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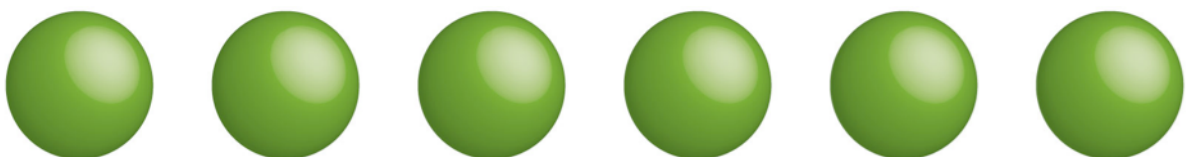
Mental Health Network
NHS CONFEDERATION

NDTi
National Development Team for inclusion

Reasonably Adjusted?
Mental Health Services and Support
for People with Autism and
People with Learning Disabilities

July 2012

Contents

Page

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

2

Easy Read Executive Summary

People with learning disabilities and people with autism have more mental health problems than other people.

Mental health services are not always good at working with people with learning disabilities or autism.

The law says that mental health, and other public services must make reasonable adjustments for people with learning disabilities and people with autism.

This report is about how mental health services can make 'reasonable adjustments' so that people with learning disabilities and people with autism can use them. Reasonable adjustments mean changing services so they are easier to use – like using pictures and big print on appointment letters.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

3

What health services can do

Make sure that people with learning disabilities or autism and mental health problems get good advocacy support.

Identify people with autism or learning disabilities and mental health problems in health records so that reasonable adjustments can be made.
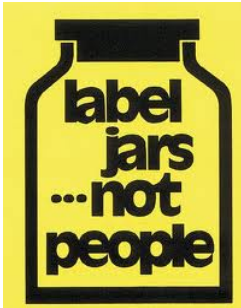
Health checks are an important way for people with learning disabilities to get their mental health needs checked out.

Health action plans can help health staff know what reasonable adjustments people need.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

4

Sometimes staff think that any changes in behaviour are to do with the person's autism or learning disability. They may need help to recognise that it is because the person has mental health problems.

There are services where people with mental health problems can go and talk to staff who can help. These are called 'psychological therapies'. These services should be accessible to people with learning disabilities and people with autism.
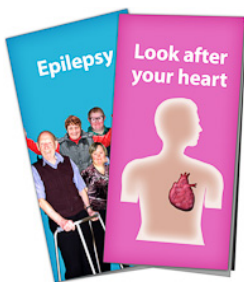
Information about health services should be available in easy read and accessible formats. There are lots of examples of accessible information people can use.

People admitted to in-patient services should have a person centred assessment and plan, so that the right reasonable adjustments can be made. They should also have support then they leave hospital.

People with learning disabilities, autism and mental health problems in prison, should be identified so that reasonable adjustments can be made.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

5

A home and a job

Specialist staff can support housing and employment services so that they are accessible to people with learning disabilities and people with autism.

Knowing about the local population

The Joint Strategic Needs Assessment which sets out the needs of local people should include information about people with learning disabilities and people with autism who have mental health problems. Local plans should say how people's needs will be met.

Getting better local services

People who buy services (commissioners) should work together to develop local services that meet people's needs.

Checking services

It is important that services know what they should be doing, so that they can check they are getting it right. The Mencap Getting it Right charter is a good example.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

6

Policies

Making sure the organisation puts reasonable adjustments in place should be written into policies, and checked by senior managers.

Buildings and furniture

There are lots of things that can be done to make buildings easier to use and be in, like signs to tell you where to go, lighting and how noisy the place is.

Staff

Staff need training and other support to work with people with learning disabilities or autism and mental health problems.

Working together

Staff from different services need to work together to share skills and knowledge.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

7

Introduction and key messages

In February 2012, the NHS Confederation commissioned NDTi on behalf of the Department of Health to write a report about the reasonable adjustments that should be made to mental health services to enable people with autism and people with learning disabilities to have equal access and effective treatment. This report describes phase one in the following process:

Phase One:

- Clarify the legal and policy context

- Locate stakeholders and examples

- Catalogue the range of adjustments that can be made across the whole of mental health services

Phase Two (not yet agreed):

- Create an audit tool to map how widely these adjustments have been adopted

- Create and maintain an internet resource bank where people can upload documents for the benefit of others

- Consider how individual adjustments have been combined to create a coherent strategy that drives improvement

- Explore whether there is a shared view about the most effective sequence in which to adopt particular adjustments

- Produce a toolkit for mental health organisations wishing to review and improve their performance in this area.

Peter Bates and Sue Turner wrote this report with support from John Hersov, Eric Emerson, Anita Eley and Alison Macadam. We thank all the people who told us about their lives and work and challenged our thinking. More details about how we did the work can be found at Appendix One.

Whilst there is still a great deal of work yet to do to improve mental health services for people with autism or learning disabilities, we found a number of examples of good practice. Individuals have created accessible information sheets and video materials and explained them, attended training courses and applied the learning, redesigned buildings

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

8

and processes, and obtained feedback from people and their family carers. The challenge for the future is to spread these pockets of good practice into every mental health service and every encounter between staff and the people they support.

Introducing the NHS Confederation

The NHS Confederation is an independent membership organisation and a charity whose charitable purpose is to relieve sickness, and preserve and protect public health. Members are responsible for commissioning and providing NHS services and the Confederation achieves its purpose by supporting the membership.

Introducing NDTi

NDTi was constituted as an Industrial and Provident Society in 1992 as the National Development Team (NDT). Initially the organisation focused on working to improve the life chances of people with learning disabilities and this later widened to include people with mental health problems. In 2009, the Older People's Programme joined NDT to form the National Development Team for Inclusion. NDTi's cross-client group approach, which is particularly relevant for this project, aims to improve the life chances of different groups of people within a broader context of equality, inclusion and citizenship across all ages.

How this report is organised

This report is organised in three main sections.

- First is a summary of the context – population, equalities and government policy, including the concept of 'reasonable adjustments' that forms the title of this report

- The second section follows a care pathway from first contact with primary care services through referral to specialist help and on to discharge, reporting on the adjustments made by individuals and organisations that are trying to provide high quality services to people and their families.

- The third section: 'Effective services in a flourishing community' begins with a broad view of active citizenship and then follows a similar journey to section two, but this time at the organisational level, showing how effective population needs mapping, gap analysis, market development and organisational design will support learning disabled and autistic people who use mental health services.

The brief for this report was to only consider services delivered by what are known as adult mental health services in England[1]. As such, it does not fully consider the needs of

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[1] The separation prevalent within most NHS adult mental health services in England between those for people under 65 (often called working age) and those over 65 risks coming into conflict with equality legislation as age is a factor covered by discrimination legislation and there is no longer a legally enforceable retirement age. NDTi has developed materials for the Department of

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

9

children, older adults and people living in the other countries of the United Kingdom. We focus upon the adjustments that mental health services can make, but acknowledge that other specialist and universal services need to offer expertise and support too. We briefly acknowledge the importance of foundational standards of care (such as dignity and respect[2]), but concentrate on the additional elements that can help mental health services to respond well to the specific needs and situation of people with autism and people with learning disabilities.

We have concentrated on positive examples in this report. Some sections include a disappointing story of service failure. Indeed, the overwhelming message we heard from people with learning disabilities, people with autism and families, was of a failure by services to meet their legal obligations to ensure equal access to services. However, we decided that the overwhelming emphasis of this report should be on what can be done and what has been done work towards equality of access and legal compliance. By highlighting the good work of pioneers, we hope to encourage others to follow their example rather than encourage complacency about the challenge ahead. The agencies we highlight are generally doing many more things in addition to the activity we mention, and a successful local solution will combine many of these items. The report is not a comprehensive list of every setting and every adjustment, but aims to prompt creative thinking and adaptation. We have changed the names of individuals where necessary to ensure confidentiality.

Whilst research has shown that there is a need for significant improvement, good work is taking place in some areas, as illustrated by the following example.

> *"Our son is 25…. We have had very good support [from the mental health service] and they always take Andrew's side and chivvy other agencies. They always warn that they can't keep cases open very long but do respond when we are desperate, such as when Andrew came under safeguarding arrangements because of his behaviour. We get help with medication from the psychiatrist and psychiatric nursing team who are very willing to help and regularly check on progress."*

At the same time as the mental health service develops its competence in responding to people with autism or learning disabilities, specialist learning disability and autism services need to respond effectively to people's mental health needs. This is outside the scope of this report, but we note its importance, as illustrated by the following case study:

Health and NHS on age discrimination, including specific work around mental health services, and these can be found at http://www.ndti.org.uk/major-projects/nmhdu-achieving-age-equality/

[2] NHS (2012) *The NHS Constitution for England*

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

10

"My gorgeous son Bill is 23 years old. He does not use speech, signing or PECS[3] – his preferred way of communicating is to bang his head. Two years ago, after moving to adult residential services, it got worse and he started targeting sinks and door frames. He often cuts his head but it is impossible to take him to hospital. The GP referred him to a general psychiatrist, who then referred him on to a learning disabilities psychiatrist, with a three month delay each time, despite regular calls to say that his behaviour was life threatening. The psychiatrist was unwilling to make a home visit, only reluctantly agreed to meet with me and refused my request for health investigations, saying there is 'no point with people like him'. At the second appointment she wanted to see him so we arranged to meet in the car park with Bill in the car. We told her not to approach him as would cause him to head bang, but she approached him anyway. She prescribed medication, but didn't explain what it was for. His behaviour has deteriorated and he now stays in bed until midday. I have asked for a change of psychiatrist as I want to feel valued as a parent and my son valued as a human. We are still waiting."

Terminology

We have selected the terms listed below to write this report, whilst recognising that some people prefer alternatives. Each term has its advocates and detractors, and so we ask the reader to look beyond the weaknesses of the language to the message of the report.

Autism is a lifelong condition that affects how a person communicates with, and relates to, other people. People with autism have difficulties with:

- "social communication (problems using and understanding verbal and non-verbal language, including gestures, facial expressions and tone of voice)

- social interaction (problems in recognising and understanding other people's feelings and managing their own)

- social imagination (problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine)."[4]

Family Carer means unpaid relatives as opposed to paid care workers. On occasions it could also be taken to apply to friends and neighbours who feel that they have caring responsibilities. "A significant number of people with caring responsibilities do not readily

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[3] PECS – Picture Exchange Communication System – using pictures to develop communication skills. See http://www.pecs.org.uk/

[4] Department of Health (3 March 2010) *Fulfilling and rewarding lives: the strategy for adults with autism in England*. Page 10.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

11

identify themselves as carers. They understandably see themselves primarily as a parent, spouse, son, daughter, partner, friend or neighbour."[5]

Inclusion. People with learning disabilities, autism, mental health issues or a combination, have a right to full and effective participation in society on an equal basis with others. This includes participation in education and health, the labour market, access to justice, home and family life, information, political and cultural life[6].

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."[7]

Mental Health Issues. The Government defines mental illness as "A term generally used to refer to more serious mental health problems that often require treatment by specialist services. Such illnesses include depression and anxiety (which may also be referred to as common mental health problems) as well as schizophrenia and bipolar disorder (also sometimes referred to as severe mental illness)."[8] We refer to issues rather than illnesses.

Reasonable Adjustments. The term reasonable adjustments was first used in the Disability Discrimination Act 1995 and refers to the duty on those providing goods, services and employment opportunities to ensure that their arrangements do not discriminate against disabled people

Universal Design[9] is a concept promoted by the United Nations that suggests that the following provisions are needed in this sequence:

- basic designs to meet the needs of the greatest number of the population

- alternative designs for those who need them, such as environments that can be individually controlled through the use of lighting dimmer switches and so on

- additional assistive technology should be provided for those who require it, and finally;

- personal assistance should be available for those for whom nothing else will work.

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[5] HM Government (2010) *Recognised, valued and supported: next steps for the Carer's Strategy* page 8.

[6] United Nations (2006) *Convention on the rights of persons with disabilities.*

[7] Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century*. A more detailed definition is available at: www.ihal.org.uk/about/definition/detail

[8] Department of Health (2011) *No health without mental health* page 88.

[9] See http://www.udinstitute.org/history.php

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

12

Summary

This report identifies things that mental health services have changed so that people with autism or learning disabilities receive a good service. Some people receive a poor service and the evidence suggests that many services are failing to meet their responsibilities under equalities legislation - so this is an important topic. Mental health services need to take specific action to address this agenda.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

13

Section 1: Context

Population

> *My therapist told me I was a sociopath with schizophrenia and paranoid tendencies. It took me two years to get an appointment for an autism assessment. I asked my therapist how she would feel when I returned with a diagnosis of autism what would she then think. She told me that it would never happen!*

There is some evidence that people with learning disabilities and people with autism have a higher prevalence of mental health needs than the wider population[10]. There is stronger evidence in relation to children with a learning disability[11]. These difficulties increase where people have difficulties with communication, when the presence of one diagnosis stops people looking for others (known as diagnostic overshadowing) and when services are perceived as inaccessible.

The Learning Disability Public Health Observatory tracks service delivery and has found[12] that people who use mental health services and also have autism get very variable treatment[13].

The Equalities agenda

The importance of actively addressing the health inequalities experienced by people with learning disabilities and autism has been highlighted by recent reports from: The Disability Rights Commission[14], Sir Jonathan Michael's independent inquiry into the healthcare of

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[10] "People with learning disability have a two-fold increased risk of depression and a three-fold increased risk of schizophrenia." Smiley, E. (2005). Epidemiology of mental health problems in adults with learning disability: an update. *Advances in Psychiatric Treatment* 11, pp. 214–22.

[11] Einfeld, S. L., Ellis, L., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability* 36, 137-143.

[12] See the findings from the Self Assessment Frameworks for learning disability at www.improvinghealthandlives.org.uk/projects/self_assessment/regions/ and for autism at www.improvinghealthandlives.org.uk/projects/autism_saf_initial

[13] Copeland A and Glover G (2012) *Autism Self Assessment Framework 2011: Initial findings.*

[14] Disability Rights Commission (2006) *Equal Treatment - Closing the Gap*. London: Disability Rights Commission, 2006.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

14

people with learning disabilities[15], the Parliamentary, Health Services and Local Government Ombudsman[16], the House of Lords and House of Commons Joint Committee on Human Rights[17], the Department of Health[18] and Mencap[19].

It is a statutory requirement under the Equality Act 2010 and the NHS and Social Care Act 2008 that public sector agencies make reasonable adjustments to their practice that will make them as accessible and effective for people in the protected groups as they are for people who are not in these protected groups. People with autism, learning disabilities, mental health issues or a combination are protected by this legislation. Reasonable adjustments include removing physical barriers to accessing health and social care services, as well as making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities or autism[20].

This legal duty is 'anticipatory'. This means that mental health agencies are required to consider in advance what adjustments people with learning disabilities or autism will

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[15] Michael J (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Independent Inquiry into Access to Healthcare for People with Learning Disabilities.

[16] Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009) *Six lives: the provision of public services to people with learning disabilities*. London: Parliamentary and Health Service Ombudsman and Local Government Ombudsman.

[17] Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: The Stationery Office Limited.

[18] Department of Health (2007) *Promoting Equality: Response from Department of Health to the Disability Rights Commission Report, "Equal Treatment: Closing the Gap".* London: Department of Health. Also Department of Health (2009) *Valuing People Now: A new three-year strategy for people with learning disabilities.* London: Department of Health. Also Department of Health (2009) *Valuing People Now: The Delivery Plan* London: Department of Health, 2009. Also Department of Health (2010). *Valuing People Now: Summary Report March 2009 - September 2010. Good Practice Examples*. London: Department of Health. Also Department of Health (2010). *'Six Lives' Progress Report.* London: Department of Health.

[19] Mencap (2012) *Death by indifference: 74 deaths and counting. A progress report 5 years on.* London: Mencap.

[20] Equality and Human Rights Commission (2011) *The essential guide to the public sector equality duty.* Manchester: Equality and Human Rights Commission. Also Government Equalities Office (2010). *Equality Act 2010: What Do I Need to Know? Disability Quick Start Guide.* London: Government Equalities Office, 2010. Also Government Equalities Office (2010) *Equality Act 2010: What do I need to know? A summary guide for public sector organisations*. London: HM Government. Also Equality and Human Rights Commission (2010) *Equality Act 2010 guidance for English public bodies (and non-devolved bodies in Scotland and Wales). Volume 1: The essential guide to the public sector equality duty.* Manchester: EHRC. Also Equality and Human Rights Commission (2010). *Equality Act 2010 guidance for English public bodies (and non-devolved bodies in Scotland and Wales). Volume 5: Your rights to equality from healthcare and social care services.* Manchester: EHRC.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

15

require, rather than waiting until such individuals attempt to use their services to put reasonable adjustments into place.

The recent NHS Equality Delivery System provides a framework of questions for all parts of the health service in relation to all protected groups. Its recently published 'Grades Manual' sets out four overarching goals and invites NHS organisations to identify evidence about their progress in relation to these[21]. The first two (better health outcomes for all, and improved patient access and experience) ask healthcare organisations to look for evidence of how members of protected groups are faring in terms of their health and their use of health services. Answering these questions comprehensively, systematically and regularly requires that information systems identify people in the protected groups so comparisons can be made.

The Equality Delivery System also emphasises the need to include members of protected groups in discussions about service arrangements. The Health Self-Assessments (SAF)[22] are one way of discussing services with people with learning disabilities and autism and with family carers, and includes a section on the equitable application of mental health policy to people with learning disabilities or autism who require mental health services.

More generally, the Health Select Committee, NICE and the Marmot Review have highlighted the importance of adopting strategies to reduce health inequalities that take account of the specific situation and characteristics of high risk and marginal groups - such as people with learning disabilities, autism and mental health issues[23]. The UK has entered into international obligations to progressively realise the right to health of people with disabilities and to take specific measures to address the health inequalities faced by vulnerable groups such as people with learning disabilities, autism and mental health issues[24].

Government Policy on mental health, learning disability and autism

Having considered the equalities agenda, the three strands of mental health, learning disability and autism are also shaped by the following policy statements:

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[21] NHS East Midlands (Edition dated 29th July 2011) *The Equality Delivery System for the NHS, and The Equality Delivery System for the NHS Grades Manual*.

[22] Details at http://www.improvinghealthandlives.org.uk/projects/self_assessment/materials2012

[23] The Marmot Review (2010) *Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post-2010.* London: The Marmot Review. Also House of Commons Health Committee (2009) *Health Inequalities: Third Report of Session 2008–09. Volume I.* London: House of Commons. Also National Institute for Health and Clinical Excellence (2007) *Behaviour change at population, community and individual levels.* London: National Institute for Health and Clinical Excellence.

[24] United Nations (2006) *Convention on the Rights of Persons with Disabilities* New York: United Nations. Also World Health Organization (2011). *Rio Political Declaration on Social Determinants of Health* Geneva: World Health Organization.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

16

- *No Health without Mental Health 2011* sets out the Government's goal for high quality mental health services that are equally accessible to all

- *Valuing People Now 2009* sets out the Government's ambition for learning disabled people

- *Fulfilling and Rewarding Lives 2011* sets out the Government's strategy for adults with autism.

We need to mention here a small number of other topical themes that are influencing the shape of services at present. This will be a changing list, but at the time of writing this includes:

- **The Green Light Toolkit** was published by the Department of Health in 2004[25] to support local efforts to improve mental health services to people who also had a learning disability. A learning set followed and found that good data, organisational stability and senior leadership assisted service improvement[26]. Some areas, such as Lincolnshire, employ a Green Light Facilitator to coordinate the work.

- **Winterbourne View.** The current Department of Health Review into the abuse of people with learning disabilities at Winterbourne View Hospital recommends that all local services should build understanding of the reasonable adjustments needed so that for people with learning disabilities who have a mental health problem can make use of local generic mental health beds[27]. Consequent inspections by CQC have highlighted the substantial failings of a large proportion of bed based assessment and treatment services for adults with learning disabilities and/or with autism[28].

- **Primary Care.** The increasing emphasis on a primary care led NHS may require GP led services to understand and address the mental health needs of people with learning disabilities and people with autism more than in the past. .

  "My son is agoraphobic, not even able to go into the garden. My GP made a referral to the Mental Health Service. Six weeks later I discovered they had decided that he was not a mental health problem."

- **Personalisation.** An increasing number of people have taken up the right to a personal budget and used the funds to arrange support away from traditional

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[25] Available from http://www.scie-socialcareonline.org.uk/profile.asp?guid=4d7de6e9-70bc-4756-9113-c4c01cb56aa2

[26] Cole A (2010) Going green. *Learning Disability Today*, 10(5), June, pp.20-21.

[27] Department of Health (25 June 2012) *DH Review: Winterbourne View Hospital Interim Report* page 8.

[28] http://www.cqc.org.uk/public/news/half-learning-disability-services-did-not-meet-government-standards

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

17

sources of support, such as day centres. This, combined with tighter eligibility criteria and financial pressures has challenged the existence of these services is anecdotally reported as increasing the social isolation of some people assessed as having low-level needs.

- **Eligibility.** Disputes about eligibility criteria and boundaries are not uncommon[29] and need to be resolved so people with autism or a learning disability receive fair and equal treatment. Care is needed to avoid misunderstanding or misrepresenting an unpopular rationing decision as an unfair manifestation of discrimination unless there is evidence that it is discriminatory. Meanwhile, third sector organisations are reporting that the narrowing of eligibility to social care has left many people with autism or learning disability in combination with mental health issues without access to services.

- **What counts as 'reasonable'.** The question of what counts as a 'reasonable' adjustment has been discussed[30] and we note that assigning people to a learning disability service or a mental health service on the basis of a disability label, rather than in response to individual assessed need, counts as discrimination.

- **Service Integration and mainstreaming.** Although Government policy in the UK expects services to work together and specialists will help mainstream services make reasonable adjustments, there is a long history of learning disability and mental health services working separately[31], and people with autism falling in the gaps between services.

In Section 1, we have seen that there is a need for mental health services to anticipate that people with autism or learning disabilities will utilise their services, and make reasonable adjustments so that their work is as effective with these people as with others. The policy and service environment is complex and dynamic, but, in many services, action is needed to improve outcomes. We now move on to examine those actions.

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[29] The Royal College of Nursing (2010) *Mental Health Nursing of Adults with Learning Disabilities.* RCN Guidance.

[30] See for example, Lawson, A. (2008) People with Psychosocial Impairments or Conditions, Reasonable Accommodation and the Convention on the Rights of Persons with Disabilities, *Law in Context*, 26, pp.62-84.

[31] For example, a decade ago in the South West region, only 11% of people with learning disabilities hospitalised for mental health treatment were admitted to mainstream mental health units. See Simons K and Russell O (2003) *Lines in the sand: Summary.* Bristol University: Norah Fry Research Centre. More recently, the West Midlands Review of Services for 2011 found mental health and learning disability services working separately, even when they were situated within the same NHS Trust.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

18

Summary and Recommendations

The law requires mental health services to make reasonable adjustments so that they stop discriminating against people with autism or learning disabilities. Many reports and guidance documents published by the UK Government have provided evidence of the level of need, the extent of inequality and the need to make adjustments. Current changes to health and social care provision, such as personalisation and financial austerity, provide both a challenge and an opportunity to those seeking to make adjustments.

Mental health services need to act within the law by ensuring that they provide fair and equal access to mainstream mental health services for people with autism or learning disabilities.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

19

Section 2: Adjusting the Care Pathway

In this section we follow the process from self-management, through first contact with health or social care services, primary care, referral to specialist mental health provision, interventions and eventual discharge.

Self-management and families

Before addressing the mental health issues that are sometimes faced by people with learning disabilities or autism, it is vital to recognise the contribution of factors that affect everyone. An opportunity to exercise choice and control, to work, live independently, to take up the five ways to wellbeing[32] and belong within a family and friendship circle buffers all of us against life's inevitable difficulties.

When mental health difficulties arise, the person and their family need to be able to recognise them and seek both informal and, if needed, professional help. While it is true that some relatives are not supportive, in other situations family carers play a crucial role and can help with self management[33] and referral – and so for some, it may be best to think in terms of 'family-centred planning' rather than 'person-centred planning'. In one project, family members played a key role in the development of a mental health guide for families of people with learning disabilities[34], and elsewhere family members use validated assessment tools[35] to decide whether a formal assessment for a mental health issue is required. One commentator[36] recommends that healthcare staff should normally allow family carers to be present at any time. Staff need to let family carers know that their effort and expertise is valued. Family carers may also need support in their own right, as the demands of caring can weigh heavily. For example, in Avon and Wiltshire, the planning

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[32] See http://www.neweconomics.org/publications/five-ways-wellbeing-evidence

[33] Biza Stenfert Kroese & John L. Rose (2011) *Mental Health Services for Adults with Learning Disabilities* The Judith Trust page iv.

[34] Gratsa, A., Spiller, M.J., Holt, G., Joyce,T., Hardy, S., Bouras, N. (2007) Developing a Mental Health Guide for Families and Carers of People with Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities* 2007, Vol 20, pp.77–86

[35] The PAS-ADD Checklist was developed for use by family carers by Dr Steve Moss. See http://79.170.44.140/pasadd.co.uk/pas-add-checklist/ . Alternatively, see the Developmental Behaviour Checklist for Adults by Mohr,C., Tonge,BJ. & Einfeld,SL., (2005) The Development of a New Measure for the Assessment of Psychopathology in Adults with Intellectual Disability, *Journal of Intellectual Disability Research* Vol:49 pp: 469-480

[36] Blair, J., (2011) Care Adjustments for People with Learning Disabilities in Hospitals, *Nursing Management*, Vol 18, Iss: 8 pp 21-24.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

20

team began by contacting family carers groups as well as people using services and staff before writing their *Getting it Right* strategy.

Advocacy

Where people need support to make their views heard, advocacy is a reasonable adjustment that enables people to more fully participate in decisions about their care and treatment. For example, in Westminster, mental health commissioners employed an advocate to support people with learning disabilities using mental health services. The advocate brought together a group of 'experts by experience' who conducted a 'mystery shopper' review of mental health services to ground their subsequent training activities in local experience. Recently there appears to have been a move away from small, specialist and local advocacy organisations toward the provision of professional advocacy by larger generic agencies[37]. While professional advocacy is important, self-advocacy groups can help people gain important skills and increase their confidence, which has the potential to make people more resilient when problems occur. A recent study also found gaps in the provision of advocacy, such as a lack of non-instructed Independent Mental Health Advocacy, which may be caused by a failure to recognise that some people with mental health issues also have learning disabilities[38]. Advocacy should be available to everyone who needs it, especially people who are in residential settings, those who have few choices and those subject to legal restrictions.

More widely, adjustments can be made to Patient Advice and Liaison Services (PALS), Local Involvement Networks (LINks) and the emerging HealthWatch organisations, such as by ensuring that policy, feedback and service evaluation information is accessible to all stakeholders. For example, Lancashire Care Trust have produced an easy-read satisfaction survey for people who have spent time in hospital, while Hertfordshire Partnership Trust have canvassed learning disabled people's experience of using mainstream mental health services.

Recognising need

It is important to train care workers and primary care staff so that they can recognise the needs of people who have a combination of mental health issues, autism and learning

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[37] Roberts H, Turner S, Baines S & Hatton C (March 2012) *Advocacy by and for adults with learning disabilities in England: Findings from two surveys and three detailed case studies* Improving Health and Lives page 67.

[38] Newbigging K, Ridley J, McKeown M, Machin K & Poursanidou D (2012) *The right to be heard: Review of Independent Mental Health Advocate (IMHA) Services in England* (with Laura Able, Karen Cruse, Paul Grey, Stephanie de la Haye, Zemikael Habte-Mariam, Doreen Joseph, Michelle Kiansumba and June Sadd). University of Central Lancashire.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

21

disabilities. A checklist is available[39] to help care staff working in mental health services develop their skills in responding to people with autism, and improvements may be accomplished through staff training, which is discussed in Section 3 of this report.

Staff working in primary care settings can help to identify patients with learning disabilities or autism who have mental health needs. *Healthcare for All* was the most recent of a number of Government reports that recommended the implementation of Health Checks as one component of a policy response to the poorer health of people with learning disabilities[40]. In 2009, Health Checks became part of a Directed Enhanced Service (DES) which means that Primary Care Trusts were required to offer GP practices the opportunity to provide health checks in return for payment.

The health check is a review of an individual's physical and mental health, and the DES specification covers training on learning disability awareness for primary care staff and says that GPs should use the Cardiff Health Check[41] or a similar approach to carrying out health checks[42]. The Cardiff Health Check includes a section on 'the presence of behavioural disturbance' which may help GPs identify mental health problems, though it does not provide a comprehensive review of mental health needs. There is also a section for medication review.

However, the DES only covers people with learning disabilities who are also known to social services, and therefore tends to exclude people with mild learning disabilities. 53% of those eligible received a health check in 2011/12 although some areas did considerably better than others. The top 10% of Primary Care Trusts provided health checks for nearly 73% of eligible adults in 2011/12 while the bottom 10% provided health checks for fewer than 28%[43]. Data for individual Primary Care Trusts areas is available[44].

We note that primary care staff are obliged to make reasonable adjustments for people with autism, learning disabilities and mental health issues, whether or not they are covered by the Direct Enhanced Service arrangements, and some GP practices have offered health checks to all people with learning disabilities they are aware of. In some places, primary care services have taken up the challenge in other ways too. For example, in

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[39] Skills for Care & Skills for Health (2011) *Autism skills and knowledge list, for workers in generic health and social care services*.

[40] Turner S and Robinson C (2010) *Health Checks for People with Learning Disabilities: implications and actions for commissioners*. Improving Health and Lives

[41] www.improvinghealthandlives.org.uk/securefiles/120411_1226/MjMxMQ__/CardiffHealthCheck2.pdf

[42] NHS Employers (2011) *Clinical Directed Enhanced Services (DESs) for GMS contract. Guidance and audit requirements for 2011/12.*

[43] Emerson E, Copeland A, & Glover G. (2011) *The uptake of health checks for adults with learning disabilities 2008/9 -2010/11*. Improving Health and Lives.

[44] http://www.improvinghealthandlives.org.uk/news/?nid=2015

Wolverhampton, everyone with Down's Syndrome over the age of 30 was invited for dementia screening and suitable people were referred to a learning disability memory clinic or other services[45].

Appointments

> *"It took over a year to get an appointment with the psychiatrist for my daughter. There was a crowded waiting room and she was stressed by all the people so we asked to wait somewhere quiet and had to stand in a corridor."*

Recording systems in the GP practice and elsewhere should identify people with autism, learning disabilities, mental health issues or a combination and show any reasonable adjustments they require, such as:

- easy read appointment letters and reminder phone calls or texts, along with more frequent contact in the waiting time so they know that they are not forgotten. Central and North West London Trust have a model format for an easy-read appointment letter that is made available to all their staff via the Trust website. Such letters routinely include a photograph of the letter writer to aid recognition. In South Gloucestershire, people were asked for their views about receiving such letters[46];

- appointments at specific times (as some people become distressed by delays). This may be the first appointment (for people who find it difficult to sit in the waiting room[47]) or last or double appointments (for people who need more time to explain their thoughts and feelings). Sometimes the 'next appointment' beeper in the waiting room needs to be switched off;

- avoiding cancelling appointments at short notice and prepare people for change whenever possible.

- tolerance of missed appointments if the person does not understand, struggles to book their own appointment or has difficulty complying with invitations to attend.

- regular health checks[48] – as some people do not refer themselves back to the doctor if health issues arise or psychiatric or other medication is causing problems.

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[45] Good Practice: Dementia screening for adults with Down's Syndrome http://www.wmqi.westmidlands.nhs.uk/wmqrs/publications?keyword=&programme_id=&publication_type_id=18&year=&organisation_id=&submit.x=62&submit.y=21

[46] Hovey, T., Cheswick, C.(2009) Copying Letters to Service Users with Learning Disabilities: Opinions of Service Users, Carers and Professionals Working within Learning Disability Services, *British Journal of Learning Disabilities*, Vol:37, pp: 50–55

[47] Royal College of Nursing (2010) *Dignity in health care of people with learning disabilities* page 5.

[48] Turner, S. and Robinson, C. (2010) *Health Checks for People with Learning Disabilities: Implications and actions for commissioners. Evidence into practice report no.2* Improving Health and Lives Learning Disabilities Observatory.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

23

A periodic audit of appointments will uncover whether these reasonable adjustments are being implemented and are delivering equality of access to healthcare.

Offering treatment

"When I go in, they offer me time and space to settle down if I am upset."

Staff should ask if the individual has a health action plan so that this can be updated appropriately[49]. In Hertfordshire, health action plans are kept in a purple folder supported by a 'Purple Strategy' to raise awareness about adjustments for people with learning disabilities. This kind of initiative can help to combat stereotypes that have previously restricted access for people with learning disabilities or autism, for example to talking therapies ('they lack sufficient communication skills', or 'they lack emotional insight'), behavioural interventions ('they won't remember the homework') or memory clinics ('they can't improve')[50].

Such beliefs can mean that the first choice of intervention is often medication, sometimes without a clear diagnosis or evidence that it works. Some people with autism or learning disabilities are hypersensitive to medication, and so prescriptions should begin at below average dose, and increased gradually with careful monitoring for both common and rare side effects. Guidance is available on the use of psychotropic medication for managing challenging behaviour[51].

There are many alternative ways in which autistic or learning disabled people can be involved in managing their psychological and emotional wellbeing, including the following: social prescribing, peer experts and mentors, health trainers, psychological wellbeing practitioners, cognitive behavioural treatments and access to offline and online peer support groups. Alongside this might be employment support, family carer support and other social care services.

Where the person is simultaneously negotiating the process of obtaining a diagnosis and support for a learning disability or autistic spectrum condition, the proper recognition of, and appropriate response to mental health needs may be more complex. Practice in all these fields has changed rapidly over recent years, and so people of different ages, living in different parts of the country, may well have had quite different experiences. However, anecdotal evidence suggests that diagnostic overshadowing remains a problem, and staff

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[49] Turner S & Robinson C (2011) *Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare: Evidence into practice report no. 3.* Improving Health and Lives Learning Disabilities Observatory

[50] Hejl, A., Hogh, P. and Waldemar, G. (2002). Potentially reversible conditions in 1000 consecutive memory clinic patients. *Journal of Neurological Neurosurgical Psychiatry*, 73,390-394.

[51] Unwin, G. L. and Deb, S. (2010). The use of medication to manage behaviour problems among adults with an intellectual disability: a national guideline. *Advances in Mental Health and Intellectual Disability*, 4(3), 4-11.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

24

sometimes fail to see the person's capabilities or their mental or physical health needs because the learning disability or autism is seen as dominant.

> *"My daughter's Asperger's syndrome was misdiagnosed as mental illness and psychiatric medication made her problems worse."*

Another person with autism wrote to us. He had spent time in prison and recently been through major heart surgery. He is currently awaiting prostate surgery, has been obliged to move out of his home to have a long-term damp problem addressed and has ongoing mental health issues. Despite these things, he continues to live independently. His resilience in the face of such diverse challenges highlights the need to treat each person as a whole, to recognise their strengths and to offer a variety of skills blended into one coherent plan. But it also illustrates the fact that autistic and learning disabled persons do not escape the challenges and setbacks that everyone else has to address in life. Indeed there is evidence that they are more likely to experience life's adversities[52] and these things should receive a helpful response too[53].

A small number of individuals will benefit from full assessment[54] to pinpoint the impact that their autism or learning disability is having on specific areas of functioning and primary care services will need to refer appropriately. Others will benefit from a briefer screening assessment or a wider assessment through the social care assessment process. Sometimes the simple things are best, as illustrated by the following comment by one learning disabled respondent who described his experience of an effective mental health service in this pithy summary remark:

> *"You can talk about what's on your mind."*

Psychological therapies

The UK Government has insisted that the Increasing Access to Psychological Therapies (IAPT) programme in primary care must be accessible to people with learning disabilities[55]

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[52] See Emerson, E. (2012). Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *Journal of Intellectual Disability Research* Online early doi: 10.1111/j.1365-2788.2012.01577.x

[53] The LANTS scales comprise a self-report and an informant measure of the effects of traumatic life events on people with learning disabilities. See Wigham,S., Hatton,C., Taylor,J. (2011) The Lancaster and Northgate Trauma Scales (LANTS): The Development and Psychometric Properties of a Measure of Trauma for People with Mild to Moderate Intellectual Disabilities, *Research in Developmental Disabilities*, Vol: 32 pp: 2651–2659

[54] A variety of assessment tools are available, such as DISCO and ADI-R for autistic spectrum conditions.

[55] Department of Health (2008) *Improving Access to Psychological Therapies (IAPT): Best Practice Guidance Commissioning Toolkit*. London: Department of Health. Also Department of Health (2009). *Improving Access to Psychological Therapies (IAPT): Learning Disabilities Positive*

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

25

and so reasonable adjustments are needed. Research has been commissioned into the success of these adjustments[56], and the following vignette illustrates why it is important.

> *"A lot of GPs use a questionnaire to determine the person's level of depression and anxiety, and will refer people to the IAPT (Increasing Access to Psychological Therapies) service if they score 15 or above on the questionnaire. As an IAPT therapist, I recently worked with someone who scored zero. At the second session I asked him about his answers and he admitted that he could not actually read the questionnaire and had just circled numbers without knowing what they meant."*

Greenwich are planning to create a specialist IAPT service for people with learning disabilities, and a number of the IAPT services we heard from aim to make adjustments to their mainstream service so that people with learning disabilities or autism can use them effectively.

The table below shows what some IAPT services have done to make reasonable adjustments so that people with autism or learning disabilities achieve the same outcomes as others with mental health issues. All of these adjustments are applicable to all kinds of community team working in any branch of mental health services.

What did you adjust?	How do you do it now?	Who has done this?
Advertising the IAPT service	We give presentations and issue handouts at learning disability events	West Sussex
Work with family carers	We involve family members in assessment and interventions when appropriate	Shepway
Triage	We offer face-to-face rather than the usual telephone triage to people who need it	Northumberland Tyne & Wear
Joint working	IAPT staff seek advice from the learning disability team and often do joint assessments.	Talking Changes
Joint working	A member of the IAPT team is part of the Bristol Autism BASS) drop in service, and in return, BASS provides training to the IAPT team	Bristol

Practice. See also Dodd, K., Joyce, T., Nixon, J., Jennison, J., Heneage, C. (2011) Improving access to psychological therapies (IAPT): are they applicable to people with intellectual disabilities?, *Advances in Mental Health and Intellectual Disabilities*, Vol. 5 Iss: 2 pp. 29 - 34

[56] Research into the experiences of learning disabled people using IAPT services will begin in late 2012 and be led by Dr Deborah Chinn at King's College, London.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

26

What did you adjust?	How do you do it now?	Who has done this?
Location of appointments	We offer home visits when needed	Southampton City
Length of the appointment	Appointment times can be extended	Northumberland Tyne & Wear
Number of appointments	More sessions offered than the usual 6-8.	Shepway
Staff training	All our IAPT staff have been trained by the senior psychologist in the learning disability service on how to adapt materials for learning disabled people.	Talking Changes
Cognitive Behaviour Therapy	Has been adjusted for learning disabled people[57]	Shepway
Workbooks	We have large print and audio materials available	Shepway
Recording	Family carers or IAPT staff can help with completing documents	Shepway
Supervision	The senior psychologist in the learning disability service offers supervision to our IAPT staff.	Talking Changes
Management	The same manager oversees the learning disability service and IAPT	Talking Changes
Research	A study of the impact of adjustments to IAPT work is under way	Wandsworth

Communication

"The clinical psychologist would sit opposite my daughter, despite my suggestions that perhaps participation in a joint activity and sitting shoulder to shoulder might

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[57] They adapt materials from Stallard, P., (2005). *A Clinician's Guide to Think Good-Feel Good, Using CBT with children and young people*, Wiley. Also Stallard, P., (2002*). Think Good- Feel Good, A Cognitive Behaviour Therapy Workbook for Children and Young People*, Wiley. Such adaptations will clearly need to be done in age appropriate ways.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

27

make it easier for her to talk. She opened each appointment by asking my daughter what she was there for, what she wanted to achieve and what she wanted to talk about, all questions which have infinite possible answers and so are very stressful for a person with autism. She was aware that my daughter found speaking made her very anxious and that email had become a preferred method of communication but she was not willing to offer any alternative methods of communication, either between or during appointments.

Some people find communication via text or email much more acceptable than meeting face to face and staff may need guidelines to ensure that these approaches are available, safe to use and recognised as a lifestyle choice rather than a measure of the person's mental health. This should include contact arrangements for out of hours and emergency services. Others will communicate pain or discomfort in an unusual way, and so understanding the individual is central to making appropriate adjustments[58].

Simple guidelines on face-to-face communication can help, such as the following;

- maintain a quiet, calm, low voice with people who dislike too much expression;

- replace gesticulation, facial expression, body language and metaphor with clear, literal statements;

- do not demand eye contact;

- avoid an angry or aggressive tone as the person may fear that they will be harmed by you;

- allow longer for the person to establish trust.

The following table illustrates how some adjustments made by local services.

What did you adjust?	How do you do it now?	Who has done this?

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[58] Turner S & Robinson C (2011) *Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare: Evidence into practice report no. 3.* Improving Health and Lives Learning Disabilities Observatory

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

28

What did you adjust?	How do you do it now?	Who has done this?
Our inpatient mental health team	A new inpatient was autistic and deaf so the staff team learned basic British Sign Language	Oxleas
Independent Mental Health Advocacy service	Two advocates received training in the use of Talking Mats[59]. Two advocates received training in Makaton.	Quoted in Newbigging 2012
Our use of language	We stopped using opaque and threatening terms, such as 'close obs' and 'enhanced levels of observation'	Oxleas
Crisis Resolution and Home Treatment service	We use Communication Passports[60] that set out how people communicate	Avon and Wiltshire
Communication assessment	A Complex Communication Clinic is available to people aged 0-19	NHS Nottinghamshire County
Communication Supports	An Access to Communication and Technology Service is available for people of any age	Birmingham Community Healthcare[61]
Communication Support Plan	We use a tick list that shows how the individual prefers to communicate with others.	Derbyshire Healthcare NHS Trust

Information

> *"They use jargon words. It's long and not broken down."*

People with autism or learning disabilities may require information about mental health in an accessible format and in manageable amounts. This includes material in larger font, in particular colours or in easy read formats. Appendix two lists some sources of easy-read leaflets and audio recordings on staying well, identifying a problem, getting help,

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[59] Talking Mats help people to communicate. See www.talkingmats.com/

[60] A survey found just one communication passport in Avoin and Wiltshire in January 2012, but a development project and benchmarking club resulted in this increasing to 36 in just three months. For an example of a communication support plan, see page 14 of Aylett J (2011) *The Autism Act 2009: developing specialist skills in autism practice* Harrow: RCN Publishing Co.

[61] http://www.bhamcommunity.nhs.uk/about-us/divisions-and-directorates/specialist-services/rehabilitation/west-midlands-rehabilitation-centre/services/act/

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

29

medication, and rights and the law, which some organisations have uploaded to their own websites. Help is available on creating easy-read materials[62] and a study of the quality of these documents is under way[63]. Websites should be accessible to people with learning disabilities[64] and people using services and family carers can advise on whether the right information is available in the right format. For example:

- Cornwall consult with local People First groups before issuing easy read documents;

- professional and learning disabled staff employed by Hertfordshire Partnership NHS Foundation Trust have together delivered accessible information workshops where staff learn how to make messages accessible. Medication leaflets are available in three formats, each with less text and detail and printed with larger font than the last;

- Hillingdon Community Health provide an online easy-read directory of all their services;

- in St Charles Hospital there is a folder on each ward with information about learning disabilities which includes accessible easy-read information, including materials on the Mental Health Act.

Even with the right kind of information in the right format, the most important thing is often the availability of someone who has the time and willingness to spend enough time going through it with the person. For example, in Central and North West London NHS Trust, the mental health trust pharmacists meet with learning disabled people on three occasions to go through the easy-read medication leaflet, and at least one of these meetings must include a family carer. A research project found that showing an information video in short clips with time in between to discuss the message was much more effective for learning disabled people than showing the uninterrupted film[65].

Inpatient care

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[62] For example, Department of Health (revised 2010) *Making written information easier to understand for people with learning disabilities: Guidance for people who commission or produce Easy Read information.* Others can be commissioned to provide easy read materials (such as www.clearforall.co.uk) or train people to create their own (such as http://www.inspiredservices.org.uk/downloads/EasyReadTrainingFlyer.pdf).

[63] Dr Deborah Chinn at King's College, London is conducting a research study on the quality of easy-read health information.

[64] See for example http://www.calderstones.nhs.uk/easyread/

[65] Dunn, A., Stenfert Kroese, B., Thomas, G., McGarry, A., Drew, P. (2006) 'Are you allowed to say that?' Using Video Materials to Provide Accessible Information About Psychology Services, *British Journal of Learning Disabilities*, Vol 34, pp. 215–219

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

30

"*No-one showed me around.*"[66]

The Acute Care Declaration[67] and other guidance[68] provides a baseline of expectations around how inpatient mental health units need to respond to people with autism or learning disabilities. Hft have created a checklist for a hospital admission meeting[69] to ensure that all the key issues are covered and built into the care plan, including communication, basic needs, safety and keeping the person and family carers informed. Whilst this was written for acute hospital care, it is clearly applicable in all admissions. For example;

- the person may need to spend some time in a quiet room without a television and avoid large formal meetings and ward rounds[70];

- physical healthcare needs may need to be addressed as some people will need support with personal care[71]. Nottinghamshire Healthcare have set out their expectations for staff working in mainstream mental health services in respect of personal care[72], and protocols should be agreed for those occasions when additional expertise needs to be brought on to the ward[73];

- some people like familiarity and routine, so it is important to explain clearly, and perhaps repeatedly, how the routine of the ward works, especially if the pattern is not easy to discern;

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[66] Quality Check Group (January 2012) *People with Learning Disabilities using mental health services in West Sussex.* Section 3.4.

[67] http://its-services.org.uk/silo/files/acute-care-declaration-leaflet.pdf

[68] Such as the following guidance on how mental health services respond to people with autism: http://www.nhsconfed.org/Publications/Documents/Briefing_202_MHN_autism.pdf and Clarke K (2012) *Quality of Care Principles* West Bromwich: Changing our Lives.

[69] Available in http://www.hft.org.uk/p/4/121/working_together.html

[70] Royal College of Nursing (2010) *Dignity in health care of people with learning disabilities* page 6.

[71] Department of Health (2010) Essence of Care includes guidance on bladder, bowel and continence care, communication, food and drink, prevention and management of pain, personal hygiene, promoting health and well-being, respect and dignity, safety, and self care. See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119969

[72] Carr, D & Wellington S (2008) *Basic Personal Care MOT* Nottinghamshire Healthcare NHS Trust.

[73] "Family carers and care staff have sometimes been expected to provide unreasonable amounts of personal care to the person with learning disabilities while they are in hospital. Therefore it is important that clear protocols on the provision of extra personal care, and clear boundaries between the carer supporting role and the responsibilities of nursing, medical and allied professionals are in place." Turner S & Robinson C (2011) *Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare: Evidence into practice report no. 3.* Improving Health and Lives Learning Disabilities Observatory page 12.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

31

- some people who find it difficult to express themselves face to face and on demand will be able to write or draw a daily diary of their thoughts and feelings, which they can then share with mental health staff.

Whilst staff need to be alert to these general themes, a fully person-centred assessment tailors the care team's response to the particular individual. For example, in Avon and Wiltshire Partnership NHS Trust, people with learning disabilities have their own hospital book that provides useful information to the inpatient team about how the person prefers to communicate, their preferences and support needs. At CNWL, people with autism or learning disabilities usually transfer between wards during office hours, so that support staff can be available to smooth this process.

On rare occasions, the person may need highly specialist skills or an environment beyond the reach of mainstream mental health services. For example, Camden and Islington Mental Health and Social Care Trust have developed a 'virtual' mental health team for people with learning disabilities to provide specialist health care, care management, early intervention and community support. The team has representation from adult mental health inpatient services, learning disability health and social services. Beds and additional staffing have been allocated within a general mental health ward. Alternatively, South London and Maudsley NHS Foundation Trust provide a specialist mental health service for adults with learning disabilities that generally works with the mainstream mental health service, but also includes a small specialist admission ward for those where mainstream admission is not appropriate[74].

A review[75] of outcomes of specialist units compared with placement in mainstream psychiatric settings found insufficient evidence from which to draw bold conclusions, but people stayed longer on specialist units and made more friends there, while the arrangement was less popular with staff and family carers. A case has been made for specialist provision to be placed within mainstream mental health provision[76] but formally evaluated examples are scarce[77].

Forensic and Criminal Justice services

[74] Royal College of Nursing (2010) *Mental health nursing of adults with learning disabilities: RCN guidance* Page 12.

[75] Chaplin,R. (2009), New Research into General Psychiatric Services for Adults with Intellectual Disability and Mental Illness, Journal of Intellectual Disability Research, Vol:53 part 3 pp 189-199

[76] Hackerman, F., Schmidt, C.W., Dyson, C.D., Hovermale, L., Gallucci, G. (2006) Developing a Model Psychiatric Treatment Program for Patients with Intellectual Disability in a Community Mental Health Center, Comm*unity Mental Health Journal*, Vol. 42, Iss: 1, pp.13-24.

[77] Work has been done in individual disciplines (see for example) Jackson,T. (2009), Accessibility, Efficiency and Effectiveness in Psychological Services for Adults with Learning Disabilities, Advances in Mental Health and Learning Disabilities, Vol. 3 Iss: 4 pp. 13 – 18, but there is little on which to base general conclusions about service design.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

32

> *"I have three times given advice to the Forensic Wards about people who have Aspergers and the adjustments I ask them to make surprise and challenge them."*

People with autism, learning disabilities and mental health issues are over-represented in the criminal justice system, so it is important that agencies active in the forensic and justice field make reasonable adjustments. The adjustments illustrated here might be appropriate in other specialist services too, such as addiction teams.

In some services, adjustments are coordinated by a learning disability practitioner, such as at Bristol Court Assessment and Referral Service and Prison Mental Health Service. Similarly, there are Registered Nurses (Learning Disabilities) at Ashfield Youth Offender Institution and staff there have been trained in working with people with autistic. As a result, more offenders have transferred to hospital[78].

NHS Surrey has commissioned a full time Registered Nurse (Learning Disabilities), employed by Surrey and Borders Partnership NHS Foundation Trust to work across four prisons. Work is carried out in partnership with the mental health prison in-reach service that comprises psychiatrists, psychiatric nurses, support workers, psychologists and counsellors that offer movement psychotherapy, cognitive behavioural therapy, dialectical behaviour therapy, psychotherapy and counselling. New prisoners complete the Learning Disability Screening Questionnaire and those identified by screening as possibly having a learning disability are offered an Annual Health Check. They use the Cardiff instrument for this, which, as we have seen, includes questions on behavioural disturbance though not full mental health review and helps to generate an accessible Health Action Plan and health passport, and so assists others to provide appropriate support[79]. Suitable community health and social services are identified for people on release from custody.

Discharge from hospital

> *"When you go home from hospital, the care needs to be carried on."*

Some people find unexpected changes or new environments distressing, so careful planning is needed to ensure that discharge is not delayed, is as smooth as possible and intermediate care environments are not used inappropriately. This may require additional support in the person's home after discharge. Secondly, problems can sometimes arise due to different services having varying thresholds for discharging the person. This can lead to mental health services appearing to callously abandon the person who appears to have fewer needs than the newest referrals and who has made little discernible progress,

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[78] NHS South West (2009) *Including the Excluded: The Needs of People with Learning Disabilities in the Criminal Justice System* pages 5 and 38.

[79] Health Passports are part of the *Getting it right* charter. See http://www.mencap.org.uk/sites/default/files/documents/2010-06/PCT_Booklet.pdf

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

33

when colleagues in learning disability consider that the person needs ongoing support. Such variations may become more common as demand grows.

Oxleas Mental Health Foundation Trust help learning disabled people prepare for discharge with a workbook[80] that sets out diagnosis, treatment, when to return for follow up, any possible side effects from medication, and details of someone to contact if necessary. Gateshead have an intensive support team in their inpatient mental health service that coordinate and oversee discharge.

Conclusion

In this section, we have followed the autistic or learning disabled individual from a lifestyle that builds resilience through recognising mental health difficulties, referral to primary care and specialist mental health services, treatment, inpatient care and on to discharge. We have not tried to list every kind of service, but pick out those that illustrate specific themes most starkly. The most obvious gaps might seem to be health promotion where little evidence of good practice was found, and community teams - but this is because such teams need to be involved everywhere, borrowing adjustments and applying them to their own practice and to their partner agencies.

Adjustments are often quite simple responses – finding out how the person thinks and feels, what they need, how to communicate well, and what support the individual needs to remain in charge of their life to the fullest possible extent. In order to do this, staff need to engage with the person themselves, family carers and colleagues who have complementary skills. The next section examines what needs to happen behind the scenes to ensure that frontline workers can do these things.

Summary and Recommendations

Every step of the mental health care pathway needs to be adjusted so that people with autism or learning disabilities can receive equal treatment. This starts with supporting people to have a good life, maintain their wellbeing and exercise choice and control. Health checks at the GP surgery should include mental health state, and adjustments should be made to appointment times, duration and interventions with the doctor, staff offering psychological therapies and others. Information about medication and other treatments should be provided in accessible formats and referral to inpatient services and other specialists will need to take account of how autistic or learning disabled people cope in unfamiliar environments. Highly specialist teams and services that assess and treat people with complex needs must also assist mainstream services to respond well in their turn, and discharge planning needs to accommodate the distinctive support needs of

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[80] Royal College of Nursing (2006) *Meeting the health needs of people with learning disabilities* page 13.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

34

autistic and learning disabled people.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

35

Section 3: Effective services in a flourishing community

This section looks at what need to happen in the wider community so that people can have a good life. The reader is invited to follow an organisational pathway from population needs mapping, through market development and commissioning, to designing provider organisations and staffing them with appropriately qualified and supported workers. Adjustments designed to support people to obtain access to good communication, employment, education, housing and social capital opportunities are considered along with ways that services can support this agenda.

Population needs mapping

Guidance indicates population needs mapping should include people with autism[81], learning disabilities,[82] mental health issues or a combination. Currently available information includes:

- the number of children with learning disabilities known to schools

- the number of children with autistic spectrum conditions known to schools

- the number of learning disabled adults known to social care services

- the number of learning disabled people registered with GPs

- the number of adults with learning disabilities admitted to hospital for psychiatric reasons[83]

- the number of adults with learning disabilities in settled and non-settled accommodation

- the number of adults with learning disabilities in employment.

Health and Wellbeing Boards have the potential to provide a setting where all relevant stakeholders can meet to pool their insights and coordinate their response to the needs of

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[81] The Autism Act 2009 requires local service planning to include people with autism.

[82] www.ihal.org.uk/profiles

[83] Technically, the definition refers to 'psychiatric ambulatory care sensitive conditions' and defines this as 'Persons aged 18 + who were admitted to hospital with a primary diagnosis of Schizophrenia, schizotypal and delusional disorders who have been assigned an explicit diagnosis of learning disability, or a diagnosis of a condition usually associated or a degenerative condition associated with learning disability.'

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

36

the local population. Health and Wellbeing Boards should lead on the development of the Joint Strategic Needs Assessment (JSNA), which is the means by which leaders in health and social care understand the needs of the local population. The information they contain provides the basis for health and wellbeing strategies that set out agreed local priorities for action[84]. Primary Care Trusts or Clinical Commissioning Groups, along with local authorities will work with Health and Wellbeing Boards and the local community to plan integrated services that meet the needs of the whole community, and particularly those members who are vulnerable and have the worst health outcomes.

Changes in the NHS will identify new service commissioners and a range of new relationships between commissioners and providers. There is a risk that people with a combination of needs will be neglected, and so it is particularly important that people with autism or learning disabilities in addition to a mental health issue are included in the JSNA. Easy-read information about JSNAs is available[85].

Learning Disability Partnership Boards can help Health and Wellbeing Boards in population needs mapping and strategy development, as they are a source of local expertise and represent people with learning disabilities and family carers. Most Partnership Boards wrote a report in 2011/12 setting out local priorities and issues. The individual reports and an analysis of responses are available[86].

Commissioning and market development

Where mental health and learning disability services are commissioned by separate people, these colleagues need to work together to ensure that people with a combination of needs are not overlooked. Once they have identified the level of need and mapped current services against it, a gap analysis may show that there is a need to encourage new organisations to emerge or existing organisations to adapt in order to meet that need. Such demand should be considered in the light of the values and outcomes that shape commissioning and define effective services.

For example, the policy agreed across Lancashire Care NHS Foundation Trust, NHS Central Lancashire, NHS North Lancashire, Blackburn with Darwen NHS Teaching Care Trust Plus and NHS Blackpool explicitly promotes local rather than out-of-area placements whenever possible for people with learning disabilities and co-occurring mental health needs. Similarly, the commissioning strategy can promote supported living and open employment in place of institutional care. Guidance for commissioners is available[87, 88],

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[84] Department of Health (2011) Joint Strategic Needs Assessment and joint health and wellbeing strategies explained: Commissioning for populations

[85] http://www.inclusionnorth.org/useful-documents/

[86] www.improvinghealthandlives.org.uk/projects/partnershipboardreports

[87] Joint Commissioning Panel for Mental Health (February 2012) *Guidance for commissioners of primary mental health care services: Volume 2: Practical mental health commissioning.*

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

37

and the Joint Commissioning Panel is planning to issue some guidance on commissioning mental health services for people with learning disabilities.

Some areas choose to commission pan-disability rather than single client group provision. Such services start with a diverse array of skills and can accommodate people with a combination of needs. For example, Boscombe Resource Centre opened in 2005 and works with people with learning disabilities, people with mental health issues and people with physical or sensory impairments. Some staff are recruited from a specialist background, but quickly learn about unfamiliar areas from their colleagues, as long as the right culture is in place.

Another approach is to include a clear statement in all contracts with mental health service providers that their clientele may include people with autism or learning disabilities, as Kirklees Council have done. In passing, we note that this solution is sometimes qualified by the problematic concept of 'primary need', and a change in attitude may be required in addition to a change in the wording of the contract.

> *"The main barrier I experience is an attitude that learning disability and mental health are separate worlds and that mental health services are a little puzzled as to why they need to offer a service to someone with a learning disability. Don't we do all of that? There is always a discussion about the reasons why I want to use "their" service."*

The most successful work may be done through a co-production approach to planning. For example, the independent provider Vision MH developed a new supported living service. The steering group met for two years and included the mental health joint commissioners, the lead for Asperger's within the local Mental Health Trust, family carers representatives, the National Autistic Society, County Council Estates staff and the provider.

Where co-production and consensus is insufficient, a more vigorous approach to reasonable adjustments may be necessary. Avon and Wiltshire Mental Health Partnership NHS Trust, Leeds Partnership and Rampton Hospital have all used the CQUIN process[89] in addition to negotiation to secure change.

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[88] Improving Health and Lives and the RCGP (July 2012). *Improving the health and wellbeing of people with learning disabilities. An evidence-based commissioning guide for emerging clinical commissioning groups (CCGs). Final draft.* www.ihal.org.uk/publications

[89] The NHS CQUIN (Commissioning for Quality and Innovation) framework began in 2009/10 and enables commissioners to reward excellence by linking a proportion of providers' income to the achievement of local quality improvement goals. See guidance at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091443 and examples of CQUIN schemes that have been agreed at

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

38

Mission and monitoring

"I vowed never again to go to an appointment without a witness"

A clear mission will help mental health services to prioritise and align their activities. The Mencap Getting it Right charter[90] sets out what healthcare organisations may commit to in all their activities, while the recovery movement in mental health brings together themes of empowerment, self-directed support, social inclusion and living well within the limitations of impairment. We were interested to find little evidence that the Recovery approach[91] had reached autistic or learning disabled people, despite its potential relevance.

Monitoring requirements are formed by blending national and local requirements. The government are consulting on proposed changes to national data collection systems[92] and the following table illustrates some of the things that local mental health services are monitoring to ensure that people with autism or learning disabilities receive a good service. There are many other things that could have been listed here – for example, nobody told us that they tracked hospital re-admission rates for this group.

Things to monitor	Example
Consent to treatment	In one trust[93], doctors were provided with a rubber stamp to quickly mark the notes instead of being obliged to write or type. The recording rate showing that a discussion about consent to treatment and side effects of medication rose from 30% to 51%.

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http://www.institute.nhs.uk/commissioning/pct_portal/locally_developed_cquin_schemes_2012_and_2013_/

[90] Available from http://www.mencap.org.uk/campaigns/take-action/getting-it-right. The Board of Lancashire Care Trust has signed up to this charter.

[91] Recovery is a journey made by the person themselves towards their self-defined sense of what it means to live well whilst utilising support. See Shepherd G, Boardman J & Slade M (2009) *Making recovery a reality* London: Sainsbury Centre of Mental Health.

[92] See http://www.ic.nhs.uk/adultsocialcareconsultation12 for consultation documents regarding national data collection on social care. This consultation closes on 2 August 2012.

[93] Roy,A., Jain,S., Roy,A., Ward,F., Richings,C., Martin, M., Roy, M.(2011) Improving Recording of Capacity to Consent and Explanation of Medication Side Effects in a Psychiatric Service for People with Learning Disability: Audit findings *Journal of Intellectual Disabilities* Vol: 15 pp:85-92.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

39

Things to monitor	Example
Electronic CPA records	At Lancashire Care Trust a section has been added to the eCPA system to capture information about mental capacity. In Hertfordshire Partnership, the electronic patient record identifies learning disabled people who will need adjustments to be made.
Reasonable adjustments	2gether systematically monitor their Reasonable Adjustments[94] to collect evidence of impact.
Use of Independent Mental Capacity Advocates	The Central area of Lancashire Care Trust monitor referrals to IMCAs by people with learning disabilities and autism
Safety	Sheffield Care Trust and Sheffield City Council developed a benchmarking tool to promote the safety of people with learning disabilities in acute mental health and general hospital settings[95].
Untoward incidents	Lancashire Care Trust use structured approaches[96] to review serious incidents and near misses that affect people with learning disabilities alongside mental health needs
Review the local provision of mental health services	The West Sussex Quality Check group (a group of people with learning disabilities and family carers) reported in 2011 on reasonable adjustments made to local NHS mental health provision[97].
Mystery shopper	Learning disabled people have reviewed service quality in the addiction service and elsewhere in CNWL

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[94] Details can found at http://www.improvinghealthandlives.org.uk/adjustments/index.php

[95] Royal College of Nursing (2010) *Dignity in health care of people with learning disabilities* page 15.

[96] The structured approaches include Oxford Model Events, Dare to Share and reviews of Serious Untoward Incidents.

[97] Quality Check Group (January 2012) *People with Learning Disabilities using mental health services in West Sussex* Report provided by Pam Hall.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

40

Things to monitor	Example
Disability Equality	In Lancashire Care Trust the annual Disability Equality Action Plan includes people with autism or learning disabilities alongside mental health needs.
Review arrangements using the Green Light Tool Kit	Mental health and learning disability services have worked together to do this in Leicestershire Partnership NHS Trust[98] and in Kensington and Chelsea.

Policies and Governance

Reasonable adjustments can be made to governance arrangements, policies and procedures, and people with autism, learning disabilities and mental health issues can be involved in the design, day-to-day management and evaluation of the organisation. For example, a person with learning disabilities has been elected to the shadow governing body at Leicestershire Partnership NHS Trust.

All NHS Foundation Trusts are required by Monitor[99] to certify on a quarterly basis that they have:

1. a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients

2. provided readily available and comprehensible information to patients with learning disabilities about treatment options, complaints procedures and appointments

3. protocols in place to provide suitable support for family carers who support patients with learning disabilities.

4. protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff.

5. protocols in place to encourage representation of people with learning disabilities and their family carers.

6. protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports.

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[98] Royal College of Nursing (2010) *Mental health nursing of adults with learning disabilities: RCN guidance* Page 12.
[99] Monitor (31 March 2011) *Compliance Framework 2012/13* page 53-54.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

41

Whilst all Foundation Trusts are required to meet these six expectations, the Board of Oxleas NHS Foundation Trust has set out detailed actions that show how they have complied with these requirements[100].

The following table provides some examples of policies and procedures established by mental health services to ensure that people with autism or learning disabilities receive a good service.

These documents have been adjusted	Examples
Benchmarking	Avon and Wiltshire have established a benchmarking club for all inpatient mental health wards and carry out an annual rating against seven clearly defined performance indicators related to the experience of learning disabled people on the ward.
Care pathway	Sussex Partnership NHS Foundation Trust have a policy setting out the care pathway for people with learning disabilities and co-occurring mental health needs
Clinical interface	Kensington and Chelsea have a referral system for joint working between mental health and learning disability community teams
Dementia care pathway	Derbyshire Healthcare NHS Trust have developed a care pathway for people with learning disabilities and dementia.
Fire drill	Oxleas make a plan for how to support people who are frightened by the fire alarm and need help to leave the building. They provide ear defenders, kindness, gentle explanations and guidance.
Job description – desirable characteristics	All job descriptions at Derbyshire Healthcare include 'knowledge of learning disabilities' as a desirable competence
Job description – linkworker role	Derbyshire Healthcare have created a role description for the linkworker role that one staff member from each team takes on to ensure that learning disability and mental health services relate well to each other.

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[100] Oxleas Foundation NHS Trust (2011) *Protocol for Improving Access to Healthcare for People with Learning Disabilities.*

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

42

These documents have been adjusted	Examples
Risk assessment	Hertfordshire Partnership have adapted their risk assessment documents for people who have autism or learning disabilities alongside mental health issues.

Further adjustments could be made on a range of other policies to ensure that people with autism or learning disabilities are well informed and supported when using mental health services - Advanced Directives, Deprivation of Liberty Safeguards, Mental Capacity, Patient Satisfaction, Recruitment and Selection of Staff, Safeguarding[101], and Support for Family Carers to name but a few.

Buildings and furnishings

> "I have terrible problems under fluorescent, low energy or blue lights[102]. I'm awaiting a reply from my GP to see if a reasonable adjustment can be allowed for me to attend with his office fluorescent light switched off. The GP Manager has so far denied my request."

We were told about the simple adjustments made by some health and social care professionals, such as meeting in a north-facing room with natural light, offering a home visit, allowing the person to move in and out of the interview at will, wearing calming clothing and allowing inpatients to leave a bedside light on through the night[103]. At an organisational level, co-locating staff who work in autism, learning disability and mental health services will ease communication flow. Other agencies have changed furnishings and fittings to accommodate people's needs[104], as illustrated in the following table.

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[101] "Rates of abuse are higher in the learning disabilities population because of high dependency on others and difficulties in recognising and reporting abuse." (Biza Stenfert Kroese & John L. Rose (2011) *Mental Health Services for Adults with Learning Disabilities* The Judith Trust page 6.

[102] Seventy percent or more of people with autism may experience sensory sensitivities. See Aylott J (2011) *The Autism Act 2009: developing specialist skills in autism practice* Harrow: RCN Publishing Co. page 7.

[103] Royal College of Nursing (2010) *Dignity in health care of people with learning disabilities* page 14.

[104] Advice on shaping the environment is available at http://www.autism.org.uk/working-with/leisure-and-environments/architects.aspx.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

43

The person has difficulties with	How the service responded	Who has done this
Finding the right room	We use pictures and symbols from easy read leaflets to label rooms such as the toilet and dining room[105].	Lancashire Care Trust
Loud noises	Additional soundproofing, extra insulation under carpets and sound absorbing wallpaper. Some people like to reduce sensory input by wearing ear defenders, sunglasses and socks rather than shoes indoors. Bedrooms are located away from noisy areas.	Vision-MH
Visual stimuli	Decoration in pastel or muted colours, 'dimmer' light switches and minimal clutter	Vision-MH
Getting lost	Paint colour on the walls is used to help with wayfinding	SLAM
Equipment	A 'sensory suitcase' is available via the equipment library and can be used by staff to develop a calming atmosphere on any ward.	East Sussex Hospitals NHS Trust
Leisure activities	Special film screenings[106] where the volume is reduced and the lights left on to reduce the sensory intensity.	Odeon Cinemas
Posters and notice boards	Use muted colours and calm, ordered designs to communicate on posters[107]	Estia Centre
Sensory sensitivity	The Consultant Occupational Therapist is trained in sensory modulation. Some people find touch very difficult and their preference should be respected as far as possible.	Vision-MH

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[105] The Trust has obtained limited permission to use electronic versions of these signs through Boardmaker at http://www.mayer-johnson.com/boardmaker-v-6/.

[106] http://www.ansaar.org/index.php?option=com_content&view=article&id=80:autism-friendly-screenings-at-odeon&catid=1:latest-news&Itemid=50

[107] We noticed an unfortunate use of brilliant rainbow colours on a poster about autism produced by one organisation – illustrating how easy it is to neglect this adjustment!

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

44

The person has difficulties with	How the service responded	Who has done this
Shopping	Some shops have a disability sign above particular tills, enabling people who find it hard to stand in line to be served immediately[108].	Many supermarkets

Workforce

There are some fundamental requirements that must be in place if staff are to do their job effectively, whether in a mental health service or anywhere else. When things go wrong, it is more often to do with these basic things than highly sophisticated and technical matters. The Judith Trust[109] have underlined the need for:

- Staff who are people of goodwill and willing to learn

- A manageable task with clear indicators of success and a chance to maintain a healthy work/life balance

- Recognition and appreciation for their efforts

- A safe environment and learning culture rather than a blaming one

- Sufficient training, supervision and monitoring to ensure that quality is maintained

For example, Bristol Autism Spectrum Service work to make the care pathway accessible to people with autism across a range of mental health services by supporting staff through a mix of training and supervision. The training is delivered by members of the team, who can draw on their own experience and give participants practical ideas regarding issues like communication, and making services more predictable. To back up the training, the team offer time limited (4 sessions maximum) supervision, as in their experience, the combination of training and supervision has a better chance of changing practice.

The staffing profile and individual job roles can make a difference too. In one area, there were difficulties in recruiting consultant psychiatrists. The solution was to create a post that covered both learning disability and mental health services, and this brought an additional

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[108] http://www.dimensions-uk.org/yourautismfriendly/

[109] Biza Stenfert Kroese & John L. Rose (2011) *Mental Health Services for Adults with Learning Disabilities* The Judith Trust page vi.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

45

benefit of improving access to mainstream mental health services for people with learning disabilities[110].

Staff Training

> *"Each time I tried to explain that I felt Lauren had developed mental health problems as a result of years of bullying and a lack of understanding in school, I was made to feel as if I was an interfering parent. I organised for Lauren to have a private assessment only to be told by the school that I would be wasting my money as they did not recognise assessments from outside the school system. We were made to sit through hours of family therapy. When it was pointed out to her psychiatric nurse that Lauren had Aspergers syndrome, she asked 'What's that?' When I questioned the psychiatrist, he informed me that 'they didn't treat autism, they treated mental health problems'."*

Qualifying training does not usually include much information on how to work with people who have a combination of needs[111], but advice is available[112]. Even a small amount of training can help mental health staff to become more confident and effective in responding to people with learning disabilities[113]. The Royal College of Nursing says that all nurses should have training in working with people with learning disabilities[114] and the Autism Act 2009 requires all health and social care organisations to train staff in autism[115]. Staff can also benefit from placing their activities within a broader framework of equalities and work with people with any kind of disability[116]. Involving experts by experience[117] and family

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[110] Commission for Social Care Inspection, Healthcare Commission, Mental Health Act Commission (2009) *Commissioning services and support for people with learning disabilities and complex needs: National report of joint review.* London: CSCI.

[111] Turner S & Robinson C (2011) *Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare: Evidence into practice report no. 3.* Improving Health and Lives Learning Disabilities Observatory

[112] See, for example, Perry D, Hammond L, Marston G, Gaskell S & Eva J (2011) *Caring for the Physical and Mental Health of People with Learning Disabilities.* London: Jessica Kingsley Publishers. ISBN-13 978-1849051316.

[113] Costello, H., Bouras, N., and Davies, H. (2007). The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities,* 20 (3), 228-235.

[114] Royal College of Nursing (2010) *Dignity in health care of people with learning disabilities* page 5.

[115] Aylott J (2011) *The Autism Act 2009: developing specialist skills in autism practice* Harrow: RCN Publishing Co. page 3.

[116] For example, Lancashire Care Trust has used the Disability Equality and Etiquette Learning (DEEL) programme for health and social services that was launched by the Department of Health and the Disability Rights Commission in 2007. Details at http://www.gbdtc.org.uk/

[117] Service user consultants (experts by experience) assist in the design and delivery of training at the Estia Centre and in Westminster. See also Heneage C, Dhanjal K & Morris D (2009) Training

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

46

carers in staff training can be highly valued, as can training in specific issues, such as dementia[118] or swallowing difficulties[119].

These staff have received training	On this subject	Training was provided by
Mental health nursing students	A placement in learning disability services	Canterbury Christ Church University
Continuing professional development	An accredited course titled *"Managing the Complex Needs of People with Coexisting Learning Disability and Mental Health Problems."*	Canterbury Christ Church University
Staff working in mental health services	Learning about autism	University of Hertfordshire
All staff at induction	Reasonable adjustments for people with learning disabilities	Derbyshire Healthcare use the Sunnyarts film 'Not the Doctor's'[120]
Staff in mental health recovery teams	How to improve access and interventions for people with learning disabilities	A specialist learning disability nurse employed to work in the mental health service

'IAPT' psychological wellbeing practitioners about learning disabilities as 'expert by experience' and clinical psychologist together: Part 1 – Evaluation of a training session. *Learning Disabilities Faculty Newsletter* quoted in Dodd, K., Joyce, T., Nixon, J., Jennison, J., Heneage, C. (2011) Improving access to psychological therapies (IAPT): are they applicable to people with intellectual disabilities?, *Advances in Mental Health and Intellectual Disabilities*, Vol. 5 Iss: 2 pp. 29 - 34

[118] People with learning disabilities have a higher prevalence of dementia. See Cooper, S-A. (1997). A population-based health survey of maladaptive behaviours associated with dementia in elderly people with learning disabilities. *Journal of Intellectual Disability Research*, 41, 481-487.

[119] Guidance on the management of swallowing difficulties is available at http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823

[120] Film available from http://www.sunnyarts.co.uk/pages/dvds-currently-available/1720

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

47

These staff have received training	On this subject	Training was provided by
Third sector service provider	The SPELL approach[121] to support effective response to people with autism	MCCH in-house trainers use National Autistic Society materials under licence to train their own staff
Staff in the mental health inpatient unit	Learning disabilities and autism	St Charles hospital
People who run the Hospital Manager's Hearings under the Mental Health Act	Training on how to adjust the arrangements for the Hearings	SLAM
All mental health staff	Learning disability awareness training	Online course provided by Sussex Partnership Foundation Trust
Open to all	An extensive programme of training[122] on addressing the mental health needs of people with learning disabilities	Estia Centre, London

Interventions

> *"I was given a care plan with a 'traffic light system' to help me manage the voices that I hear. We did not really understand it. Once, when my symptoms got really bad, we went to the Crisis Team but they told us off, as they said that we had not used the Traffic Light System, but I thought we had."[123]*

A first step in making adjustments is to avoid inappropriate interventions. One respondent explained to mental health staff about "…rocking, hand flapping, hand wringing, vocalisations, pacing, arranging or 'fiddling' with a small object. Please do NOT stop or

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[121] Information about SPELL is at http://www.autism.org.uk/living-with-autism/strategies-and-approaches/spell.aspx

[122] The Estia Centre arranges around 50 training days a year.

[123] Quality Check Group (January 2012) *People with Learning Disabilities using mental health services in West Sussex* section 3.4.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

48

reprimand these behaviours as they are important in enabling autistic individuals to calm themselves and can also facilitate concentration and communication."

There is evidence that reasonable adjustments can make cognitive behavioural therapy (CBT) and other 'talking treatments' effective with learning disabled people[124] and the NHS Constitution states that patients have a right to NICE-approved therapies when these are clinically appropriate[125].

Adjustments can be very varied. For example:

- psychotherapists in Somerset Partnership Trust have used sandplay with adults who have difficulty with words and some are able to create representations of their thoughts and feelings using this creative medium.

- Similarly, family or systemic therapy has been adjusted to become accessible to learning disabled people[126]

- Speech and Language therapists at Rampton Hospital have adapted Dialectical Behaviour Therapy and Arson Treatment for use with people with autism or learning disabilities.

- Psychologists at Hillingdon Substance Misuse Services offer neuropsychology tests to tailor treatment to the clients' level of understanding and then provide simple pictorial information materials explaining their health and wellbeing messages.

- At CNWL, the eating disorders service have adapted their work to focus more on behavioural and less on cognitive interventions for people with learning disabilities.

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[124] Willner, P., and Hatton, C. (2006) CBT for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*. 19, 1-3. Also Stenfert Kroese, B. (2008) Carers' expectations and views of cognitive behavioural therapy for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 52, 732. Also Pert, C., Jahoda, A.,Trower, P., Stenfert Kroese, B., Dagnan, D. and Selkirk, M. (2008). Making sense of therapy: Clients' views of cognitive behavioural therapy, *Journal of Intellectual Disability Research*, 52, 732. Also Hare, D.J., Searson, R., Knowles, R., (2011) Real Listening – Using Personal Construct Assessment with People with Intellectual Disabilities: two case studies, *British Journal of Learning Disabilities*, Vol 39, pp.190–197. Also Bishop, A.,   Henry, J., (2008),The assessment and treatment of a man with mild learning disability, violent behaviour and chronic low self-esteem: a case study, *Advances in Mental Health and Learning Disabilities*, Vol. 2 Iss: 1 pp. 38 – 44.

[125] See, for example, http://publications.nice.org.uk/autism-recognition-referral-diagnosis-and-management-of-adults-on-the-autism-spectrum-cg142

[126] Baum, S. (2007). The use of family therapy for people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 1 (2), 8-13.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities NDTi July 2012

49

Boundary spanning

"I am based in a Community Learning Disability Team and work with a gentleman who has dementia. I contacted colleagues in Older Peoples Mental Health Services hoping to meet and share experience, foster working relations and improve care. They were unwilling to engage, claiming that they had no experience of people with learning disabilities and it would be inappropriate to offer advice. On another occasion during a joint assessment my colleague from Working Age Mental Health services took no part in the assessment and showed no interest in learning about how to work with people who have a learning disability".

Some people will need expertise from two or more teams, and so staff need to work together and navigate differences in approach, language or priorities.

There are a variety of ways to do this, including:

- A dedicated Liaison Service, such as at Lancashire Care NHS Foundation Trust

- An initiative to train and appoint 'champions', such as at Mid Yorkshire Hospitals NHS Trust where a one-day training course equips professional staff working in acute hospital settings to take on additional responsibilities surrounding the care, treatment and patient experience for people with learning disabilities or autism. By March 2012, 95 staff had taken up this role as 'Learning Disabilities Champion' and been provided with a role description[127], bi-annual meetings and ongoing support. We notice that this Trust does not provide mental health services, but the approach could easily be adopted by mental health organisations. For example, in Hertfordshire, around 20 mental health staff in a wide range of teams have taken on a role as Asperger's Champions.

- In Norfolk[128], mental health nurses can swap roles with nurses in acute hospitals for anything from a few days to three months.

Further examples are shown in the following table.

Type of mental health service	Boundary Spanning activity	Who is doing it
Mental health team	Link workers with learning disability teams	Derbyshire Healthcare

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[127] Available from http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=186.

[128] Norfolk and Suffolk NHS Foundation Trust is working with Norfolk and Norwich University Hospitals NHS Foundation Trust, James Paget University Hospitals NHS Foundation Trust and Norfolk Community Health and Care NHS Trust.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

50

Type of mental health service	Boundary Spanning activity	Who is doing it
Crisis team	Learning disability champions identified and trained to roll out training, be key links into learning disability services and support specific pieces of project work.	Hertfordshire Partnership
Dementia service	A representative of each dementia team and each learning disability team meet together from time to time to share good practice	Derbyshire Healthcare
IAPT	Green Light Facilitator attends IAPT assessments and sessions to support the IAPT practitioner in asking questions in a way the person understands	Lincolnshire Partnership
Inpatient unit	Each ward has a learning disability link nurse who receives training and advice from learning disability staff.	East Sussex Hospitals NHS Trust
Recovery Team	Learning Disability specialist nurse with additional mental health training employed to work across three recovery teams and link with learning disability community team	Sussex Partnership
Managers	A meeting occurs every two months between managers in mental health and learning disability services to solve problems and clarify best practice	North Lincolnshire
Older person's mental health teams	Link worker with learning disability teams	Derbyshire Healthcare

Meeting basic human needs

Wellbeing and community inclusion.

South London and Maudsley have used the Mental Wellbeing Impact Assessment toolkit[129] to help their mental health services take a broad view of mental wellbeing rather than the narrow focus of mental illness. However, at the time of writing, there are no

[129] http://www.apho.org.uk/resource/item.aspx?RID=95836 Over 70 reports of mental wellbeing impact assessments have been posted at http://www.apho.org.uk/default.aspx?RID=44538

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

51

recorded examples of this toolkit being used to specifically look at the experience of people with autism or learning disabilities in mental health services.

STEPS in Stockton-on-Tees is an inclusion service that is open to people with autism, learning disabilities or mental health issues and provides support to engage in mainstream employment, education, volunteering, arts, sports, faith and identity-based activities alongside the general public. People with a range of needs can be supported this single, diverse team.

Housing and Employment.

> *"When visiting the person, the Family Support Worker asked if it was okay to come into the property as the person didn't know to invite people in. Community Mental Health Team staff had previously several failed visits as the person didn't say "Come In" so they stood on the door step and then left!"*

Effective housing and employment support will include adjustments to adverts and application processes, interviews, matching, training and support, and retention[130]. Where housing or employment support is commissioned separately for people with learning disabilities and people with mental health issues, attention is needed to ensure that people with autism and those with a combination of difficulties have fair and equal access.

For example, the specialist employment support service in Kirklees includes a worker who focuses on autistic jobseekers. This is open access so that eligibility for adult social care is not a barrier. The Bristol Autism Spectrum Service work in partnership with Mental Health Matters, and run a drop in service that includes advice on employment.

Summary and Recommendations

In a flourishing community, basic human needs are met, including the need for communication, mental wellbeing, a home, job and friends, and this is no different for people who have autism or learning disabilities in addition to a mental health issue.

Commissioners then need to work with others to map the needs of their local community and compare the result with service provision. Tracking those with autism or learning disabilities in addition to a mental health issue is a key part of this wider task, and then ensuring that mainstream mental health services play their part in the response to

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[130] Further information is available at: http://www.valuingpeoplenow.dh.gov.uk/content/employment-resources-hub. Also Sainsbury Centre for Mental Health (2009) *Commissioning what works: the economic and financial case for supported employment.* Also http://odi.dwp.gov.uk/odi-projects/jobs-for-people-with-learning-disabilities/project-search.php

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

52

identified need. This begins with developing a market for the provision of mental health services and then commissioning and monitoring a suitable range of services. Buildings need designing and furnishing to meet needs and the workforce appointed, trained and supported to deliver a high quality service. Staff will remodel and deliver interventions by working across traditional boundaries to address the needs of people with autism or learning disabilities in addition to a mental health issue.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

53

Conclusion and recommendations

Adjusting the mental health service to accommodate people who have autism or learning disabilities will not only meet legal obligations, but is likely to improve service quality for everyone. The actions that have been taken by individual services across England might be summarised as the five Fs:

- Specialist learning disability or autism services **facilitating** access to mainstream mental health services rather than doing it themselves and setting up more specialist services.

- Meeting with mental health professionals **face to face** rather than over the phone or via written assessments (unless otherwise requested as a personalised reasonable adjustment).

- In **familiar** surroundings and with **friendly** support. This gives the person the opportunity to choose where to meet the mental health professional and who they would like be there to support them.

- Be **flexible**. This applies both to organisational procedures and the practice of professionals. It can be liberating for all concerned as well as being a legal requirement!

This report has focused on the innovations that have been made in local mental health services around England. There are a significant number of examples of good practice, but good practice is far from common practice, and much more needs to happen to ensure that people with learning disabilities and people with autism get a good deal in mental health services and legal requirements are met. Many tasks remain outstanding, such as resolving thorny issues about differences in eligibility thresholds, effective health promotion, access to sophisticated assessment, the availability of evidence regarding efficacy of particular interventions, the best mix of adjusted mainstream services and specialist separate provision, to name but a few. We hope that the examples contained in this report will encourage people using services, staff and family carers to find ways of ensuring that people with autism, learning disabilities, mental health issues or a combination fair and equal treatment.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

54

Appendix One: How we did the review

After agreeing the project with the NHS Confederation, we built a Stakeholder map, invited people to contribute by email and phone and reviewed relevant literature. Some meetings were held with experts by experience, family carers and professionals. Over 100 people responded to the call for evidence.

The literature review searched for documents written in English and published since 2000 with content that may be applicable to the mental health service in England. Search terms included:

> Mental health/psychopathology/psychiatric disorders/illness

> + learning/intellectual disability/ies OR learning difficulty/ies OR autism/ASD/ASC

> + inclusive service/s OR accessible service/s OR service change OR adapting service/s OR adjusting service/s OR reasonable adjustment/s

We searched websites and publications databases of organisations, schemes, forums and networks linked to mental health / learning disability / autism, including those listed in our stakeholder map. This included Medline and PsychINFO as well as grey literature and publications written from a viewpoint of 'Expert Opinion' – e.g. by bodies such as the NHS Confederation, Royal College of Psychiatrists and British Psychology Society. A content analysis grid was developed and completed, structured around review prompts.

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

55

Appendix Two: Easy read leaflets for mental health services

We found all the leaflets listed in this appendix online[131]. They have been grouped under a series of headings. Some are also available as audio recordings.

Having a good life and staying well

Topic	Further Details
Activities	'Having things to do'
Eating	'Eating a healthy diet'
Eating	'Easy read menu'
Employment	
Exercise	
Family Carers	'Helping people to look after their mental health'
Handwashing	
Home	Housing options
Home	Renting
Home	Buying

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[131] http://www.inclusionnorth.org/useful-documents/, Karen@change-people.co.uk, http://www.pathwaysassociates.co.uk/info-accessinfo.asp, http://www.apictureofhealth.southwest.nhs.uk/, http://www.bild.org.uk/easy-read/easy-read-information/, http://www.booksbeyondwords.co.uk/books, Lancashire Care Trust, Leeds Teaching Trust, http://www.improvinghealthandlives.org.uk/adjustments/, http://www.learningdisabilities.org.uk/publications/176171/, http://www.ld-medication.bham.ac.uk/medical.shtml, Derbyshire Healthcare NHS Trust, http://www.slam.nhs.uk/patients/patient-information/easy-to-read-leaflets.aspx, http://www.easyhealth.org.uk/, http://www.kmpt.nhs.uk/easyread, http://www.nht.nhs.uk/main.cfm?type=YOURMENTALHEALTHAC3&objectid=2944

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

56

Topic	Further Details
Home	Your tenancy agreement
Membership of the Foundation Trust	
Mental Health	Factsheets
Politics	The Big Society – ten big questions
Politics	Think local act personal
Sleep	'Getting enough sleep'
Social life	'Having a social life'
Staying well	'Looking after your mental health'
Staying Well plan	Workbook
Wellbeing	'Staying healthy'

A problem has been identified

Topic	Further Details
Abuse	
ADHD	Attention Deficit Hyperactivity Disorder
Anger	
Anxiety	
Anxiety	
Autism	
Bipolar affective disorder	
Challenging behaviour	
Debt	What to do if you can't pay your rent
Dementia	2gether
Dementia	A picture bank

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

57

Topic	Further Details
Depression	'All about feeling down – for young people'
Depression	A film
Depression	A book 'Ron's feeling blue'
Depression	A book 'Sonia's feeling sad'
Feelings	'Feeling upset all the time'
Mental health problems	
Obsessive Compulsive Disorder	Devon
Personality Disorder	Devon
Post traumatic stress disorder	
Psychosis	
Schizophrenia	
Schizophrenia	NHS Choices
Self harm	
Stress	Devon
Tenancy	An acceptable behaviour contract with your landlord

Ways to get help

Topic	Further Details
Admission to hospital	'Things to bring into hospital' 'Staying in hospital'
Admission to hospital	Workbook - finding your way around the hospital
Admission to hospital	Workbook - things the staff need to know about me
Appointment letter	'Accessible appointment letter'
Assessment	'Mental health assessment'

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

58

Topic	Further Details
Assessment	'Your stay in hospital - Finding out what is wrong'
Assessment Tools	Glasgow Depression Scale
Assessment Tools	Alcohol Screening Checklist
Care Programme Approach	'So you're on CPA – what does it mean?'
Care Programme Approach	A care plan in symbols
Cognitive Behaviour Therapy	
Community Mental Health Teams	
Community Psychiatric Nurse	
General Practitioner	
NHS	What to expect from the NHS
Occupational Therapy	
Personalisation	Personalisation and personal budgets
Pharmacist	'Getting to know your pharmacist'
Psychiatrist	
Psychology	Seeing the psychologist for a cognitive assessment
Recovery Plan	Notts Healthcare
Relaxation	
Social worker	
Speech and language therapist	

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

59

Medication

Most of these are available as an easy read leaflet or as an audio file.

Topic	Further Details
Amisulpride	
Aripiprazole	
Atenolol	
Carbamazepine	
Chlorpromazine	
Citalopram	
Clozapine	
Diazepam	
Dosulepin	
Escitalopram	
Fluoxetine	
Flupentixol	
Fluphenazine	
Fluvoxamine	
Haloperidol	
Lithium	
Lofepramine	
Lorazepam	
Medication	'All my medications' 'All my medications workbook' 'How to make choices about taking medication'
Mirtazapine	

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

60

Topic	Further Details
Naloxone	
Naltrexone	
Olanzapine	
Paroxetine	
Propranolol	
Quetiapine	
Risperidone	
Sertraline	
Side effects	Workbook - On neuroleptic medication
Side effects	'What do I do if my medications make me ill?'
Side effects	An easy read chart to help someone choose for themselves which medication is best
Sulpiride	
Topiramate	
Trazodone	
Trifluoperazine	
Valproate	
Venlafaxine	
Zuclopentixol – injection	
Zuclopentixol - tablets	

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

61

Your rights and the law

Topic	Further Details
Advocate	
Advanced directive	
Appeals	Appeals under the Mental Health Act
Complaints procedure	'Making a complaint'
Confidentiality	
Consent	
Consent form	'Permission to share form'
Deprivation of Liberty Safeguards	
Discharge	'Discharge from hospital against medical advice'
Guardianship	
Human Rights	
Informal patient	'Your rights and responsibilities as an informal patient'
Mental Capacity Act	NHS Office of the Public Guardian has produced a booklet called 'Making Decisions'
Mental Capacity Act best interest pathway	Humber NHS Foundation Trust
Mental Health Act	Your rights under Section 2
Mental Health Act	Your rights under Section 3
Mental Health Act	Your rights under Section 4
Mental Health Act	'Your rights' 'Making an appeal' Section 132

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

62

Topic	Further Details
Mental Health Act	A film about Section 37/41
PALS	Patient advice and liaison service
Reasonable adjustments	Reasonable adjustments for people with learning difficulties
Safeguarding	Stop hate crime
Satisfaction survey	
Tenancy rights	

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

63

Appendix Three: How We Did the Literature Review

Background

As part of this project, a literature search was undertaken to identify and review examples of good practice. The focus of the search is on changes that have been made to mental health services aimed at making those services more accessible to, and better used by, people with learning disabilities and people with autism.

Methodology

PART I - Search strategy

Geographical scope: This project relates to England, however the search was undertaken on an international basis to draw upon examples from disparate sources to illustrate what is possible. Where non English examples were found we reviewed these to ensure that these were applicable to the situation in England before inclusion in the report of this work.
Retrospective timespan: Documents from 2000 to present

Search keywords and phrases:
Search terms used to identify relevant literature & learning from the above sources included:
Mental health/psychopathology/psychiatric disorders/illness
+ learning/intellectual disability/ies OR learning difficulty/ies OR autism/ASD/ASC
+ inclusive service/s OR accessible service/s OR service change OR adapting service/s OR adjusting service/s OR reasonable adjustment/s

Sources: We used online and academic search engines and libraries to find and gather relevant published and grey literature. The Research indexes and libraries used were:

- Medline

- PsychINFO

- Web of Knowledge

Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities
NDTi July 2012

64

A selection of other publications & resources, e.g. reports and presentations (some sent directly to the project team following a call for information) written from a viewpoint of 'Expert Opinion' – eg. by bodies such as the NHS Confederation, Royal College of Psychiatrists and British Psychology Society were also reviewed as part of this process.

PART II - Reviewing, organising and analysing evidence

The searches on the 3 indexes and libraries listed above returned details of 607 published articles and other materials. These were reviewed and 38 published documents were obtained, read and reviewed in full, in addition to several reports and publications obtained directly as described above.

Where examples of good practice (and other information) were found which were felt to be useful in informing the findings of this report within the documents reviewed, reference details were logged and coded and a content analysis grid was compiled.

Rather than provide a separate summary of the literature review, findings from it have been then used as examples throughout the report to illustrate evidence about both service shortcomings and when good practice can be applied to support better use of mental health services by people with learning disabilities and / or autism.