inside" the condition, have empathy for people who process and see things differently to themselves and to work from that place to help people and families to create the lives people truly want for themselves. The courses can be delivered to groups or designed individually and delivered around the needs of one person, focussing on improving understanding and developing the core of a person centred plan. The courses are particularly useful, when combined with consultancy, to help organisations struggling to find the right support strategies.

Contact: Judith North Tel: 07980297819, e mail: judithn@paradigm-uk.org, www.paradigm-uk.org

Foundation for People with Learning Disabilities:
The foundation runs three courses:
- A 1 day awareness course covering values and understanding ASD. Participants gain an understanding of support strategies to work effectively with people who have autism.
- A 4 day in depth workshop on Developing individualised lifestyles for people with Autism. This includes an awareness course + 3 day intensive workshop on developing individualised lifestyles for people with autism .This course is aimed at people who directly support people with autism including family carers.
- One to one work to establish a lifestyle plan for the future while aiming to develop an inclusive community. Working with the team that supports the person and their family by offering mentoring to establish more person centred work practice. Number of days for this depends on the needs of the person.

Contact: 020 7803 1100, Molly Mattingly: mmattingly @fpld.org.uk, Jill Davies: jdavies@fpld.org.uk
Christine Burke: cburke@fpld.org.uk

Helen Sanderson Associates:
Provide awareness and person centred planning training with a specific focus on people who have autism.

Contact: barbara@helensandersonassociates.co.uk

Appendix 3
Demographics

Demographics

Data on the numbers of people with an ASD is very variable making it difficult for local areas to assess their responsibilities. Variation in numbers, plus differences and changes in diagnostic practice, lead to differences in prevalence rates even locally

Valuing people estimates that there are about 210,000 people in England with severe and profound learning disabilities, around 65,000 children, 120,000 adults and 25,000 older people. There are an estimated 1.2 million people with mild and less complex learning disabilities. There are an estimated 535,000 people in the UK with an ASD

The estimated administrative prevalence rate (i.e. the number of people known to services) of people with moderate to severe learning disabilities is 2.5 per 1000. This does not include people with mild learning disabilities. There are no figures for administrative prevalence for people with an ASD. The most frequently quoted number of people with an ASD is a population estimate of 9.1 per 1000. This includes all ASDs people with an IQ above and below 70, people with severe and profound learning disabilities, with mild learning disabilities and without learning disabilities and people known and not known to services. Additionally the figures for ASD are drawn from studies on children as no prevalence studies have been done on adults. The *administrative* prevalence for LD and *population* prevalence for ASD can not be meaningfully compared. This underlines the importance of local authorities collating local information on the number of people with an ASD in their area to inform planning of services.

"Prevalence estimates will depend on exact assessment tools and ascertainment methods, and variations across studies will likely reflect such methodological differences. However, according to recent reviews, there appears fairly good agreement that the Autism Spectrum Disorders affect approximately 60, and narrowly-defined Autism 10-30, per 10,000 children under 8. The prevalence of Autism among adult populations is not known"[40]. Recent reviews put the figure at 1 in 100 British children with some form of Autism[41].

A further survey by the National Autistic Society [42] found that 49% of adults with an ASD are still living at home with their parents. 70% of parents felt that their son or daughter would be unable to live independently without support and 65% of these adults had not had a community care assessment and were therefore unlikely to be known to the statutory agencies.

40 Medical Research Council, Review of Autism Research, Epidemiology and Causes, 2001,

41 http://news.bbc.co.uk/1/hi/health/5174144.stm

42 Barnard et al, 2001, Ignored or ineligible? The reality for adults with Autism spectrum disorders, London: National Autistic Society, p.5)

Appendix 4
Definitions

Definitions

Medical Research Council Definition of ASD

Autistic Spectrum Disorders are diagnosed on the basis of qualitative abnormalities in social, communicative and imaginative behaviours, and the presence of repetitive and stereotyped patterns of interest and activities. Diagnosis is complicated by the varied manifestation of these core deficits, by wide variation in ability, level and by developmental changes. There is considerable heterogeneity, and sub groups might be usefully distinguished.

What is learning disability?

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development. This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with Autism who also have learning disabilities, but not those with a higher level ASD who may be of average or even above average intelligence – such as *some people* with Asperger Syndrome.

Valuing People White Paper 2001 (emphasis added)

What is mental health?

Mental ill health is so common that at any one time around one in six people of working age have a mental health problem, most often anxiety or depression. One person in 250 will have a psychotic illness such as schizophrenia or bipolar affective disorder (manic depression).

National Service Framework, Mental Health, 1999

The Evidence Base

There is a lack of direct formal evidence for service models, support strategies, and treatment for people with an ASD. For example a recent review of the benefits and costs of models for providing residential and vocational supports to adults with an ASD indicates that the research evidence is scarce.[43] Where relevant this paper is informed by what consensus there is amongst people with ASD, providers and practitioners about what constitutes best or better practice. It is consistent with the general themes arising from the evidence base in the NSF for Mental Health and the evidence base about services for people with learning disabilities[44]. Some people with an ASD and their families are raising

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43 Robertson, J., and Emerson, E., (2006): A systematic review of the benefits and costs of models for providing residential and vocational supports to adults with an ASD. Institute for Health Research, Lancaster University.

44 Emerson, E., Hatton, C., Felce, D., & Murphy, G. (2001). Learning Disabilities: The Fundamental Facts. London: The Foundation for People With Learning Disabilities.

Emerson, E., Hatton, C., Thompson, T., & Parmenter, T. (2004). The International Handbook of Applied Research in Intellectual Disabilities. Chichester: Wiley.

Grant, G, Goward, P, Richardson, M & Ramcharan, P (2005) Learning Disability: A Life Cycle Approach To Valuing People. Maidenhead: McGraw Hill & Open University Press.

Lakin, K.C., & Turnbull, A. (2005). National Goals & Research for People with Intellectual & Developmental Disabilities. Washington, DC: American Association on Mental Retardation.

Odom, S.L., Horner, R.H., Snell, M. & Blacher, J. (in press) Handbook on Developmental Disabilities. New York: Guilford Press.

Stancliffe, R., & Lakin, K.C. (2005) Costs and Outcomes: Community Services for People with Intellectual Disabilities. Baltimore: Brookes.

concern about the use of neuroleptic medication[45] in the treatment of ASD but that is outside the scope of this paper for comment. Specialist advisors need to take care to offer a wide range of solutions in the absence of an evidence base. New developments proposed in primary care (i.e. "mental health worker" roles and GPs with special interests) as well as primary care support provided by learning disability and mental health teams are an obvious place for locating this responsibility and for supporting prescribers. There is some evidence that difficulties with communication mean that some kinds of treatment, like cognitive behavioural therapy, need to be adapted by a therapist that understands the needs of the person with an ASD (e.g. brevity, clearer agreements on turn taking, low arousal) and that group therapy is not appropriate.

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45 http://apana.org.uk