The lives of people with learning disabilities
A policy briefing

Foundation for People with Learning Disabilities
25th June 2007

Conclusions
As people's aspirations are captured through parent-centred planning, commissioners need to aggregate the plans and to work in partnership with them. Local authorities, the do-it-yourself sector, voluntary sector, and the voluntary sector who are involved in providing the services that meet the needs of people with learning disabilities must work closely with local A and E departments and the voluntary sector to ensure that services meet individual needs. A significant point is that the meeting of the needs of people with learning disabilities is largely the responsibility of local area planning; for example, such as Sheffield, where databases have included records of need and are regularly updated. This also contributes to effective planning and should lead to services that are better 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 have their individual needs assessed. Learning Disability Partnership Boards should aim to have their approach to 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 approaches to a more modern approach and the Government has indicated that it will keep the needs of people with learning disabilities high on the agenda. In England, the appointment of a Minister for People with Learning Disabilities is encouraging. The Government will need to be vigilant and that people in the community support people with learning disabilities to lead safe lives.

Background
There are no accurate figures, but estimates suggest that there are 900,000 people with learning disabilities, 2% of the population. 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 children born with complex and vulnerable adults, because of improved neo-natal and trauma survival care, and they are now more likely to survive into adulthood. The projected increase known to services is 1% between 2001 and 2011.

During recent decades there has been an increasing emphasis on rights, choice and inclusion for people with learning disabilities. Rights have been entrenched in legislation and people with learning disabilities can benefit from these rights.3 However, some people who live in learning disabilities from minority ethnic communities, who are doubly disadvantage, have their rights respected.

The implementation of the Same As You? 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 "mainstream", the needs of people with learning disabilities become more "mainstreamed", the needs of people with learning disabilities are being met. In Wales, concerns are taken in the proposed policy statement from the Welsh Assembly on policy and practice for adults with learning disability, which will not only outline the strategic direction for policy with respect to the lives of people with learning disabilities.

In conclusion, the paper presents the views of people with learning disabilities and their families. It has been at the forefront in breaking down barriers through its Total Communication policy. It has been at the forefront in breaking down barriers through its Total Communication policy. It has been at the forefront in breaking down barriers through its Total Communication policy. It has been at the forefront in breaking down barriers through its Total Communication policy.

Valuing People
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 "incapable" of making decisions. The Act spells out a number of ways of communicating before deciding someone lacks capacity in order to be opened up and widely used to people with learning disabilities. They should be led to their lives in an open house in a public house or in the public house. They should be led to their lives in an open house in a public house. They should be led to their lives in an open house in a public house. They should be led to their lives in an open house in a public house. They should be led to their lives in an open house in a public house. They should be led to their lives in an open house in a public house. They should be led to their lives in an open house in a public house.

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The supported employment model using a job coach is valuable in furthering employment opportunities. A policy brief

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The supported employment model using a job coach is a valuable option. Parents of children with learning disabilities are now seeing that this model is effective, especially when paired with necessary resources and training for staff being able to support the children.

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Older people with learning disabilities. The risk that the needs of the population, who in recent years have been brought to the attention of society, is that too little and too late support is given. Some consider that the needs of older people with learning disabilities are not being adequately addressed. It is often funding for transition that is needed and it is critical that the transition is made with the same level of support and care that is provided to younger people with learning disabilities.

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The supported employment model using a job coach is a vehicle to move people with learning disabilities out of isolation. The job coach is a professional who has the responsibility of being a key point of contact. The job coach has a considerable amount of flexibility and can be contracted to work part-time or full-time.

Other opportunities and friendships
Employment, lifelong learning, volunteering, leisure pursuits, family and community support are all important rights. They have been highlighted by the movement of disabled people as the core rights of people with learning disabilities. The National Service Framework for Children and Young People sets the stage for a future based on autonomy for all. There should be, for example, greater opportunities for children with learning disabilities to go to the cinema, a work place, and to school with their peers. This will allow the children who have taken steps to try to get a job to spend time with other young people.

Families need support from the time of diagnosis that children have a learning disability. The Foundation for People With Learning Disabilities' recent research highlighted the lack of employment opportunities for young people with learning disabilities. In England, the current unemployment rate is over twice that of the general population. However, the unemployment rate is not the only issue to consider. People with learning disabilities also need to be supported in their transition to adulthood. The role of family carers and the Deputy Prime Minister instigated the Supporting People programme, which has been very popular in enabling vulnerable people to live in ordinary settings either alone or with friends, with appropriate support, which may include continued practical support from family members. The Office of Disability Issues within the Department for Work and Pensions will make transition a priority for young disabled people in England and Wales.

The role of family carers
At the heart of the lives of many people with learning disabilities are their families. They are the primary carers and need practical and emotional support. About half of adults with learning disabilities live in the 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 research into family carers and their needs. At the Foundation, research suggests that a key worker or liaison worker would be welcomed by some people with learning disabilities and their families. Employment opportunities for family carers are an important way for family carers to have a working life. The Steps project, in which the Foundation is a partner, has indicated the important role that family carers can play in supporting people with learning disabilities.

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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, includes a significantly reduced ability to manage their own money, to live independently, to learn new skills; a reduced ability to cope independently with accidents and emergencies and 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 190,000 people with learning disabilities, 2% of the population. 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 neonatal and trauma survival care, and they are now more likely to survive into adulthood. The projected increase known to services is 11% between 2001 and 2011.

During recent decades there has been an increasing emphasis on rights, choice and inclusion for people with learning disabilities. Rights have been emphasised in legislation and people with learning disabilities can benefit from the protections they give. However, learning disabilities from minority ethnic communities, who are doubly disadvantaged, have their rights neglected.

Policy documents relating to the lives of people with learning disabilities, Valuing People (England), The same as you? in Scotland have not been translated into reality on the ground. People with learning disabilities are often found to be excluded from mainstream services, they have difficulty accessing appropriate health care, they are less likely to vote in local elections and more likely to be a victim of crime.

Summary

This briefing examines how current government policies across the UK, and particularly in England, impact on the lives of people with learning disabilities. The briefing aims to inform and stimulate discussion through research, projects and development work of the Foundation for People with Learning Disabilities.

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.

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 that some people receive late diagnosis and/or their health problems are attributed to learning disability.

The Disability Rights Commissioners 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 involving and empowering 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.

Our Health, Our Care, Our Say promises to quickly develop the 2001 commitment to regular health checks for people with learning disabilities. Better Metropolitan Primary Care Trusts to set local targets that include targets relating to the needs of people with learning disabilities. It is recommended 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 are accessible for people with learning disabilities, that information in accessible formats is provided, and that there are people with learning disabilities involved in the training of staff.

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

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. It is important that the meetings of people with learning disabilities are recorded in their Local Area Agreements, such as Healthwatch, that have databases that include a record of needs and are regularly updated. These also contribute to effective planning and should be 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 the people with learning disabilities and the families not only about learning disability services, but also about mainstream services. The Learning Disability Foundation Trusts may offer an opportunity for people with learning disabilities and their families 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.

It is important that people with learning disabilities have their voices heard. 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 are accessible for people with learning disabilities, that information in accessible formats is provided, and that there are people with learning disabilities involved in the training of staff.

The Incapacity (Scotland) Act (2001) and the Mental Health (Easement of Guardianship) (Scotland) Act 2007 have been introduced. These are strong and long awaited steps in the right direction.

Policy papers relating to the lives of people with learning disabilities, such as yours Scotland and fulfilling the Promise (Wales) reflect the aspiration that they should be fully included in their communities and that they should be enabled to live lives of real meaning and purpose. However, these policy documents do not have the status of the National Service Frameworks, which can serve as a lever for change.

Strong leadership nationally and locally is needed to keep the commitment to meeting the needs of people with learning disabilities to the fore. It will be important to keep the focus on the needs of people with learning disabilities, in light of the high on the agenda, in England, the appointment of a national learning disabilities lead. In Scotland, the Co-Director along the current National Director for Learning Disabilities,UserProfileLink?userprofile=11 has confirmed that the Welsh People Support team in the Care Services Improvement Partnership provide 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? Scotland is on a ten year agenda, but there are similar concerns that as policies are reflected less of people with learning disabilities become more “mainstreamed”, the needs of people with learning disabilities are less noticed.

In Wales, consultation is taking place on the proposed statement from the Welsh Assembly on policy and practice for adults with learning disability, which will set out the strategic direction for policy with respect to the lives of people with learning disabilities.

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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’, includes a significantly reduced ability to understand new or complex information and to learn new skills; a reduced ability to cope independently; and the possibility of lifetime dependence on others.

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. Preventing information in accessible ways is very important for people with learning disabilities and their families. To ensure that there are effective communication policies, as recommended by Valuing People. Someone has been at the forefront in breaking down barriers through its Total Communication policy.

The Incapacity (Scotland) Act (2001) and the Mental Capacity Act (Wales) have implications for people with learning disabilities and people with mental health problems who may lack capacity for specific decisions. It will be important that the intention of the Acts is kept under review.

The Foundation for People with Learning Disabilities (part of the Mental Health Foundation) has been pressing for primary 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 disabilities services in three regions and the experts that exist in these should also be a resource for mainstream services.

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, an independent charity. Registered Charity No: 106922

References
6. 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 reducing and improving 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.

Health
In order for people with learning disabilities to lead full and useful lives, there needs to be further improvements in their health care and better support from mainstream services. 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 diagnosis and/or how their health problems are attributed to their learning disability. The Disability Rights Commissioners 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 reducing and improving 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.

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The 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.

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