

The lives of people with learning disabilities A policy briefing

Summary

This briefing examines how current government policies across the UK, and particularly in England, impact on the lives of people with learning disabilities. It identifies gaps and suggests ways forward, drawing on the research, projects and development work of the Foundation for People with Learning Disabilities.

Introduction

The briefing aims primarily to help policy makers, commissioners, providers and others working with a range of vulnerable groups to meet the specific needs of people with learning disabilities.

The definition of learning disability in the White Paper *Valuing People*¹, includes a significantly reduced ability to understand new or complex information and to learn new skills; a reduced ability to cope independently; evidenced before adulthood with a lasting effect on development. People with learning disabilities are a minority and it can be hard for them to get their voices heard.

Background

There are no accurate figures, but estimates suggest that there are 985,000 people with learning disabilities, 2% of the population.² The number is growing. It is thought that the rate of increase may be greater in some minority ethnic groups, but this is starting from low numbers in these communities. There are more children with complex needs surviving because of improved neo-natal, and trauma survival care, and they are now more likely to survive into adulthood.³ The projected increase known to services is 11% between 2001 and 2011.⁴

During recent decades there has been an increasing emphasis on rights, choice and inclusion for people with learning disabilities.¹ Rights have been enshrined in legislation and people with learning disabilities can benefit. It is particularly important that people with learning disabilities from minority ethnic communities, who are doubly disadvantaged, have their rights respected.⁵

Policy documents relating to the lives of people with learning disabilities, *Valuing People* (England),¹ *The Same*

as You? (Scotland)⁶ and *Fulfilling the Promises* (Wales)⁷ reflect the aspiration that they should be fully included in their communities and that citizenship means everyone. However these policy documents do not have the status of the National Service Frameworks, which can serve as levers for change.

Strong leadership nationally and locally will help to keep the needs of people with learning disabilities high on the agenda. In England, the appointment of a person with a learning disability to work as a Co-Director alongside the current National Director for Learning Disabilities is very welcome. The inclusion of the Valuing People Support team within the Care Services Improvement Partnership provides an opportunity for more shared learning across social care sectors. There is however a risk that the needs of people with learning disabilities will be swamped by the needs of larger vulnerable groups such as older people and those with mental health problems.

The implementation of *The Same As You?* in Scotland has a ten-year agenda, but there are similar concerns that as policies which affect the lives of people with learning disabilities become more "mainstreamed", the needs of people with learning disabilities can be overlooked.

In Wales, consultation is taking place on the proposed statement from the Welsh Assembly on policy and practice for adults with a learning disability, which will set out the strategic direction for policy with respect to the lives of people with learning disabilities. The Section 7 *Guidance on Service Principles and Service Responses*⁸ was issued in 2005. These developments build on *Fulfilling the Promises*⁷ and reflect a strong contribution from the Implementation Advisory Group. There are strong hopes that the policy statements will ensure quality services across the board.

Recent policy documents such as the *Improving the Life Chances of Disabled People*⁹, the Adult Social Care Green Paper, *Independence, Well-being and Choice*¹⁰ and the White Paper *Our Health, Our Care, Our Say*¹¹, point to a future based on autonomy for all. There should be, for example, greater opportunities for control by individuals over how money is spent, through Direct Payments and individual budgets, which have been piloted through In Control.¹² These documents address the needs of many client groups and it is important that they do not overlook the specific requirements of people with learning disabilities, many of whom will need additional support. There is a risk that in implementing the White Paper, health issues may swamp social care, but it is social care that should be dominant in the lives of people with learning disabilities.

Towards a better future

The young family

Families need support from the time of diagnosis that their child has a learning disability. The Foundation for People With Learning Disabilities' First Impressions research project¹³ drew attention to the continuing shortcomings in the way professionals share the news of a child's disability. About half the participants in the study reported a poor experience. Another Foundation study, *Recognising Fathers*, is seeking to understand the issues faced by fathers. If there is good information and emotional and practical support, this will impact positively on the future of people with learning disabilities and their families.

Families are often bewildered by the range of professionals with whom they come into contact. A key worker is a part of the Early Years Support Programme in England.

Research at the Foundation would suggest that a key worker or liaison worker would be welcomed by some people with learning disabilities and their families throughout the lifespan.^{14 15}

Generic early support services, such as Sure Start, should be sensitive to the needs of children with special needs and their families. It is particularly important that parents who themselves have a learning disability have appropriate support.¹⁶

The childhood years

Since the 1989 Children Act, children with learning disabilities are now seen as children first, with the same rights as other children. In England the development of Children's Trusts has the potential to coordinate services to meet a range of needs.

Educational needs are covered by generic Education Acts and policy documents such as *Every Child Matters* and the *National Service Framework for Children*. Recently there has been a welcome trend to include children in mainstream schools and colleges.¹⁷ Similar initiatives have driven forward inclusive practices in colleges.¹⁸

The Steps project, in which the Foundation is a partner, has indicated the important role that Learning Support Assistants play in promoting inclusion.¹⁹ Currently, the Foundation in partnership with the University of Cambridge is researching ways of improving the emotional well-being of young people in mainstream settings with young people themselves as co-researchers. In an ideal world all children and young people with learning disabilities would be educated with their peers within their own communities and would also receive the specialist help that they need. It is important that imaginative ways are found to include young people in the mainstream while not losing the expertise that exists in good special schools. Ways forward could include the sharing of resources and expertise from good special schools with mainstream schools and some young people dividing their time between mainstream and specialist settings.

Opportunities outside schools and colleges

It is also important to look beyond the world of school to the broader life experience of children and young people, most of whom will live with their families. Extending person-centred planning (PCP) from adulthood into childhood, initially by piloting PCP at the year nine review, should enable a broader approach to creating opportunities for children and young people. Local support for advocacy organisations and facilitation for circles of support²⁰ can help children, young people and their families to be included in their communities. These supports should also be available for adults with learning disabilities.

Mainstream provision such as leisure centres, after school clubs and holiday play schemes need to accommodate children with learning disabilities

and crucially, transport needs have to be addressed. These should be a priority within local authorities with necessary resources and training for staff being provided.

Short-term breaks are often a lifeline for families to recharge their batteries, while the children and young people can extend their social contacts, which often become more restricted, particularly in teenage years. These breaks need to be varied according to the needs of individuals and their families and to continue into adulthood. They need to be available at times of emergency. Families may wish to purchase their own support and the extension of Direct Payments can enable them to do this. If the above suggestions are well resourced, along with local specialist provision for example from a clinical or educational psychologist if needed, it may make it less likely that families are compelled to seek placements in residential schools with the heartbreak that this may entail.

Transition

Although there is a clear process laid down in law for young people to make the transition to adult life there is evidence that it is often a distressing time for them and their families.^{21 22} Until there is an extensive range of opportunities available to young people with learning disabilities, the transition process will remain unsatisfactory and it is this aspect which must be the focus of attention. Young people with learning disabilities have said that they want to lead similar lives to their brothers and sisters^{22 23} and yet there are significant barriers to achieving work, independent living and long term relationships. The new Office of Disability Issues within the Department for Work and Pensions will make transition a priority for young disabled people in England and Wales.

If young people themselves are supported to be at the centre of the process and it is based on person-centred approaches then there is likely to be greater success as long as options for work and activities are available. Individual budgets will help, particularly if Centres for Independent Living become skilled at giving advice to young people with learning disabilities and their families.

In England, the current uncertainty over the future of the Connexions service is a complicating factor. Where it has operated well, Connexions has offered young people with learning disabilities a service on the same basis as other young people.²³ The split between child and adult services makes the transition process difficult and strong links and partnership between the two are crucial.

Further education

Further Education Colleges have often become the next step for young people with learning disabilities on leaving school. Although there are examples of good practice, the challenge is to ensure that staff are well trained, courses are meaningful and enable students to progress. The link between college courses and the workplace needs to be strengthened. It is of crucial importance that colleges do not become the new day centres for people with learning disabilities. There are reports of students repeating courses year after year.²⁴ The Foundation supports the recommendations from the Learning and Skills Council that greater clarity and prominence are attached to provision for people with learning difficulties/ learning disabilities and for legislation for the provision of transport for those over 19. However the Foundation is concerned that the proposal to involve other agencies in personal support to release 'millions of pounds' will lead to wrangling between services to the detriment of these students.²⁵

Employment

Many people with learning disabilities want to work, including some people with high support needs. Yet only 11% access paid work, much of which is part-time.²⁶ Barriers include worries about losing benefits, wages being insufficient to cover residential care and lack of appropriate training. The Green Paper²⁷ *A New Deal for Welfare: Empowering people to work* provides an opportunity to overcome some of the barriers to employment and to lessen the poverty of many people with learning disabilities. Imaginative thinking can bring about change. Some people with learning disabilities are developing micro enterprises. Others play a powerful role as experts in advising on the needs of people with learning disabilities and in training. The public sector has an important role to play as a major employer and can demonstrate good practice as it implements the Disability Equality Duty from December 2006.

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The supported employment model using a job coach is valuable in furthering employment opportunities.²⁴

Other opportunities and friendships

Employment, lifelong learning, volunteering, leisure pursuits, hobbies, daily living, friendships, membership of faith communities for some,²⁸ could make up a potentially rich pattern of daily living. Communities too need support to become welcoming places, where people with learning disabilities, whatever their age, can contribute. People with complex needs, who are most likely to experience social exclusion may need a community base, as well as access to a range of ordinary activities. It is important that the whole fabric of people's lives is acknowledged and community as well as service supports are established.

Too often the importance of friendships is overlooked. Relationships are usually the most significant aspect of everyone's existence.²⁹ Unusually for a policy document, friendships were mentioned in *Valuing People*.

The role of family carers

At the heart of the lives of many people with learning disabilities are their families. They are often under pressure and need practical and emotional support. About half of adults with learning disabilities live in their family home. Some families will have been together for five or six decades or more. Family carers of people with learning disabilities in this respect, differ from other carers. There is increasing recognition that the needs of carers cannot be overlooked. Generic carers' legislation has acknowledged that the needs of carers should be assessed and recently that this assessment must consider their interest in work, study and leisure.³⁰ There is ambiguity at the heart of government policy in that it has acknowledged its dependence on family carers to meet the needs of vulnerable people. Yet it is also suggesting that these families should be able to lead the same lives as all other families. There would be enormous resource implications for government to enable family members to pursue employment and leisure opportunities of their choice, but this needs to happen.

When families are thinking about their family member with a learning disability leaving the family home, they value sensitive support over time to plan for this big step. There needs to be continuity of personnel, but too often funding for such posts is for the short-term only.¹⁵

Housing

There needs to be wider recognition that people can live in ordinary settings either alone or with friends, with appropriate support, which may include continued practical support from family members. The Office of the Deputy Prime Minister instigated the Supporting People programme, which has been very popular in enabling vulnerable people to access their own housing and support. It would be regrettable if the cost of this approach should lead to its curtailment. Accessible information about housing options needs to be available and thinking needs to be 'outside the box' to address the shortfall. Shared Ownership and inheriting the family home and tenancies are possible ways forward.^{31 32} It was estimated in 1996 that 27,000 people with learning disabilities needed to leave the family home within five years³³ and there is no evidence that this number has been substantially reduced.

Our Health, Our Care Our Say is prioritising those in NHS residential provision for relocation, but has not addressed the needs of those living in older families. It is also a retrograde step if those with complex needs are housed in private mini- institutions away from their own locality, a development that disability organisations and others are opposing.

Older people with learning disabilities

People with learning disabilities, like the rest of the population, are living longer. The Foundation for People with Learning Disabilities in its pioneering GOLD (Growing Older with Learning Disabilities) programme³⁴ underlined the importance of older people having meaningful activities in the day. It suggested that homes should be able to be adapted so that people do not necessarily have to move in later years. It demonstrated that too many people with learning disabilities go to a residential or nursing home for older people at an earlier age than others when it is inappropriate for them.³⁵ People with learning disabilities too may develop dementia and people with Down's syndrome are particularly at risk.³⁶ It is important that they have the environment and support that are appropriate.

Health

In order for people with learning disabilities to lead a full life there needs to be further improvements in their health care and better support from mainstream services.³⁷ The Foundation is hosting the UK Healthcare Network to enable practitioners and others to share ideas on meeting the health needs of people with learning disabilities.

The Foundation's research has indicated how some people receive late diagnoses and/or their health problems are attributed to their learning disability.³⁸ The Disability Rights Commission's formal investigation, *Equal Treatment: Closing the Gap*, into the health inequalities experienced by people with learning disabilities and people with mental health problems in primary care is indicating possible ways forward. These include better and ongoing training for primary care staff, with people with learning disabilities involved in the training; information in accessible formats on health promotion and flexibility in appointments with financial incentives for GPs and others.³⁹

Our Health, Our Care, Our Say promises to implement quickly the 2001 commitment to regular health checks for people with learning disabilities. *Better Metrics*⁴⁰ aims to help Primary Care Trusts to set local targets that include targets relating to the needs of people with learning disabilities. It is encouraging that the Quality Outcomes Framework for GPs since April 2006 includes people with learning disabilities. GPs with a special interest in learning disability can be a resource for other GPs. There are however gaps in primary health care provision, including postural care support and pain management, which need to be addressed.

It is important that there are initiatives in secondary healthcare to ensure that people's needs are better met. There are limited examples of hospitals taking specific steps to ensure that outpatient appointments and in patient visits are a positive experience for people with learning disabilities.

The Foundation for People with Learning Disabilities (part of the Mental Health Foundation) has been pressing for mainstream mental health services to address appropriately the needs of children and adults with learning disabilities. The two Foundations have

recommended that those with complex needs should have access to specialist learning disability services in their region and the expertise that exists in these should also be a resource for mainstream services.^{22 41}

Bullying, harassment and abuse

Too often the well-being of people with learning disabilities is undermined by bullying and harassment. A recent survey of adults with learning difficulties⁴² showed that 32% did not feel safe in their own homes, in their local area, or using public transport. Those from black and minority ethnic communities are likely to feel less safe since July 7 bombings.⁴³ A minority will experience physical or sexual abuse. Although the *No Secrets* Guidance 2001, the *In Safe Hands* guidance (Wales) the Sexual Offences Act 2003, the Protection of Vulnerable Adults scheme (2004) and the Safeguarding Vulnerable Groups Bill, if enacted, will help, it is important that inspectorates are vigilant and that people in the community support people with learning disabilities to lead safe lives.

Communication and decision-making

At the heart of improving the lives of people with severe learning disabilities is respect for the range of individual ways of communicating. Presenting information in accessible ways is very important for people with learning disabilities and their families. Local authorities need to encourage communication policies, as recommended by *Valuing People*. Somerset has been at the forefront in breaking down barriers through its Total Communication policy.

The Incapacity (Scotland) Act (2001) and the Mental Capacity Act (2005) are seeking to improve decision making for elderly people, people with learning disabilities and people with mental health problems who are deemed to lack capacity for specific decisions. It will be important that the intention of the Mental Capacity Act to explore a range of ways of communicating before deciding someone lacks capacity for a particular decision is respected. Even where a decision is reached that someone lacks capacity, they need to be as involved as possible in supported decision making.

Conclusions

As people's aspirations are captured through person-centred planning, commissioners need to aggregate the plans and to work in partnership with other departments and the voluntary sector to ensure that services meet individual needs.⁴⁴ It is important that meeting the needs of people with learning disabilities is included in Local Area Agreements. Some authorities such as Sheffield have databases that include a record of needs and are regularly updated. These also contribute to effective planning and should be more widely developed.

Commissioners need to work with Learning Disability Partnership Boards to set the frameworks for opportunities to be available, but not to determine in detail the pattern of people's lives. It will always be important to find imaginative ways of gaining the views of people with learning disabilities and their families not only about learning disability services, but also about mainstream services. For example, NHS Foundation Trusts may offer an opportunity for people with learning disabilities to further their involvement in local governance building upon their experience in Partnership Boards.

The Association of Directors of Social Services has warned in a 2005 report from its Resources Committee that there needs to be a moratorium on cuts for learning disability services and a Wanless-style review. There are financial implications in moving from traditional style services to individualised approaches which need to be recognised.

Our vision is that as often physically disabled people find a personal assistant enables them to participate more fully in society, so such opportunities need to be opened up more widely to people with learning disabilities. They should have the budgets, resources and support. They should be able to lead their lives in an ordinary house in an ordinary street. They should be able to have paid work if they wish. If they need specialist help for health or other needs they should not have to leave their own region. Their gifts should be appreciated and used.

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A short easyread version of this briefing is also available.

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