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Fulfilling the Promises

Introduction

In December 1999 a group of people were asked by the National Assembly for Wales to get together to write some ideas about the services people with learning disabilities would need in the future. This group of people were known as the Learning Disability Advisory Group and this booklet is the short version of their report that has been presented to the National Assembly.

The Advisory Group have tried to cover all areas of people's lives - their early years through school and training, where they live, leisure, work and daytime activities.

The Advisory Group and its subgroups were made up of professionals, parents / carers and people with learning disabilities. There was also consultation with groups of people with learning disabilities and parents groups across Wales who contributed to the first draft of this report.



Disabled people have the same rights as other citizens.

They have the right to expect a lifestyle which is the same as people of a similar age and background, whatever difficulties they may have.

The All Wales Strategy (1983) tried to make sure that people with learning disabilities had opportunities and choices. It said that people had the right to...

- ◆ a normal life in the community
- ◆ be treated as individuals
- ◆ get extra help and support so that they can reach their potential

The National Assembly has written ideas about the quality of life they want for the people of Wales. They wrote a report called Better Wales which says that everyone in Wales should

- ◆ be involved and taking part in their community
- ◆ be treated fairly
- ◆ get the services they need
- ◆ be able to learn and grow throughout their lives so that they continue to develop skills

The Advisory Group agreed that the ideas in the All Wales Strategy are as important today as they were in 1983 when it was written. They also felt that people with learning disabilities should be included in the hopes and wishes of society as a whole, like the ideas in Better Wales.

The Vision for 2010

The Advisory Group had a vision for how services should be by the year 2010.

First of all, they felt that their vision should be supported by the belief that people with learning disabilities ...

have the same value and status as everyone else and have an equal right to expect:

- Ø good education,
- Ø good health
- Ø good housing
- Ø safety and financial security
- Ø protection from harm
- Ø positive roles in the community and in the family
- Ø opportunities to find work
- Ø opportunities to learn and improve their skills
- Ø civic rights

have a right to make important decisions for themselves or with support if they need it

have a right to support from their communities and families, and any other support which will help them achieve their wishes and goals

They felt that a firm belief in these ideas would support their vision for the future

The Advisory Group's Vision for the Future

There will be a wide range of choices of services within the community which will support people to become included in life in Wales

Services will be chosen by people with learning disabilities so that they have control over their lives

Services will link together so that there are no gaps at important times of change such as from child services to adult services
Services will deal with the whole person (not one bit of them at a time)

Advocacy services of all kinds will be available to people

Good, clear information of all types will be available about services

Services will be as close as possible to people's homes

Services will work together to make sure people have choices.
Services will change and develop in line with the changes people go through in their lives.

Services will be open about how much they cost. The things that services do well will be developed

The people who work in services will be supported to do their jobs well and to get the training and qualifications they need.

Everyone who is able to will have returned from long stay hospitals to live in the community with the right support.

Background to the action

Suggested by 'Fulfilling the Promises'

The 'Better Wales' report, which the Learning Disability Advisory Group used for advice in writing 'Fulfilling the Promises', looked at what sort of things people in Wales need to live better lives. Some of the things the report said were that people should all be equal, they should have the right to make their own choices, and they should be able to join in all decisions which affect their lives.

The actions suggested by 'Fulfilling the Promises' on the following pages look at what needs to happen for people with learning disabilities to be treated as equal people, and how they can be helped to make more choices. The actions also try to help us understand why these things are important.

Each action says who needs to do it. As people with learning disabilities should be able to join in all decisions which affect their lives, we are assuming that they, or their advocate, parent or carer, will play a part in every action, as well as the other people that have been suggested.

Each action has a date which says when it should be achieved, to give us all something to work towards.

Guidelines for the future

The aims of the All Wales Strategy are as important today as when they were first written. It said that people with learning disabilities had the right to

- A normal life in the community
- Be treated as individuals
- Get extra help and support so that they can reach their potential

The Advisory Group believes that we should go on working towards these aims so that services support people with learning disabilities to have their rights.

What needs to happen?

- Make a commitment to improve the quality of services for people with learning disabilities.
- Make sure that there are ways of checking that services support people to have a good quality life in the community.

Why does it need to happen?

- To make sure that people with learning disabilities get the right services and support so that they can lead full and quality lives.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Local Authorities
- Ø Health Authorities

When does it need to happen by?
2002



Funding

The 1983 All Wales Strategy made a difference to the lives of people with learning disabilities because the government found extra funding to carry out the aims of the Strategy.

The beliefs in Fulfilling the Promises will need the same commitment from the government to find extra funding.

What needs to happen?

- Set aside funding which will improve and increase services in Wales.
- Work out how people's needs will be met and what it will cost – at least 5 years ahead.

Why does it need to happen?

- To make sure that services don't stand still or get worse.
- To make sure that services plan ahead and know there is a budget to do it.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Local Authorities

When does it need to happen by?
2002



Finishing off what has been started

The Advisory Group would like to see the National Assembly for Wales go on supporting the ideas in the 1983 All Wales Strategy. These ideas were about people with learning disabilities having support to lead their lives in the same way as anybody else. It includes people making their own choices, being seen as individuals, and having the chance and supports to reach their goals. In particular, the Advisory Group want to see some of the good changes that were started, now finished off.

What needs to happen?

- Long-stay hospitals need to close.
- New homes must be found for people who want to move out of places that are not right for them.

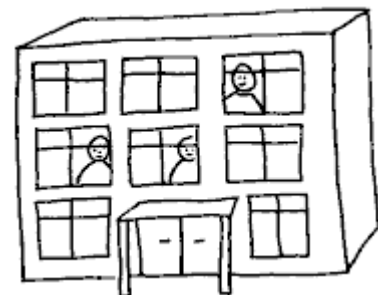
Why does it need to happen?

- People with learning disabilities have been forced to live in hospitals for far too long.
- If people are not happy where they live, they won't feel able to reach their goals.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Local Authorities
- Ø Health Authorities

When does it need to happen by?
2006



Support for people with learning disabilities to plan what they want out of life

Planning meetings should be for people with learning disabilities (and/or their parents and carers) to decide what they want, especially from services. If a person with a learning disability is unable to speak for themselves, they may need an advocate or someone else with their interests at heart to speak for them.

All people involved in a person's individual plan should make an effort to work well together to make sure people are given a chance to have a say about their futures. Individual plans should be reviewed at least once a year to make sure what is in the plan is still what a person wants. People with learning disabilities not only have a right to have their own individual plan, but also to change their minds about things.

What needs to happen?

- Professionals need to agree that the most important people to involve in individual planning are people with learning disabilities, advocates and/or their parents and carers.

Why does it need to happen?

- To make sure people with learning disabilities get what they want and need to make their lives worthwhile.

Who can make it happen?

- Ø Local Authorities
- Ø Advocates

When does it need to happen by?
2003 - 2004



Parents and Carers

Parents and Carers need support to care for people with learning disabilities living at home. Like people with learning disabilities themselves, carers should have planning meetings to decide what services they need. Their needs will be different from the person that they care for, and each carer's needs will be different.

What needs to happen?

- Find out what every parent and carer needs.

Why does it need to happen?

- To make sure that parents and carers get the support they need to care for people with learning disabilities who choose to live at home.
- To make sure parents and carers get their rights.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø National Carers Strategy Review Panel

When does it need to happen by?
2001 - 2002

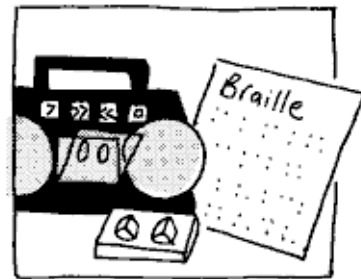


Information

Having good information at the right time and in a way it can be understood is very important to people with learning disabilities and their parents and carers. It helps them to make important decisions in their lives and to exercise their rights. It is important that every organisation providing services for people with learning disabilities offers good quality information. It is also important that people with learning disabilities know that they have a right to be involved in planning their services.

What needs to happen?

- Find out what information people want locally and nationally.
- Find out how to gather together information from different organisations and to share it in ways that everyone understands.
- Give information about people's rights to take part in planning their services.

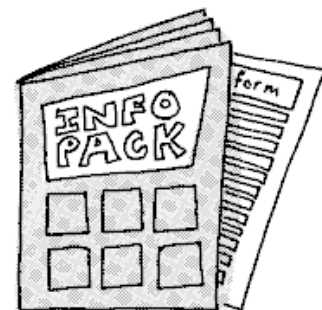


Why does it need to happen?

- To make sure people get the right information they need to make important choices in their lives.
- To make sure people know what is available and what is possible.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Health Authorities
- Ø Local Authorities



When does it need to happen by?
2002 - 2003

Advocacy

There are many kinds of advocacy:

- Self-advocacy is when people speak up for themselves, or express their views themselves in other ways.
- Citizen advocacy is when people have an independent volunteer who speaks up just for them.
- Paid advocacy is when people are employed to speak up for more than one person, particularly at difficult times, or times when lots of changes are happening in their lives. Paid advocates often work in long-stay hospitals and help people to have a say in their resettlement plans.

Advocacy can help people to have a voice, a voice that is hopefully heard and listened to. It is important that advocacy services are not run by the same services that people with learning disabilities might want to challenge because they don't agree with the way they are doing things.

What needs to happen?

- Work out how much it would cost to set up an advocacy service for the whole of Wales.
- Look at ways it can help all people with learning disabilities to have a voice.

Why does it need to happen?

- All people with learning disabilities in Wales have the right to an advocacy service.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Existing Advocacy services

When does it need to happen by?

2002 - 2003

Working together to plan services

People with learning disabilities need a wide choice of different services to choose from and should not be fitted into services that only deal with a part of them. If a person is going to get the services they want, a lot of different people need to meet to plan them – different organisations, people with learning disabilities themselves, and parents and carers. Social Services have an important role in getting people to work together.

In the past it has been difficult for organisations to work together because of the way they are organised and because of the way money is managed.

What needs to happen?

- Get people together to plan good quality services.
- Involve people with learning disabilities and parents and carers in planning.
- Help organisations to find ways of working together and to become more flexible.

Why does it need to happen?

- To make sure that a person gets the all round service they need.
- To break down the barriers that get in the way of people working together.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Local Authorities
- Ø Health Authorities

When does it need to happen by?
2003 - 2004



Children and Families

Parents and families of children with learning disabilities should have the biggest say about what happens to their child. They may need support or help from professionals to understand more about learning disabilities, and to make sure their child gets the most out of life.

It is important that children with learning disabilities mix with children who don't have learning disabilities before they go to school, and during their school years.

What needs to happen?

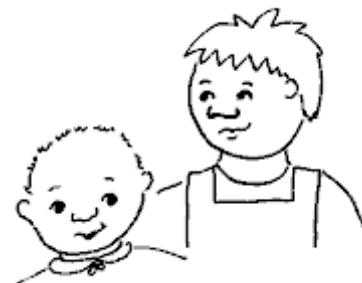
- Find out how much help children with learning disabilities and their families get early on in their lives.
- Include children with learning disabilities in ordinary pre-school nurseries and schools.

Why does it need to happen?

- To make sure children have the support they need to grow and learn early on in their lives.
- To help children get their message over.
- To make sure children have their right to learn alongside children without disabilities.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Health Authorities
- Ø Local Authorities
- Ø Local Education Authorities



When does it need to happen by?

2003 - 2004

Education and Learning

Everyone has a right to learn new skills throughout their lives. Children and adults with learning disabilities should be able to continue learning so that they can reach their full potential. They should be able to do this alongside people who are not disabled. Children who attend a special school have a right to a good quality of education with extra support.

What needs to happen?

- Make more opportunities for children, young people and adults to learn skills in ordinary places with extra support if they need it.
- Train teachers and teaching assistants about people with special needs.

Why does it need to happen?

- To make sure that all people with learning disabilities, from school age to adults, can learn skills alongside other people.
- To make sure that children with special needs get a good quality education.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Local Education Authorities

When does it need to happen by?
2004



Living in the Community in the Family Home

People with learning disabilities should be able choose where they want to live. Some people choose to live with their families. It is important to remember that their families have a right to services that will support them to provide a home for their son or daughter with learning disabilities. Each family's needs will be very different.

Carers also need a rest. From time to time they need to have a break away from caring for someone.

What needs to happen?

- Give carers the opportunity to choose from a range of different support services.
- Give carers more quality choices so that they can have a short break from caring for someone.

Why does it need to happen?

- To make sure that every carer gets the right support they need.
- Every carer has the right to a break when they need it.

Who can make it happen?

- Ø Local Authorities
- Ø Care Providers

When does it need to happen by?
2005



Living independently in the community

Living in the community is about having control over:

- where you live and who with
- what kind of lifestyle you choose to lead
- how other people in the community see you and
- the relationships you have with them.

More and more people with learning disabilities want to live in their own homes, away from their families, so that they feel more grown up and independent.

People with learning disabilities who choose to live in their own homes may need staff to support them. It is important that staff are well-trained, and able to work in ways that don't take away the control people want over their own lives. It can also be important that staff don't live too far away from the people they support, so that they can pass on what they know about the community.

What needs to happen?

- Find the money to help people with learning disabilities move into the most suitable homes for them, with any support they need.
- Train staff to work with people with learning disabilities in ways which make sure they can do as much for themselves as possible.

Why does it need to happen?

- At least 1500 people with learning disabilities will want to leave home and be more independent over the next 8 or 9 years.
- Adults with learning disabilities have the right to rent or own their own homes.

Who can make it happen?

- Ø The National Assembly for Wales
- Ø Care Providers
- Ø Local Authorities
- Ø Housing Associations

When does it need to happen by?

2010

Direct Payments

A scheme called Direct Payments gives people with learning disabilities the chance to buy in the services they want. For instance, instead of social services choosing who works with people in their homes, people are given the money and then they employ who they want support from.

Usually, a social worker will visit the person with a learning disability and talk to them about the help they need. This is called an assessment. It may be that the person needs help with cooking, cleaning, washing or shopping. Social services will then work out how much the support will cost, and give the money to the person with a learning disability (usually every 4 weeks) so that they can pay the person, or people, they have chosen to work for them.

What needs to happen?

- People with learning disabilities need more control over their own lives.
- People with learning disabilities need to choose the support they want.

Why does it need to happen?

- To make sure people with learning disabilities get the support they want, when they need it, and from staff they have chosen.

Who can make it happen?

Ø Local Authorities

When does it need to happen by?
2003



Living in the Community

Behaviour that Challenges Services

Living in the community should be a choice for all people with learning disabilities. People that are challenging in their behaviour can live in ordinary places if they are supported in the right way. Yet they are not often given the choice of living in the community.

What needs to happen?

- Plan carefully how and where people with challenging behaviour are going to live.
- Plan the support they will need to live in the community.
- Make sure that extra support in the community is always a part of planning when people leave long stay hospitals.
- Give extra help, support and advice to carers.
- Reduce the number of people who have to live outside Wales.

Why does it need to happen?

- To make sure that people with challenging behaviour have the same choices about the support they get and where they live as everyone else.
- There are still some people who are living in long stay hospitals. They will need extra support to live in the community.
- Carers need support from specialists to help them to cope.
- People have a right to live near their families and stay in Wales if they want.

Who can make it happen?

- Ø Health Authorities
- Ø Local Authorities
- Ø Care Providers
- Ø Accommodation Providers

When does it need to happen by?
2003 - 2008



What People do During the Day

What people do during the day makes a difference to how they are viewed by the rest of the community and to how they feel about themselves. Employment and education allows people to develop new skills throughout their lives. This increases their confidence and independence. People with learning disabilities have a right to work if they are able to but the rules around Social Security Benefits often make it difficult to get started.

What needs to happen?

- Find more opportunities to do meaningful things during the day, such as work, training and education.
- Work with the Government to find ways of allowing people to get paid for work without fear of losing all of their income from Benefits.

Why does it need to happen?

- So that people with learning disabilities can develop skills that are useful to themselves and the community.
- To break down the barriers which get in the way of work opportunities.

Who can make it happen?

- Ø Government
- Ø ELWa
- Ø Benefits Agency
- Ø Careers Advisors
- Ø Supported Employment Agencies

When does it need to happen by?
2004 - 2005



Health needs

People with learning disabilities do not get their health looked after as well as other people. Partly, this is because some health professionals don't understand much about learning disabilities. It is also because some people with learning disabilities find it difficult to express what is wrong. This means they often have poorer general health than other people, especially in areas such as eyesight and hearing.

What needs to happen?

- Staff who work in health services need to understand more about people with learning disabilities so that they can get better at finding out what is making someone unwell.
- G.P's need to make sure they offer people with learning disabilities regular health check ups to stop them becoming ill, or getting more ill.
- People with learning disabilities need information about how to stay in good health in ways they can understand.

Why does it need to happen?

- Some G.P's and other health professionals are not aware that people with learning disabilities might need support and time to explain about their health problem.
- People with learning disabilities are more likely to have poor general health than other people.
- People with learning disabilities don't always understand the kind of things that cause bad health (smoking, lack of exercise etc).

Who can make it happen?

- Ø G.P Training Units in Medical Schools
- Ø Training Units for other health professionals

When does it need to happen by?
2010



People who work with people with learning disabilities

People with learning disabilities need support from staff for many different parts of their lives, such as their health, where they live, what they do during the day, their work, their personal support needs. It is important that people with learning disabilities know that staff members and other people that work with them are good at their jobs. It is also important that staff and other professionals understand people with learning disabilities.

What needs to happen?

- People who work in Social Care settings e.g. Workers, Care Managers should have the right qualifications for their job.
- People such as doctors, dentists, opticians, teachers, the police, benefit agency staff, housing agency staff, all need to have some training about people with learning disabilities.

Why does it need to happen?

- Lots of people don't understand the issues for people with learning disabilities.
- People with learning disabilities need to trust staff and professionals to give them the support, advice and health care they need.

Who can make it happen?

- Ø Local Authorities
- Ø Health Authorities
- Ø NHS Training Units

When does it need to happen by?
2005



Your views

The National Assembly for Wales are very keen that people with learning disabilities and their parents / carers have a say in what they think of this report. We have tried to keep it as short and plain as possible, which has not been easy when the full report is 85 pages long! However we hope you will have a chance to look through it, or listen to it on CD, and tell The National Assembly for Wales what you think. You can contact them at:

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Or you can submit your views through other learning disability organisations such as MENCAP Cymru or SCOVO.