

Government policy and people with learning disabilities

Introduction

In 2015 NHS England, the Local Government Association (LGA) and The Association of Directors of Adult Social Services (ADASS) launched ***Building the Right Support***. It sets out a Framework for developing community based services for all people with learning disabilities. This is widely regarded as underpinning current policy.

This paper explores the background to the development of this policy and then analyses the current issues that face people on a day to day basis.

Government policy since 2000

Valuing people

A new approach to supporting people with learning disabilities was set out in 2001 in Government's policy paper ***Valuing People, a new strategy for learning disability in the 21st century***. It was the first White paper for 30 years and it stated the key principles of choice, independence, rights, inclusion. It had widespread support. It was accompanied by ***Learning Difficulties and Ethnicity*** and ***Nothing About Us Without Us*** produced by a group of service users and self advocates. It was given further impetus in 2009 by ***Valuing People Now: From progress to transformation***, a three year strategy.

The principles of ***Valuing People*** have additionally been supported by legislation:

The Disability Discrimination Act 1995, replaced by the Equality Act 2010

The Human Rights Act 1998

The Mental Capacity Act 2005

The Care Act 2014

The Children and Families Act 2014

Valuing People was not accompanied by legislation. However there was an infrastructure to encourage its implementation, which included

- The Valuing People Support Team with paid staff in the 9 regions of England to facilitate change
- Guidance materials on a designated website
- A learning disability task force
- A National Director for Learning Disability and a Co Director with a learning disability
- Substantial funding.

The aim was to improve people's lives in a wide range of areas such as giving people choices and control; tackling health inequalities; employment opportunities; leading fulfilling lives; supporting carers.

The infrastructure was largely dismantled from 2012 onwards. Learning Disability Partnership Boards had also been set up in all local authorities with a social services function, as a result of *Valuing People*. They were established to strengthen interagency working for adults with learning disabilities. Some continue in various formats.

The National, and Regional Forums and National Valuing Families Forum were set up respectively to enable people with learning disabilities and their families to represent the nine regions of England and to feedback directly to government. All funding for the National Forums was finally withdrawn in 2017.

Now people with learning disabilities as a group can no longer speak directly to government. They may be included in advisory boards with professionals but this is less effective as their voices may be drowned. People First England and The Housing and Support Alliance set up Learning Disability England in 2016, a membership organisation with self advocacy groups, other organisations and family carers. This has been a positive and useful step but it is not the same as having a body of people with learning disabilities with direct access to government.

As a result of Valuing People, many people's lives were made better but for others there was still a lot of room for improvement: for example, in relation to health more progress is needed as people with learning disabilities are likely to die younger and despite ongoing focus on employment, numbers in work have not gone up over the last two decades: only 6% of people with learning disabilities known to services have a job. The report, *Raising our Sights* in 2010 highlighted shortcomings in the support of people with profound intellectual and multiple difficulties.

After Valuing People

The impact of ten years of austerity

The ending of the support to implement Valuing People along with a decade of austerity measures and a couple of scandals adversely affected the lives of many people with learning disabilities.

In May 2015 there was a memorable moment on Question Time when a mother told Matt Hancock who was then Paymaster General in the newly formed Tory government:

I have a son with a learning disability and he has no social worker, no care plan, his transport to and from school is threatened, his college place has just been withdrawn.

This would be detrimental to the young man's future and his wellbeing as well as affecting his family. Along with the impact of benefit changes, many people's lives have become more difficult, with opportunities that others might take for granted, for example, access to further education, being withdrawn.

We do know people with learning disabilities can have a good life, when they get opportunities to speak up about their concerns and have activities and a social life that give confidence, self esteem and new skills. At People First Dorset we can see the work of the

local authority, the health bodies and our charity contribute greatly to improving people's lives. However there will be many who do not fall within the Local Authority's assessment criteria. While People First Dorset touches the lives of about 400 who use our services regularly, there are many more in the county. The Dorset Community Teams for adults with learning disabilities support 1300. It is estimated there may be up to 7500 people with mild learning disabilities not known to services living here given that it is estimated that 2.16% of the population have a learning disability. Those who live at home depend heavily on support from their families well into adulthood. Sometimes parents continue caring into their 70s and 80s, until they are no longer able to or there is a crisis.

Several scandals and the government response

A scandal at Winterbourne View near Bristol hit the headlines following a Panorama programme in 2011. At this NHS funded Assessment and Treatment Unit people were being horribly abused.

Despite the closure of long stay hospitals in the latter part of the last century there were at that time still 3400 people with complex needs in NHS funded provision, often a long way from home and for a long period of time.

There were a series of reports and programmes to address this situation including ***Transforming Care: A National response to Winterbourne View*** Dec 2012 and the ***Transforming Care- Next steps*** 2015.

The 2015 Green Paper: ***No Voice Unheard: No Right Ignored***, put forward four principles underlying policy towards people with learning disabilities:

- People in charge, supported by family and friends
- Inclusion and independence in the community
- The right care in the right place
- Very clear accountability and responsibility throughout the system.

At the same time in 2015 the ADSS, the LGA, NHS England and the Chief Nursing officer had a similar message in their report ***Building the Right Support***. This sets out current policy for a course of action to reduce the numbers in these units substantially and the principles underlying care and support more generally. It puts forward:

'a simple vision that people with learning disability and/ or autism have the right to the same opportunities to anyone else to live satisfying valued lives and to be treated with dignity and respect. They should have a home, be able to develop and maintain relationships and get the support they need to live healthy, safe and fulfilling lives in the community.'

There were still over 2000 people these units in 2019, when another scandal, this time at Whorlton Hall was revealed again by the BBC through undercover work.

In September 2020 it was reported that the CQC had found abuse at a Cygnet Yew Trees Hospital in Essex. Cygnet Healthcare is the same company that owned Whorlton Hall.

Progress has been abysmally slow in closing these assessment and treatment units and providing the appropriate local intensive support that is needed.

It is important to note that the focus on these issues in policy documents, despite these poor outcomes, has risked detracting from many other areas of the lives of people with learning disabilities living in the community that need improvement.

What are the other issues that need addressing?

There are many aspects of the lives of some people with learning disabilities that need improvement. Overall there is a need for coordination of care across local and national government. As over half the adults with learning disabilities live with their families, issues affecting them will also impact on their family carers. It is also important to ensure that people with learning disabilities and their families from BAME communities do not experience double discrimination.

Health

We know that people with learning disabilities die significantly younger than others. For example, Mencap ran campaigns ***Death by Indifference*** (in 2007 and 2012) while the University of Bristol in 2013 carried out a ***Confidential Inquiry into Premature Deaths of People with Learning Disabilities***. Its latest ***Review of Learning Disability Deaths*** (LeDeR) in 2019 indicated that women with learning disabilities died 27 years earlier and men 23 years earlier, when compared with the general population. It provides evidence that although the problems are in the process of being addressed, people with learning disabilities can experience inferior treatment: just under half received care which met or exceeded good practice in 2018, but this is far too low. The issues that people with learning disabilities face include the risk of diagnostic overshadowing where a problem is wrongly attributed to their learning disability. It is estimated that only 53% of people with learning disabilities have the annual health check to which they are entitled and which can identify problems earlier.

Work, education and daytime opportunities

Many people would like to work but only 6% of people with learning disabilities known to services have a job. Others want more interesting things to do in the day. People need a purpose and meaningful activity, otherwise they feel isolated and lonely with adverse effects on their mental health.

Supported employment is a strategy which enables people to have a job coach and help especially in the early stages of a job. Benefits can be a barrier to people taking up employment, as people need support to balance earnings and benefits.

There is also the need for lifetime learning and access to adult education and training.

Benefits

The transition to Universal Credit and the change from the Disability Living Allowance to Personal Independence Payments have been fraught with problems. Poverty is a risk for

some disabled people, as a result of the squeeze on benefits and the extra costs of being disabled.

Housing and Social care

A problem that has been shelved for far too long is the reform of social care. Often it is focused on elderly people but there are many of working age who need it. For every parent who has a son or daughter with a learning disability there is the constant worry of what will happen when they are too old to care. There is also the question of whether more adults with learning disabilities should be supported to live more independently anyway. In

Through Peter's Eyes, (Arthur James (1990), I wrote, when my son Peter was 12:

'Shall we want him to live more independently when he is adult? Would we cope with the wrench of allowing him to join a local group home?...Would we get funding ... at a time of financial stringency? ...The overriding consideration should be to see him happily settled before we are too old to look after him. These are the questions that worry and nag away at all parents...' Thirty years on the questions remain the same.

No political party has developed details plans for this longstanding problem, despite many calls to do so.

Whereas political discussion focuses on residential care, it is important that in line with the Care Act 2014, there is a much broader vision about provision of housing, care and support for people with learning disabilities enabling them to live 'an ordinary life' within the community, with respect for their friendships and relationships.

There are also no accurate figures for how many people with learning disabilities are homeless or in prison, where they are known to be overrepresented.

Hate crime

Some people with learning disabilities experience offensive and criminal behaviour towards them. The Foundation for People with Learning Disabilities in 2018 published a report ***A Life without Fear***. It argued that unless the police record separately the specific crimes against people with learning disabilities, the problem will remain hidden. People with learning disabilities also may experience problems in getting justice.

The need for more advocacy

People being able to speak up for themselves was a key part of *Valuing People*. Self advocacy and peer advocacy enable people to give voice to their lived experience and what needs to change. Now there is less funding, opportunities are less and the money that is available tends to go on Independent Mental Capacity Advocates, Independent Mental Health Advocates and independent advocacy as these are statutory requirements. Many People First and similar groups have closed. We are fortunate here that we have speaking up groups across the county, which promote self advocacy.

Concluding reflections

Brexit delays and negotiations have hindered the development of further policies to improve the lives of people with learning disabilities. The Covid 19 pandemic has and will cast a long shadow; the emergency legislation, which changes aspects of the Mental Health Act and the Care Act risks undermining the rights of disabled people. There should be an opportunity for a rethink about care and support.

When Rob Greig, who was the first National Director for learning disabilities (2001-8) and subsequently the Director of an influential consultancy, the National Development Team for Inclusion, retired in 2015, his words were prophetic:

‘We are going backwards on learning disability – there needs to be a fresh narrative.’

What should this fresh narrative include?

- A new look at benefits and the possibility of a universal basic income
- A new approach to social care, including thoughtful planning for people with learning alongside sufficient community support
- A thorough and searching look at areas of possible discrimination over the right to a family life. What say do people with learning disabilities have over who they live with?
- An evaluation of how to meet physical and mental health needs, recognising that lack of opportunity impacts negatively on people’s health, and that there are health inequalities
- Creative ways to provide employment with appropriate support
- Workforce planning and training which recognises the importance of the support work and values it
- A determination to uphold the rights of people with learning disabilities
- Always ensuring that it is people with learning disabilities themselves who are at centre of decision making about their support, both at an individual and policy level.

Norman Lamb, the Minister of State at the Department of health in 2015 in ***No Voice Unheard: No Right Ignored*** said of people with learning disabilities and autism: *they should have the same choices, freedoms and dignity as others’, which means ‘being members of their community, part of a family, having meaningful friendships and a social life, access to paid employment opportunities.’*

Hazel Morgan November 2020

Hazel Morgan has had an interest in government policy and the lives of people learning disabilities since the birth of her younger son, Peter, in 1977. He had Down’s syndrome. She learnt a lot through him in the 18 years of his life. Subsequently she became Co Director of the Foundation for People with Learning Disabilities. She is a trustee of People First Dorset.