

North West Association of Directors of Adult Social Services

REPORT

Subject: Learning Disability Policy and Associated Issues in the North West
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1. Introduction

1.1 The purpose of this report is to provide an overview of learning disability policy and associated issues across the North West

2. Background and Overview of National Policy

2.2 Successive governments have retained a commitment to improve the life chances of people with learning disabilities and the support provided to their families. The coalition Government's policy position is that people with learning disabilities should lead their lives like any other person, with the same opportunities and responsibilities, and be treated with the same dignity and respect. This means inclusion, particularly for those who are most often excluded and empowering those who receive services to make decisions and shape their own lives.

2.3 Within that context the vision set out in Valuing People (*A New Strategy for Learning Disability for the 21st Century* Department of Health (2001) remains relevant:

'that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens.'

2.4 Valuing People set the foundation for subsequent learning disability and related policies including:

- Putting People First (A shared vision and commitment to the transformation of Adult Social Care, Department of Health (2007)
- The Independent Living Strategy (a cross-government strategy for all disabled people, Office for Disability Issues 2008)
- The Carers Strategy, (Carers at the heart of 21st-century families and communities, Department of Health 2008)
- Aiming High for Disabled Children: (Better Support for Families, HM Treasury/Department for Education and Skills 2007)
- The Children's Plan: building brighter futures (DCSF 2007)
- Valuing People Now: (a three-year strategy for learning disabilities, Department of Health, January 2009)

North West Association of Directors of Adult Social Services

2.5 The last national Learning Disability Strategy, 'Valuing People Now' (DH 2009) was due to end in March 2012. It has not yet been updated or replaced. However the document's aspirations, summarised below, remain relevant:

2.6 Including everyone:

Valuing People Now aimed to promote inclusion of those groups who are least often heard and most often excluded, for example:

- people with more complex needs;
- people from black and minority ethnic groups and newly arrived communities;
- people with autistic spectrum conditions; and
- offenders in custody and in the community.

2.7 Personalisation:

Valuing People Now highlighted the importance of person centred planning, advocacy and direct payments to give people more choice and control in their lives were at the heart of the original Valuing People. It complemented the commitment of Putting People First to giving people more independence, choice and control through high-quality and personalised services.

2.8 Having a life:

Valuing People Now set out key priorities for people with learning disabilities, including better health, housing, work and education. Including learning disabled people in mainstream work and services was seen as vital to improving performance in these areas.

The strategy also emphasised the importance of helping people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need for adequate support to sustain the family unit.

2.9 People as citizens:

Valuing People Now included specific commitments to improve responses to learning disabled people in the following areas:

- Advocacy
- Transport
- Leisure activities
- Being safe in the community and at home
- Access to Justice and redress

3. **Current Policy Position**

3.1 Guiding Principles

Valuing People (2001) established principles, summarised below, that continue to guide learning disability strategy, policy and the commissioning and delivery of learning disability services.

North West Association of Directors of Adult Social Services

- Rights: People with learning disabilities and their families have the same human rights as everyone else.
- Independent living: All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.
- Control: Learning disabled people should have information and support to understand the different options and their implications and consequences, so they can make informed decisions about their own lives.
- Inclusion: Learning disabled people must get the help they need to participate in all aspects of the community, to work, learn, get about, meet people, and to access goods and services.

3.2 ADASS Learning Disability Policy Network

The network has established the following priorities in this year's ADASS Business Plan:

- Responding to the outcomes from the CQC/DH/Serious Case Review reports from Winterbourne View
- Embedding and monitoring the implementation of the Autism Strategy

In addition the network is focussing upon:

- Transition to adulthood
- Continuing Health Care and learning disability
- Development of Payment by Results in Learning Disability Services
- Diversion & Liaison scheme development for mentally disordered offenders (including people with a learning disability)

The network has also begun a series of meetings engaging with sector wide providers of Learning Disability services and a network session with people who use services and family carers is being planned.

3.3 North West Valuing People Group

The North West Valuing People Group has the following the priorities:

- To maintain a joint regional force to influence change
- To make sure that Valuing People Now and other relevant national policies are a priority and focus for the North West
- Ensure that self advocates are supported to enable true participation in the group
- To deliver joint regional action and direction to lead officers and to continue to stimulate innovative action across the North West
- To influence and inform the National Programme Board or other bodies relating to regional priority issues

North West Association of Directors of Adult Social Services

4. Current Issues

4.1 Winterbourne View

4.1.1 On 25th June the Department of Health (DH) published an interim report following the Care Quality Commission's (CQC) national review of learning disability services in the wake of abuse exposed at Winterbourne View private hospital by the BBC Panorama programme. The report:

- Sets out the strategic direction, outcomes and how the Department of Health and the NHS Commissioning Board will measure progress;
- Ensures that commissioners, providers and the workforce are clear about their roles and accountabilities, and understand good models of care.
- Creates the framework within which local action should take place;
- Sets out proposed actions at a national level to drive good practice and focus on improving outcomes for individuals with learning disabilities or autism and behaviour which challenges.

4.1.2 The report identifies 14 actions to be taken at a national level to improve the lives of people with learning disabilities, autism and behaviour which challenges (these are attached for reference as Appendix 1).

4.1.3 The DH will publish a final report when criminal proceedings relating to events at Winterbourne View have concluded. A follow up report will then be published one year later to make sure that progress has been made.

4.2 Health and Social Care for Learning Disabled People

4.2.1 In March 2007 MENCAP published 'Death by Indifference', a report which asserted that the deaths of six learning disabled adults were the result of failings in the NHS. The Parliamentary and Health Service Ombudsman conducted an investigation into the deaths. In her report, 'Six Lives: The Provision of Public Services to people with a Learning Disability' published in 2009 the ombudsman concluded:

'Our investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care.'

Our investigations found maladministration, service failure and unremedied injustice in relation to a number, but not all, of the NHS bodies and local councils involved. In some cases we concluded that there had been maladministration and service failure for disability related reasons. We also found in some cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.'

4.2.2 In 2008 Sir Jonathan Michael published 'Healthcare for All', his report of

North West Association of Directors of Adult Social Services

the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. The report concluded that despite some examples of good practice:

'People with learning disabilities appear to receive less effective care than they are entitled to receive. There is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided.'

The evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities.

Despite guidance on the delivery of effective health care, few primary care and acute services are aware that the guidance exists, and few are aware of best practice. People with learning disabilities fare less well than other vulnerable groups in what can seem like a competition for political and local attention.'

4.2.3 'Healthcare for All' made 10 principle recommendations intended to achieve an effective, fair system of general health care for people with learning disabilities, who also happen to have health problems. These included:

- Amending Core Standards for Better Health, to include explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation
- Commissioning enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working
- Establishing a learning disabilities Public Health Observatory supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities
- Developing competence-based training for staff and involving people with learning disabilities and their carers in providing training
- Improving the monitoring of health services provided to people with learning disabilities
- Improving consultation with people with learning disabilities and involving them and their carers as partners in treatment and care

4.2.4 Earlier this year MENCAP published its progress report 'Death by Indifference: 74 Deaths and Counting.' The report maintains that whilst there are some examples of significant improvement progress against the 'Healthcare for All' recommendations, provision is, overall, patchy and therefore inadequate. The organisation has *'serious ongoing concerns that not enough progress has yet been made in addressing the health inequalities experienced by people with a learning disability' and that 'progress is neither wide nor deep enough to have effected real change in all parts of the NHS.'*

North West Association of Directors of Adult Social Services

4.2.5 MENCAP maintains that key issues to be addressed include a lack of compliance with the Disability Discrimination Act (now the Equality Act), direct discrimination by staff, a lack of understanding of the Mental Capacity Act and failure to take the steps required by law. 'Death by Indifference' highlights particular concerns at what MENCAP terms '*the lack of value placed upon the life of someone with a learning disability*'.

4.2.6 The report raises a range of concerns about practice, including:

- Poor communication with people with learning disabilities and their families
- Delays in diagnosis and treatment
- Use of Do Not Resuscitate Orders

4.3 Public Sector Funding, Reform and Demographic Growth

4.3.1 Ongoing reductions in public sector funding coupled with projected demographic growth amongst groups likely to require social and health care in the future present significant challenges for the health and social care economies. For example transition to the age of 18 amongst young people who require support but have learning difficulties, rather than a learning disability and increasing referral of learning disabled adults via the criminal justice system present additional risk and financial pressure for local government. The current system will not be unsustainable as demand and costs continue to increase, and it will not be possible to maintain the safety and quality of provision without adequate resources.

4.3.2 Fundamental reform is needed, including greater integration of Health and social care strategy, commissioning and support systems in order to take a more preventative approach, maximise independence and reduce reliance upon costly services in coming years.

5. **Key Points to Consider**

5.1 Whilst the policy framework that has evolved to protect and promote the interests and wellbeing of learning disabled people remains relevant there is a lack of central focus upon learning disability policy. Ongoing improvement is needed in access to and the outcomes achieved by health services for learning disabled people, and commissioners and providers of social care and support must find new and different ways to meet the needs of learning disabled people if they are to respond effectively to growing levels of need and demand within the context of reducing resources.

5.2 The White Paper, Caring for our future: reforming care and support (DH July 2012) states:

'It is clear that we cannot improve care and support by pouring ever more money into a system that does not work. We need to do things differently. We need radical reform to promote people's independence and give them real choice and control over their lives. This will ensure that resources are used in the best possible way to promote better outcomes and a better experience of

North West Association of Directors of Adult Social Services

care and support.'

5.3 The White Paper focuses upon citizens, carers, prevention and personalisation. It proposes two simple principles to guide reform of the care system.

'The first is that we should do everything we can – as individuals, as communities and as a Government – to prevent, postpone and minimise people's need for formal care and support. The second principle is that people should be in control of their own care and support.'

5.4 These principles are not new. They have underpinned health and social care policy for many years. However in the current climate it is more important than ever that they are translated into commissioning and delivery of support that prevents and reduces dependency on expensive services and results in better outcomes and reduced costs.

5.5. Whilst the proposals contained in the White Paper do much to place citizens, entitlement and choice at the heart of service delivery and legal reform the government's aspirations will not be achieved unless social care and integration with Health are adequately resourced.

5.6 The abuse exposed at Winterbourne View highlights the safeguarding risk that arises where learning disabled and other people are cared for and supported in segregated environments, isolated from their families, friends and the wider community. Isolation renders people more vulnerable to abuse and may also stifle their awareness of options, confidence, skills and aspiration.

5.7 Elements of the support system in the North West are in need of review and reform. For example Calderstones NHS Foundation Trust, located in the North West, provides assessment and treatment to learning disabled adults in medium and low secure residential units. This is unlikely to be a preferred model going forwards.

5.8 Reform of care and support systems must make it a priority for service providers to help people in need of social care (including people with learning disabilities) to be as independent as possible, have greater control over their lives, to retain and develop social networks and be recognised as valued members of their community.

5.9 Reducing reliance upon (often expensive) segregated services will go some way to mitigating the risks arising from isolation, help to improve outcomes for individuals and rebalance care and support away from purchased services towards more active communities. However this will depend upon building the capacity of families, carers and communities to take on additional or different responsibilities.

5.10 Success depends upon the ability of the state, particularly local

North West Association of Directors of Adult Social Services

government and Health agencies to have a different dialogue with people in need of social care, their families, carers and wider communities. Local government has a crucial leadership role to play in changing expectations and raising aspiration amongst groups that need support, and in setting the conditions for carers, families, friends and wider communities to take on greater responsibility for including learning disabled people in mainstream society.

- 5.11 Working with customers, families and others with an interest, to examine and establish innovative approaches to support may help to achieve these objectives. For example it might be possible to develop a more flexible lifetime/long-term approach to individual budgets, so that customers, their families and carers can plan ahead more effectively. This in itself may bring better outcomes and reduce whole system expenditure upon individuals over their lifetime.

6. Support on this agenda for the North West ADASS

- 6.1 The North West Training and Development Team was established in 1984. Originally set up by the North Western Regional Health Authority, the Team played a major role in development and training activity associated with the resettlement programme, jointly co-ordinated in partnership by Health and Local Authorities in the North West.
- 6.2 The NWTDT mission is ‘to facilitate the full inclusion of people with learning disabilities in community life, through partnerships with people with disabilities, families and organisations’ and four major ways in which it delivers this mission. These are:
- To develop local capacity for change through courses, mentoring, supporting and developing projects
 - Linking people together and developing partnerships through interested networks, courses and conferences
 - Providing leadership, developing ground breaking projects, training and contributing to research, and translating policy and research into action
 - Sharing what is being learned through conferences and publications
- 6.3 Since 1984 the NWTDT has been providing support, training consultancy, and networking opportunities to its partners across the region. Its mission or purpose is to provide support to its major stakeholders to ensure ultimately that people with learning disabilities are supported to have the very best quality of life possible.
- 6.4 This longstanding and unique partnership in the North West has been highly valued by the Department of Health and the Valuing People Support Team. However going forwards local authorities and Health agencies may have different needs for support and all will scrutinise expenditure to make sure they receive value for money.
- 6.5 It will be necessary to determine the support that local authorities and Health agencies will require in future and then to review the role and

North West Association of Directors of Adult Social Services

functions of the team, its branding and the offer that will be available in future for local authorities, Clinical Commissioning Groups and other stakeholders. This may necessitate competitive tendering for future provision to make sure it is fit for purpose and delivers value for money.

7. Recommendations

7.1 It is recommended that NW ADASS:

- i. Notes the content of this report
- ii. Reviews the support that ADASS, local government and other stakeholders will need to respond to the needs of learning disabled people and associated policy in the future and determines how this will be arranged.
- iii. Establishes a time limited task and finish group, including people with a learning disability and families to produce a more detailed plan of action to guide reform of care and support for learning disabled people in the region that takes account of:
 - The White Paper, Caring for our future: reforming care and support
 - National ADASS priorities
 - Regional priorities identified by the North West Valuing People Group
- iv. It is recommended that the outcomes of the group's work are reported to the national ADASS Learning Disability Network and the North West Valuing People Group.

North West Association of Directors of Adult Social Services

APPENDIX 1

WINTERBOURNE VIEW INTERIM REPORT

The 14 national actions

1. We have **identified 14 actions at a national level** to help achieve these objectives and to drive good practice and focus on improving outcomes for individuals with learning disabilities or autism and behaviour which challenges.
2. If these actions happen, more people with learning disabilities will be supported to live at home, fewer people will develop behaviour that challenges and those that do can be kept safe in their communities, far fewer people will be sent away to hospitals and where that happens, proper planning will mean that their stay will be as short as possible, because hospitals should not be places to live in. And we will be able to measure progress in doing this.

Improve the capacity and capability of commissioning across health and care

- i. **Contracts:** The Department will work with the NHS Commissioning Board Authority to agree by January 2013 how best to embed Quality of Health Principles in the system, using NHS contracting and guidance. These principles will set out the expectations of service users in relation to their experience.

We will also work with the Towards Excellence in Adult Social Care (TEASC)⁴ to agree how Quality of Life principles should also be adopted in social care contracts to drive up standards.

- ii. **Service specification:** The Department will work with the NHS Commissioning Board Authority and the Association of Directors of Adult Social Care (ADASS) to develop a clear description of all the essential components of a model service by March 2013.
- iii. **Resources:** NICE will develop Quality Standards on learning disabilities and the autism Quality guidelines will be published in July 2012. Draft guidance for Clinical Commissioning Groups (CCGs) developed by the Learning Disability Observatory, the Joint Commissioning Panel and the Royal College of General Practitioners is available on the Observatory website.⁵ This is being reviewed and revised guidance will be published in October 2012.
- iv. **Collaborative commissioning:** The NHS Commissioning Board Authority will support CCGs to work together in commissioning services for people Wellbeing Boards (HWBs) will bring together local commissioners of health and social care in all areas, to agree a joined up way to improve services.

Improve the quality of services which empower people with learning disabilities and their families to have choice and control

North West Association of Directors of Adult Social Services

- v. **Voice:** The Department is establishing HealthWatch both locally and nationally. It will act as a champion for those who use services and for family carers, ensuring that the interests of people with learning disabilities are heard and understood by commissioners and providers of services across health and social care.
- vi. **Personalisation:** The Department expects the NHS and local authorities to demonstrate that they have taken action to assure themselves and the public that personalised care and choice and control is available in all settings, including hospitals.
- vii. **Providers:** The Department expects providers to deliver high quality services and prevent abuse. This includes:
- actively promoting open access for families and visitors, including advocates and visiting professionals
 - making sure recruitment practices recruit the right people.

The Department will also discuss with providers developing and promoting a voluntary accreditation scheme.

The Department is working with the *Think Local, Act Personal* group⁶ and providers to identify the barriers in the housing market to increasing the availability of different housing options for people with learning disabilities with behaviour which challenges and to encourage and facilitate local solutions. This work should be completed by April 2013.

- viii. **Quality:** By autumn the National Quality Board⁷ will publish a report setting out how the new system architecture will identify and take action to correct potential or actual serious failure. This will provide clarity on the distinct roles and responsibilities of different parts of the system.
- ix. **Care Quality Commission:** The Department will look at how CQCs registration requirements could be changed to drive up the quality of services on offer and ensure that unannounced inspections can take place any day and any time of the week. CQC will review their on-going inspection of learning disability services, including the 150 hospitals and care homes recently inspected.

Clarify roles and responsibilities and promote better integration

- x. **Integrated workforce:** The professional bodies that make up the Learning Disability Professional Senate will carry out a refresh of *Challenging Behaviour: A Unified Approach* to support clinicians in community learning disability teams to clearly describe how different services fit together to deliver the best outcomes by December 2012.
- xi. **Professional standards:** The Academy of Royal Colleges and the professional bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the new health and care system by April 2013.

North West Association of Directors of Adult Social Services

- xii. **Concordat:** The Department is working with key national partners including the Association of Directors of Adult Social Services, the Local Government Association, the NHS Confederation, professional bodies including the Royal Colleges, health and care regulators, the Association of Supporting Living and the NHS Commissioning Board Authority to sign up to a concordat in the autumn committing each signatory to the actions they will take to deliver the right model of care and better outcomes for people with learning disabilities or autism and behaviour which challenges.

Promote innovation and reduce use of restraint

- xiii. **Restraint:** The Department will work with the Department for Education (DfE), Care Quality Commission (CQC) and others to drive up standards and promote best practice in the use of positive behavioural support and ensure that physical restraint is only ever used as a last resort.
- xiv. **Measuring progress:** The Department of Health will work with the NHS Commissioning Board Authority to agree what information and data we need to collect to measure progress – whether that is how long people stay in assessment units, how far they are from home, the experience of people who use care and support and their carers or other information that supports commissioners and providers to benchmark their activities