



Service for adults with autistic spectrum conditions (ASC)

Good practice advice for primary care trust and local authority commissioners

Services for adults with autistic spectrum conditions (ASC):
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Services for adults with autistic spectrum conditions (ASC)

Good practice advice for primary care trust and local authority commissioners

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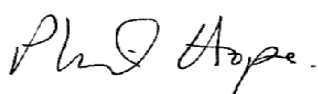
Ministerial foreword

This advice note for commissioners of services for adults with autistic spectrum conditions (ASC) is one of a number of actions that I have publicly committed to taking forward to make real changes to the health, well-being and social inclusion of all adults with ASC. The Government's programme of work aims to do a number of things, including supporting professionals who work with people with ASC; developing a better understanding through research and good practice guidance and making the right links with other strands of cross-government work that will be beneficial to adults with ASC. This work on adults is alongside the cross-government work in relation to children and, when coupled with the right transition arrangements, will help deliver more joined-up and holistic support for all people with ASC.

Central to this programme of work will be the forthcoming consultation on a future strategy for adults with ASC that will take place later this Spring and Summer. As part of that process, we will be working with commissioners to identify and develop the most appropriate tool, such as guidance or a toolkit, for supporting and informing their work. In the meantime, it is important to recognise the wealth of information already available and how it applies to adults with ASC. This advice note builds on *Better Services for Adults with an Autistic Spectrum Disorder* (2006), reminding all those engaged in supporting adults with autism that service planning and delivery cannot be taken forward in isolation from the principles and policies that underpin the wider health and social care system.

Adults with ASC have the right to live a full and meaningful life but, for many of them, achieving that starts with getting the right, person-centred, support from people who have taken the time to understand their condition and their individual needs and aspirations. Sometimes it is the smallest change that can deliver an immeasurable benefit to a person's life; sometimes it requires more – but either way both must begin with an understanding of what needs to be achieved and what the options are for reaching that goal.

I do not underestimate the challenges of effective commissioning. Nor do I underestimate the commitment and desire to change things for the better for the people for whom those services are commissioned. I am committed to making real changes for people with ASC and to supporting those who work with them to deliver that change. I hope that this document plays a part in delivering that change and I look forward to working with those involved in the commissioning of services for adults with ASC to identify how we can better support the process in the future.



Phil Hope MP
Minister of State for Care Services

Purpose

1. This good practice advice is aimed at commissioners in primary care trusts (PCTs) and local authorities who have responsibility for commissioning services for adults with autistic spectrum conditions (ASC). This advice does not identify any new expectations or requirements but aims to bring existing information and good practice to the attention of commissioners so that they may enable, empower and promote independence and meaningful choices for adults with ASC.
2. This programme of work is set within an equality and human rights approach - that people with ASC have, and should be able to enjoy on an equal basis, the same rights as everyone else. Services supporting adults with ASC need to ensure that they are fully compliant with the relevant equalities and human rights legislation (Human Rights Act (1998) and the Disability Discrimination Act (2005). The Disability Equality Duty within the Act requires public bodies to check the impact of their policies on the lives of disabled people.

Summary

3. Many adults with ASC find it difficult accessing the local services they need. Services can be set up and organised in a way that prevents access or makes it difficult, resulting in people being completely excluded.
4. The Government is committed to doing more to support people with ASC and their families, and to driving improvements in the NHS and local authority services so that people with ASC experience real improvements in their everyday lives. During late Spring and Summer we will be consulting on ideas for a strategy for services to support adults with autism. The consultation will be considering five key themes to deliver real change for people with ASC – health, choice and control, social inclusion, employment, and awareness raising. The consultation will provide an opportunity for all stakeholders, including commissioners and people with ASC, to have their say on how services can be improved and how they can best be supported in achieving that aim.
5. In addition to the consultation and subsequent strategy, there will be a number of other actions that will support the understanding of the needs of, and delivery of services for, adults with ASC. These include:
 - addressing issues relating to the collection of data on adults with ASC;
 - research on the prevalence of autism among adults;
 - research into the transition of young people with autism to adult services;

- evidence-based good practice guidance on choice and control from the Social Care Institute of Excellence;
 - links with the forthcoming strategies on employment for people with learning disabilities and mental health needs;
 - work with professional bodies to take action to address training issues, eg the work being taken forward by Skills for Care on new knowledge sets to support people with ASC;
 - links with the implementation of the learning disability strategy, *Valuing People Now*, which will secure improved support for adults with autism who also have a learning disability.
6. There are also a range of initiatives aimed at children which, when coupled with good transition arrangements and effective joint working between children's and adult services, will benefit the way services are commissioned and delivered for everyone. These include:
- the Child Health Strategy with its focus on early engagement and early intervention;
 - Aiming High for Disabled Children to transform services for disabled children, including those with autism;
 - increased funding to the Autism Education Trust (AET) to improve commissioning of services for children with autism;
 - improvements to training and support for professionals working in mainstream education; and
 - new regulations and statutory guidance for Children and Young People's Plans.
7. Commissioners have told us that they would welcome guidance around commissioning services for adults with ASC. Alongside publication of the strategy for adults with ASC, the Department of Health will publish specific commissioning guidance or a toolkit focussing on actions and outcomes and will develop this over the summer with involvement from the people who commission and use services. With that in mind, we have posed some questions at the end of this document that we would welcome commissioners' views on.
8. In the interim, before the publication of detailed commissioning guidance, this advice note seeks to support commissioners by signposting existing information that may be helpful in informing the commissioning process.

Words used and their meaning

9. Within this document the term 'autistic spectrum condition' (ASC) but we recognise that there are also other terms in use. ASC covers people from across the autistic spectrum including those who have a diagnosis of autism, autistic spectrum disorder (ASD) or Asperger syndrome. The term autistic spectrum disorder (ASD) is a common term in use today and is used and recognised in current practice when considering diagnostic issues
10. ASC is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The word 'spectrum' is used because the characteristics of the condition vary from one person to another.
11. The three main areas of difficulty, which all people with an ASC share, are known as the 'triad of impairments'. They are difficulties with social communication, social interaction and social imagination.
12. People with ASC can also experience the presence of unusual development (such as repetitive or restricted behaviours, aversion to change etc) alongside the absence of usual development (such as responses to affection and verbal/non-verbal communication.)
13. It can be hard to create awareness of ASC as people with the condition often have no obvious disability - many adults find that they are misunderstood. Some individuals will not want to have their condition recognised but their need for support may be great. In such cases, parents and other relatives often provide the care and support needed and this can lead to further stresses within the home and for all concerned.

Prevalence

14. As well as understanding the needs of people with ASC, it is also important to understand the size of the population for whom services are being commissioned. The Department of Health recognises the current lack of evidence in relation to prevalence and is commissioning research in this area.
15. The existing estimates for the prevalence rate for ASC vary dependent upon how it is diagnosed and defined. Earlier studies¹ estimated prevalence to be around 5-10 per

¹ Lotter, V. (1966), 'Epidemiology of autistic conditions in young children, I. Prevalence, *Social Psychiatry*, 1, pp 124-137

10,000 of the general population but more recent reports² have estimated prevalence rates up to 116 per 10,000. Approximately 16 people per 10,000 people have particularly complex needs linked to ASC.

16. In developing the adult autism strategy for adults with ASC and further commissioning guidance, the Department of Health will be looking at what actions need to be taken to establish a system to collate the number of adults with ASC in local areas and how to improve the information and data that adult services need to receive about the number of young adults in transition.

The planning and delivery cycle

17. Commissioners will be aware of the stages in the planning cycle from assessment of needs to the performance management of outcomes. These stages are set within the context of patient, service user and public involvement and include:

- assess needs;
- review current service provision;
- decide priorities;
- specify needs;
- shape structure of supply;
- manage demand and ensure appropriate access to care;
- clinical decision making (where required); and
- manage performance for quality and outcomes.

18. World class commissioning is about delivering better health and well-being for the population, improving health outcomes and reducing inequalities. In partnership with local government, practice based commissioners and others, PCTs supported by strategic health authorities will lead the NHS in turning the world class commissioning vision into a reality, adding life to years and years to life. We have a clear vision to develop a patient-led NHS that uses resources as effectively and fairly as possible to promote health, reduce health inequalities and deliver the best and safest possible healthcare. Our health reforms are changing the way that health care is commissioned. World class commissioning applies to all services commissioned by PCTs, including those for adults with ASC, and achieving equality of outcome is at the heart of world class commissioning. When commissioning general services, ie ones not used exclusively by adults with ASC, PCTs are expected to give consideration to the needs of all people using those services.

² Baird, G. et al (2006), 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)', *The Lancet*, 368 (9531), pp210-215

19. At the heart of world class commissioning is clinical engagement. A recognition that commissioning is at its strongest and most effective when it is a product of a partnership between local clinicians and health service managers working in tandem to enhance the quality of services and improve health outcomes. Practice-based commissioning (PBC) provides the means for this partnership to take place and thrive. Fundamentally, PBC is about the clinical leadership of commissioning and driving service quality and innovation, and provides a mechanism for GP practices to commission services to improve outcomes for individuals and groups of people with specific needs.
20. The visions and competencies for world class commissioning provide the core framework for developing commissioning strategies for people with autism. Joint commissioning across health and social care, supported by multi-disciplinary working, will help develop a holistic, personalisation approach to commissioning services for adults with ASC. Commissioners are reminded of the duty to involve and consult set out in the NHS Act (2006).
21. The following section highlights existing tools, policies and guidance that will help inform decisions made during the planning and delivery process. Although the range of existing guidance may not always explicitly refer to people with ASC, the principles and objectives still apply.

Current Guidance

22. This document builds on *Better Services for People with an Autistic Spectrum Disorder* published by the Department of Health in November 2006.³ *Better Services* clarified current government policy and described good practice; key points made in the document included:

- some people with ASC fall through gaps in local services, particularly between mental health and learning disability services;
- the need for individualised assessments, based on person-centred approaches;
- services to be provided by trained staff with the right skills to meet individual needs;
- services should focus on supporting inclusion of the individual, rather than a focus on diagnosis;
- people with ASC should have access to services on the same basis as all other people;
- there should be a clearly contracted agreement for the provision of services between the local authority and primary care trusts, underpinned by effective partnership planning which includes representatives of people with ASC and their families.

³ *Better services for people with an autistic spectrum disorder*, Department of Health, November 2006

23. *Better Services* signposted a number of government policies that are relevant in the commissioning of services for adults with ASC such as Fair Access to Care Services (FACS) guidance, *Valuing People* (updated in January 2009 with *Valuing People Now*), the NSF for mental health, *Improving the Life Chances of Disabled People* and the NSF for long-term neurological conditions. Awareness of these policies and frameworks will continue to assist commissioners of services for people with ASC.
24. This advice note provides an update on those policies and signposts commissioners to subsequent guidance and policy developments that will also have a bearing on commissioning considerations for adults with ASC. These policies and guidance are set out below.

Joint Strategic Needs Assessments

25. Local authorities and PCTs have been under a statutory duty since April 2008 to produce a Joint Strategic Needs Assessment (JSNA) to inform Local Area Agreements and the Sustainable Communities Strategy. The importance of JSNA in informing PCT operational plans is highlighted in the 2008/9 operating framework for the NHS; JSNA also underpins a number of the world class commissioning competencies. The process of JSNA will establish the current and future health and wellbeing needs of a population, leading to improved outcomes and reductions in health inequalities. JSNA is a partnership duty which involves a range of statutory and non-statutory partners, with a view to informing commissioning and the development of appropriate, sustainable and effective services. Further information on JSNAs, including tools and resources can be found at <http://www.dh.gov.uk/en/Managingyourorganisation/JointStrategicNeedsAssessment/index.htm>

Choice, control and personalisation

26. An individual's well-being is not restricted to health and social care and person-centred planning takes into consideration all aspects of a person's life that contribute to their independence, fulfilment and overall well-being – this includes the support that an individual needs to gain and keep employment, further their education and be included in their community.

Independent Living Strategy

27. The Government launched the *Independent Living Strategy*⁴ in March 2008. The strategy is a commitment to a shared understanding of the principles and practice of independent living. The aims of the five year strategy are that:

- disabled people who need support to go about their daily lives will have greater choice and control over how support is provided; and,
- disabled people will have greater access to housing, health, education, employment, leisure and transport opportunities and to participation in family and community life.

28. The Government wants every locality to have a single community based support system which focuses on all aspects of what people need to maximise their health and wellbeing and to participate in family and community life. The right of the individual disabled person to determine the kinds of services and support that they need will be at the heart of this reformed system. Further information on the strategy can be found at <http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp>

Personal budgets

29. Current changes in adult care mean that in the future the vast majority of individuals eligible for adult social care will have access to a personal budget over which they will have greater choice and control to meet their needs and outcomes. Over the period 2008-11, local authorities will be transforming the way in which adult social care is delivered so that the majority of people eligible for social care will be offered a transparent allocation of resources in the form of a personal budget, which they can take as a direct payment if they wish; a notional amount over which they can exercise choice and control; or a mixture of the two. Support will be designed around the specific needs and outcomes for the individual.

Putting People First

30. *Putting People First*⁵, published in December 2007, set out a shared vision and commitment to the transformation of adult social care. The ambition across Government is to put people first through a radical reform of public services, enabling people to live their own lives as they wish, confident that services are safe, of a high quality and promote individual needs for independence, well-being and dignity. The *Putting People First* concordat set out the shared aims and values which will guide the transformation of adult social care, and recognises that the sector will work across agendas with users

⁴ *Independent Living Strategy: A cross-government strategy about independent living for disabled adults*, ODI, February 2008

⁵ *Putting People First: A shared vision and commitment to the transformation of adult social care*, Department of Health, December 2007

and carers to transform people's experience of local support and services. It identified the following key elements of a personalised adult social care system:

- local authority leadership accompanied by authentic partnership working with the NHS, statutory agencies, third and private sector providers, users and carers and the wider community;
- agreed and shared outcomes to support people to live independently, exercise maximum control, and participate as active and equal citizens with the best possible quality of life;
- system-wide transformation including a JSNA, and other plans to inform the Sustainable Community Strategy, accompanied by an integrated approach with local commissioners and providers.

31. The local authority circulars (LAC(DH)(2008)(1) and LAC(DH)(2009)1 on transforming adult social care set out information to support councils and their partners in the ongoing programme of work set out in *Putting People First*. Further information on the personalisation agenda can be found at <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

Mental capacity

32. Central to the personalisation agenda is the principle of putting the individual at the centre of the planning process and ensuring that they are supported to take the lead in decisions that affect them. The Mental Capacity Act (2005) came into force in 2007, providing a clearer legal framework for people who lack capacity, for those caring for them and for the professionals who work with them by setting out key principles. It puts people who lack capacity at the heart of the decision-making process - this includes people with ASC and those who may not find it easy to express their choice in words. The Act requires an assumption that people have capacity to make decisions for themselves unless there is evidence to the contrary. Further information on the Act can be found at <http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/index.htm>

Common Assessment Framework

33. People with ASC often need a joined up response from health and social care. This will generally need to take account of their own support mechanisms and the possible need for support and care to their carers and family. Identifying a person's personal preferences, wishes and needs and the outcomes that are important in their life is a vital aspect of assessing and advising on their health and care needs and any subsequent care or support plan. We have launched a consultation on our proposals to improve information sharing around assessments and care and support planning. The Common Assessment Framework for Adults will look to enable the sharing of information, with the

consent of the individual, between health, social care and wider community support services.

34. The report of the consultation, due to be published in Summer 2009, will inform the approaches we take to continue to improve the sharing of a person's information to those who have a legitimate interest in their care and support. Further information on the Common Assessment Framework can be found at <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/index.htm>

Fair Access to Care Services

35. The Government's position is that all groups have the same right of access to assessment and ensuing NHS and social care services, based on an evaluation of their assessed needs and likely risks. Practice guidance on Fair Access to Care Services, specifically says it is unacceptable for local authorities to declare that they do not help particular groups of individuals, such as those with higher functioning autism or Asperger syndrome. Following the Commission for Social Care Inspection's review of the implementation of guidance on Fair Access to Care Services, the Department of Health is now working with stakeholders in reviewing the guidance. This work is addressing the needs of specific groups who are known to be 'falling through the net', including people with ASC.

Mental health and learning disability

36. Some people with ASC have a learning disability and/or mental health needs. As such, it's important that both policies and programmes of work are considered in the context of developing services for adults with ASC.
37. The 10-year National Service Framework (NSF) for mental health ends in 2009 and the Department of Health's New Horizons programme is now working closely with a wide range of stakeholders to develop a shared national vision for mental health and well-being. This programme will help to enable strategic health authorities to deliver their regional visions for mental health and build on the achievements of the NSF.
38. The Future Vision Coalition, including all key stakeholders, has initiated a major dialogue around its outline vision for change and will publish its own conclusions in the near future. Further information on this can be found at <http://www.newvisionformentalhealth.org.uk/>
39. *New Horizons* will continue to knit together these, and many other opinions, together over the coming months, with a public consultation on the way forward planned for the

summer. This consultation will consider how services are supporting disabled people with mental health problems, including people with ASC.

40. A series of New Horizons listening events is underway as part of the wider engagement process allowing service users and carers, along with commissioners and mental health professionals, to contribute their ideas about the best approach to managing mental ill-health and promoting good mental health and well-being for everyone.
41. Similarly there has been reflection on progress made with the learning disability agenda, with *Valuing People Now* published in January 2009, setting out the Government's agenda for the next three years. In particular the strategy addresses what people have told us about the support people with learning disabilities and their families need; reflects the changing priorities across government which impact directly on people with learning disabilities; sets out the Government's response to the ten main recommendations in Healthcare for All, the report of the independent inquiry into access to healthcare for people with learning disabilities chaired by Sir Jonathan Michael; and provides a further response to the Joint Committee on Human Rights report, *A Life Like Any Other? Valuing People Now* and its related documents can be found at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

Carers

42. For many adults with ASC, their carers play an integral part in their lives. The carers' strategy, *Carers at the heart of 21st Century Families and Communities* was published in June 2008, setting out the Government's commitment to support carers. The strategy is a 10-year programme that contains both short and longer-term commitments for a number of government departments including the Department of Health. Further information on the carers' strategy can be found at <http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/index.htm>

NHS Next Stage Review and Strategic Health Authority Visions

43. *High Quality Care for All*, the final report of the NHS Next Stage Review was published in June 2008. The purpose of the Next Stage Review was to build on progress made in delivering the NHS Plan and the Government's reform agenda. *High Quality Care for All* sets a new foundation for a health service that empowers staff and gives patient choice. It ensures that health care will be personalised and fair, include the most effective treatments within a safe system, and help people to stay healthy.
44. Based on improved models of care, from maternity to end-of-life, developed by local clinical working groups, each strategic health authority published its long-term vision for improving health and healthcare. These visions are being turned into practical actions at

a local level. *High Quality Care for All* responds to the challenges of delivering the visions developed locally.

45. Because of the difficulties that adults with ASC have with communication, and the challenges that they can face in accessing services, it is important to consider how the principles and objectives of the Next Stage Review and subsequent proposals relate to the delivery of high quality care for adults with ASC. Further information on *High Quality Care for All* can be found at <http://www.dh.gov.uk/en/Healthcare/Highqualitycareforall/index.htm>

Key components to inform commissioning for adults with ASC

46. Working through the planning and delivery cycle and taking into consideration the range of guidance and policies signposted above, commissioners may find it useful to consider the following aspects as key to informing commissioning decisions for adults with ASC:

Transition Planning

47. Transition to adulthood can be a particularly complex time for young people who have an ASC, as they may find change very difficult. They may also find it hard to visualise, or even consider, events beyond their daily routine. Without adequate preparation and support, the transition may provoke high levels of anxiety leading to the possible failure of the transition. If transition fails, young people can find themselves embedded more firmly than ever in the family home, potentially increasing stress on the family and resulting in lives that are more isolated. For these reasons, effective and timely planning for transition is essential.
48. Highly individualised and person-centred transition planning should enable a self-directed selection and identify funding of the services needed. It should also include all agencies involved in delivering services both currently and post transition. It is important to ensure that those with more complex communication needs, including those who are non-verbal are able to express their views and preferences.
49. Existing government policies in relation to transition from children's to adult services are:
- the Child Health Strategy, *Healthy Lives, Brighter Future*, DH/DCSF, 2009
 - National Service Framework for Children, Young People and Maternity Services, DH, 2004
 - *Aiming High for Disabled children: Better support for families*, DCSF, 2007
 - *Transition: getting it right for young people*, DfES/DH 2006

- *A transition guide for all services key information for professionals about the transition process for disabled young people*, DCSF/DH 2007
- *Transition: moving on well: A good practice guide for health professionals about the transition planning for young people with complex needs or disability*, DH/DCSF 2008.

50. As a result of all agencies working together, families are better able to access good information about options and choices. Effective transition planning requires good information and signposting about available resources, and a clear, viable pathway through services.

51. To meet the needs of young people in transition health and social care commissioners should:⁶

- ensure each young person and their family/carers are supported by a single 'trusted adult' contact who will liaise with services and support the young person and their family/carers;
- have early access to 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 for those with a statement of special educational needs (SEN). For young people without a statement of SEN to work with Connexions/Information, Advice and Guidance colleague to plan for their transition to adulthood.

Understanding Your Population

52. The prevalence estimates referred to earlier, together with what we know about the large number of identified young people moving into adult services, are a helpful starting point to inform commissioners' planning of services. (Local authorities will have information on the number of children and young people in schools with ASC from the school census.) In addition, tapping into local knowledge from third sector organisations and user groups will provide further information on the number of adults with ASC in each area.

53. Effective commissioning relies on an analysis of the needs of the population. This forms part of the JSNA referred to earlier, which involves local partners in establishing the needs of the population.

⁶ *Better Services for People with an Autistic Spectrum Disorder*, DH, November 2006

54. A helpful tool in understanding the commissioning needs of individuals within a population is person-centred planning. Person-centred planning is a process for continual listening and learning, focussing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends. This listening is used to understand a person's capacities and choices. Person-centred planning is the basis for problem solving and negotiation to mobilise the necessary resources (from someone's own network, service providers or from non-specialist and non-service sources) to pursue a person's aspirations. Person centred planning can:

- help people to work out what they want in their lives and make them feel stronger and more confident;
- clarify the support needed for people to pursue their aspirations;
- bring together people who have a part to play in supporting people for joint problem solving;
- energise and motivate people based upon better understanding of and commitment to a person;
- help to direct and shape the contributions made from service agencies, to ensure these are based on what is important to a person from their perspective and hence more effective in helping people meet their goals; and
- show service agencies how they can adjust their activities at both operational and strategic levels in order to better support people to achieve their goals.

55. Research into the impact of person-centred planning concluded that it had a positive impact on the life experiences of people.⁷ The same research showed that adults who have an ASC were less likely to receive a plan than people with learning difficulties⁸.

56. It is important that services recognise the individual needs of people with ASC and that there may also be other difficulties such as a dual diagnosis and multiple impairment. Equally, as we have seen in *Valuing People Now*, people with an ASC may also have health care needs that are not being addressed. It is therefore important for commissioners to recognise that 'one size does not fit all' and that services must be flexible and tailored to each individual.

57. Adults with ASC often fall between the gaps within social care and health services. There is a tendency to categorise people into learning disability and mental health teams, meaning that adults who have an ASC who do not have an accompanying learning disability and/or mental health difficulty often fall into the gap between teams. Recognition of this risk will help inform the commissioning of all relevant services.

⁷ Emerson, E. et al (2005). Impact of person centred planning. Lancaster University: Institute of Health Research

⁸ *Autism and independence, A guide for local authorities: enabling adults with an autism spectrum disorder to achieve greater independence*, National Autistic Society

Service Planning

58. The world class commissioning vision and competencies underpin service planning and decision making. Work to develop detailed guidance for commissioners of services for adults with ASC will focus on those competencies, identifying additional information on ASC that will help better inform the commissioning process.
59. Commissioners will be aware of the number of young people with ASC moving into adult services and will find it beneficial to take this into account in their service planning. The JSNA referred to earlier is the means by which to identify future needs. This will also lead to agreed commissioning priorities and will improve outcomes and reduce health inequalities in the local population.
60. As part of the JSNA process, local partnerships are encouraged to use their own experience and circumstances to build on the duties to consult and involve their populations, developing a more detailed approach to understanding their community's needs.
61. Open dialogue and the development of innovative practice can be achieved by sharing resources and expertise across traditional boundaries between services, individuals, parents/supporters and between public and voluntary sectors. The current consultation on improvements to the Common Assessment Framework referred to earlier considers how assessment and care planning should be undertaken and what information should be commonly shared and with whom – commissioners are identified as part of the target audience for the consultation.
62. To enable people with ASC to be actively involved in the commissioning process, consideration should be given to the choice of ways in which people can take part in decision-making, for example meetings, email, questionnaires, internet conferences etc. Meetings do not work for everyone so it is important to make available a number of ways to enable people with ASC to be involved⁹. Commissioners are reminded that the Disability Discrimination Act places a duty on public authorities to involve people in decision-making.

⁹ The National Autistic Society has produced new guidance, *Involving people with autism: a guide for public authorities* and *Autism and the Disability Equality Duty*, to help public authorities involve people with an autistic spectrum disorder (ASD).

Making it happen

63. The following are some examples of good practice that could be drawn on in developing ASC related services and commissioning plans

Nottinghamshire's Asperger Commissioning Team

Nottinghamshire County Council, working with Nottinghamshire's primary care trusts, produced an Adult Social Care and Health Commissioning Strategy in 2007. This incorporated the county's first strategy for meeting the needs of people with Asperger syndrome. It examined the policy context, analysed the number of adults with Asperger syndrome in the county, considered current provision and discussed future commissioning intentions. Actions as part of the strategy include:

- establishing a multi-disciplinary, multi-agency team to provide specialist assessment, care management and short term interventions;
- undertaking a comprehensive needs assessment to determine the level of need and demand across Nottinghamshire;
- developing a range of housing and support solutions to meet needs;
- providing community care services to an extra 20 people per year for the next three years;
- establishing protocols to identify and provide guidance for staff about the potential service overlaps and service interfaces.

Contact:

Paul Johnson, Service Manager, Nottinghamshire Adult Social Care and Health Department, Home Brewery Building, Sir John Robinson Way, Nottingham, NG5 6DB.
Tel: 0115 8546220. Email: paul.johnson@nottsc.gov.uk

Christopher.M.Mitchell, Team Manager, Nottinghamshire Adults with Asperger's Team. Chadburn House, Weighbridge Road, Mansfield. Nottinghamshire. NG18 1AH
Tel : 01623436656. Email: christopher.m.mitchell@nottsc.gov.uk

Liverpool Asperger Team

The Liverpool Asperger Team is an established example of autism good practice in England. It was established in 2003 following recommendations from a steering group regarding the need for an Asperger syndrome-specific multi-disciplinary team and is jointly funded by the PCT and local authority.

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The team has a person-centred approach and uses the concept of a managed care pathway to provide direct support, make referrals and support other service providers. The wider network includes specialist services for people involved in the criminal justice system and those receiving support from mental health and alcohol and substance misuse services. When dealing with employment support, education, and other statutory and non-statutory services, the care management role is normally undertaken by a member of the Asperger team itself.

Service users do not need to have a formal diagnosis of Asperger syndrome, as the team also carries out diagnostic work. The team have made a real difference to adults with Asperger syndrome in the Liverpool area and they are keen to share the good practice they have developed.

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

MCCH's Pathways to Inclusion

MCCH's 'Pathways to Inclusion' is one of twelve pilots being taken forward as part of the Cabinet Office's Adults Facing Chronic Exclusion (ACE) programme. The pilot aims to improve the ability of adults with learning disabilities, autism or mental health problems to access, housing, social and health care, learning, employment, leisure and financial services. It focuses on people who experience chronic exclusion, as well as those with histories of 'bouncing' in and out of services. This includes adults with autism and Asperger syndrome who are often undiagnosed, neglected, and ineligible for services.

The pilot engages service users, commissioners and providers of services in developing better outcomes, through individual support, equipping adults through person centred plans, mentoring and advocacy. It helps people to find and sustain their way through services and to support individuals in accessing individual budgets and self determined services.

The team take referrals from a wide range of services including those from family or friends, any professional and, importantly, self-referrals. The staff team comprises a project co-ordinator, three support workers and an administrator.

Contact: Maryanne Boylan, Project co-ordinator, Ph 01634 821114
or email pti@mcch.org.uk

Gloucestershire Autism Spectrum Disorders (ASD) Co-ordinator

An ASD co-ordinator was employed to work with the partnership board to develop its framework and ensure that services for adults with Asperger syndrome are available across Gloucestershire. The post was commissioned by the county council and jointly funded by the National Autistic Society. Responsibilities of the ASD co-ordinator include:

- co-ordination of multi-tier cross agency ASD specific training;
- work with commissioners in Gloucestershire to identify a lead commissioner and develop commissioning processes;
- the creation of a directory of local services for adults with higher functioning ASD and Asperger syndrome;
- establish an ASD service implementation group whose membership will include identified ASD champions from relevant disciplines;
- ensuring that the voice of individuals with Asperger is heard;
- work with local services to draw up an effective care pathway and clear guidance and protocols for adults with ASD;
- ensure that service users and carers are involved and consulted;
- working with children's services to ensure that transition planning begins at the right time and links effectively to adult services;
- work to identify barriers to accessing a range of services, including links with Further Education and employment;
- liaising with groups such as the Supported Housing Forum to ensure that the needs of people with Asperger and high functioning autism are included in planning and budgeting processes.

Contact: Barbara Russell, Gloucestershire ASD Coordinator, Gloucestershire Autism Centre Springbank Community Resource Centre, Springbank Way, Cheltenham, Gloucestershire, GL51 0LG. Ph. 01242 230398

Cumbria Council Mapping Exercise

Concerns about the potential inability to plan services for people with autism based on local data led Cumbria County Council to undertake a mapping exercise into the prevalence of autism in the area. This was carried out in October 2006, and followed a similar exercise from 2003.

As a result of the mapping exercise in Cumbria, the following recommendations were made:

- that the capacity of existing data systems to record a diagnosis of autism should be evaluated
- that the mapping exercise should be repeated every two to three years, until such time as a comprehensive data system is available, in order to plan services
- that there should be development of new or extended services, such as for regional or local diagnosis.

Contact: Marion Jones, Service Development Manager (Autism),
Marion.Jones@cumbriacc.gov.uk

Royal Borough of Windsor and Maidenhead

The Royal Borough of Windsor and Maidenhead (RBWM) ran a development worker project in 2007 to determine the number of adults with autism in the area who were not receiving appropriate support services, identify gaps in provision and work with local service providers to fill these gaps.

This project identified serious gaps, particularly in the areas of employment, housing, health and social activities and concluded that appropriate provision could only be secured through the creation of a permanent development worker post.

In response to this project, RBWM funded a full time adult ASD team of three experienced staff: a team manager, a care manager and an assistant care manager. This team has a number of responsibilities, including being the key point of contact for issues relating to adults with autism, identifying best practice and highlighting gaps in provision. The team will also be responsible for leading work with commissioners to ensure that appropriate services are established.

So far the team have developed a fortnightly social group, a health and well being group and training for professionals. All team members also hold a case load of work with individuals and they expect to support 50 individuals at any one time. The team are working closely with local voluntary organisations and the NAS to create an invaluable service that deals with every area relating to the lives of adults with autism who have previously not been eligible for services.

Contact: Royal Borough of Windsor and Maidenhead ASD Team, Ph 01628 670 117

Developing further support

If you or your organisation are involved in the commissioning or provision of services for adults with autism, or if you are an advocate or self-advocate, who would like to work with the Department of Health in developing ideas for commissioning guidance or a toolkit, please contact us at autism@dh.gsi.gov.uk

If you are unable to be involved but would still like to share your views please email ideas to autism@dh.gsi.gov.uk. We would be particularly interested in responses to the following questions:

- How can people with ASC be actively and effectively involved in the commissioning and development of services?
- Do you have examples of good practice that could be shared across the country?
- What information about local populations is available and used to inform commissioning decisions? Are there resources such as local third sector organisations that can be utilised?
- Who would be involved as members of a local strategic ASC working group?
- How do the principles of World Class Commissioning apply to commissioning services for people with ASC?
- Do changes need to be made to current working practices to ensure a person-centred approach? If so, what?
- How can services be commissioned closer to home to avoid long-term, out of area placements?
- What action has been taken in your local area to improve ASC recognition, awareness and communication?
- What would be more beneficial to the commissioning process – guidance or a toolkit?
- What do you consider to be the ‘must haves’ to be included in further commissioning guidance on adults with ASC?

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