

# REVIEW OF MENTAL HEALTH AND LEARNING DISABILITY

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(Northern Ireland)

## We have a dream...



Messages from people with a learning  
disability to the Review

# We have a dream.....

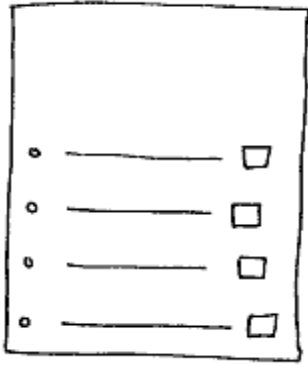
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14<sup>th</sup> January 2004



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# Who are we?

We are all people with a learning disability. Our group is called the Equal Lives Group.

The Equal Lives Group was set up to give advice to the Review of Mental Health and Learning Disability (NI). The Review is made up of people who are writing a report for the Government about how people with a learning disability should be supported in Northern Ireland.

The members of the Equal Lives Group wrote this report after meeting with many people with a learning disability and getting ideas from other groups in Northern Ireland.

These are the members of the Equal Lives Group:

Nora Smith  
Orla Cassidy  
Joe Coyle  
Hilary Gammon  
Alan Henry  
Gerald Maguire

Cathy Mc Killop  
Catherine Mc Guigan  
John Mullan  
Nigel Reid  
Trevor Rhodie  
John Paul Mc Cusker

3 advisers - Paul Roberts, Siobhan Wylie and Siobhan Bagues, support the group.

At the meetings we told people about the Review.

In small groups we asked them to tell us what was good and not so good in their lives.



Someone took notes in each of the groups.

We used these notes to write this report.

We will keep meeting until the Review is over so that we can check if the Review listens well to our ideas.

## Thank You

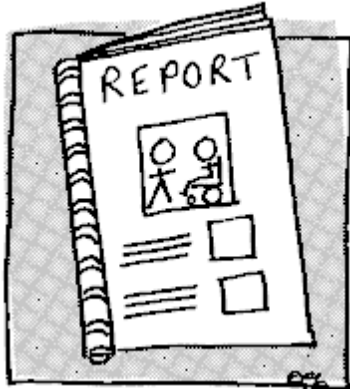
We would like to thank everyone who helped us to organise the meetings and to write this report.

Thanks for organising meetings to Katie Doran and Maureen McCartney.

Thank you to all the many people who chaired small groups and took notes.

For the use of drawings in this report thanks a lot to the people at Change Picture Bank

And last but not least for the *we have a dream* idea thank you to the members of Strule Buzz Advocacy Group



# Why have we written this report?



In October 2002 the Government said that they were going to do a study to find out about the lives of people with mental health needs and people with learning disabilities. This study is called the Review of Mental Health and Learning Disability (Northern Ireland) or the Review for short.



Committees are carrying out most of the work of the Review. These include committees that are looking at mental health and the law. There is a committee that is looking at the needs of people with a learning disability.



This committee wants to find out:

- What supports do parents and children with a learning disability need?
- What types of housing and support are needed for people with a learning disability?
- How can we make sure that people with a learning disability get the best things to do in the daytime?
- What do older people with a learning disability need?
- How do we make sure that people with a learning disability get good help if they are sick?

The Review wants to hear from people with a learning disability



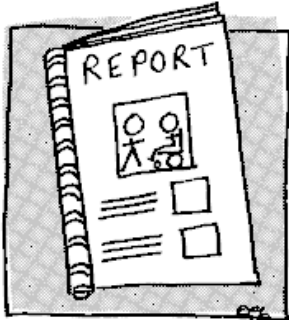
They asked us to join a group to help them to understand what people with a learning disability want to happen.

We decided to write this report to tell the Review what we think is good and bad about the services we get.

The Review will use this report to make sure they get their ideas right.

We think this is very important.

# How did we do the report?



We met 5 times in 2003 to get to know each other and to decide how we would work together.

We agreed that a report would be the best way to tell the Review what is important for people with learning disabilities.

We decided that we needed to hear from other people with learning disabilities so that we would get the report right.

We sent out invitations to meetings to

- Advocacy groups
- Services for people with learning disabilities.



These meetings were held in

- Armagh Theatre
- Silver Birch Hotel, Omagh
- Europa Hotel, Belfast
- Grosvenor Conference Centre, Belfast

Some people also asked to meet with us and we went to their meetings.

Altogether over 130 people came to the meetings.

We have a  
dream  
about...

# Our home



Many of the people we met lived at home with their families. Most people were happy living at home but some were afraid of what would happen when their parents are not around to support them. If something happened to their parents most people wanted to stay living in the same area - perhaps with 1 or 2 other people so they would not be lonely.

We were told that a lot of people do not get a choice about where they live or whom they live with. This has to change. Other people who wanted to move away from their families did not know how to go about this. They want help and advice about this.

Some people told us they wanted to live on their own but staff members were worrying about them not being safe. They thought they should get a chance to take the risk.

At each meeting there were people who were being supported to live in their own places. This was a popular choice but a lot of people do not have this choice.

## Some comments from the meetings about where we live...

*I've always lived in a home. I like the company and the staff are very kind to me*

*I lived in a hospital for more than 30 years. I have my own house now. People in hospital should get a chance to get out to their own house*

*I wish my mum would let me live on my own but she won't*

*I would like to live with Daniel O'Donnell*

*I would like to move from mum and dad's and get my own house*

*I live with my dad who is getting old. If something happened to him I would be able to live here I think. No one has asked me yet*

*I am happy enough living with my sister*

I want to live on my own.  
I was told it'd take years  
and years because I have  
to be assessed.

*I would like to  
live on my own-  
don't like living  
with other  
people*

Supporting People is not about  
people, it is about buildings.

*I live in my own flat-it is  
great. Nobody tells me what  
to do*

We have a dream about...

# Having a Full Life

## Leisure

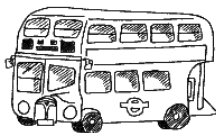
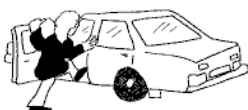


A lot of the people we met have a busy social life.

People told us about the different things that they do in the evenings including:

- Going to the Gateway Club
- Going to the cinema with friends
- Going to the YMCA
- Going to bowls
- Volunteering at the Junior Gateway Club
- Swimming
- Keep fit.

## Transport



In most places people talked a lot about how difficult it was to get out to social activities because there was no transport. In these areas we were told that the most important thing the Review could do would be to make it easier for people to travel to activities. Using taxis cost a lot of money but many people have no choice. People were keen to use ordinary buses rather than buses with the name of the centre on them. Some of the people who use wheelchairs told us that more low buses are needed. Some bus drivers do not help people in wheelchairs, while others do.

## Communities

People who use wheelchairs told us that people in the community do not understand them. They want to be part of the community but often they are ignored.



For many people loneliness was a big problem. Very often the only friends that people have were the staff. Some people do not go out at all after the day centre or at weekends. Many times people said that there should be more support so that everyone would have a chance to have a social life.

## Being Safe



A lot of people talked to us about how dangerous it was for them to go out in their areas. Quite a few people said they did not feel safe when they were out on their own. They talked about being bullied and about people calling them names because of their learning disability. We heard quite often that people in local communities need to learn more about learning disability and treat people with respect.

## Work



Everyone that we met has something to do during the day. Some people went to day centres full-time. However, most people only went to day centres for part of the week and they did a whole lot of other things during the rest of the week. For example they went to college, work or did voluntary work. Many people who went to day centres enjoyed their time and especially the company of other people.

However at some of the small groups people told us that they thought the staff in centres had

too many rules and did not treat people with learning disabilities like adults. Some people from L/Derry and Omagh told us that day centres should be in the towns. They said if day centres are in the country it makes it hard to go out to places like the library or leisure centre.



A lot of the people we met wanted to work full-time but they were not able to because their benefits would go down. Some people thought that was right because they were getting good wages they would not need so much benefits. However, most people were not getting paid enough to cover what they would lose in their benefits. This means that even though they might have a chance at a job, they are not able to afford to take it.

Some people felt very strongly that employers need to be educated about learning disability. In one of the groups we were told that employers had discriminated against people because of their learning disability. People felt this was because they did not see the good things that people with a learning disability could do in work.

The most important thing that people told us at nearly every meeting was that people should have a choice about how they spend their day. They should not be forced to work or go to day centres. If they want to work they should be paid a decent wage.

## Some comments from the meetings about having a full life...

*I would like some freedom to go out more for example to go shopping by myself instead of going with a carer.*

I have to work voluntary because if I earned a big amount of money it would mean I would lose my benefits.

Comedians need to have more consideration about people with a learning disability and not need to make jokes about them.

You should have more control about what you want to do in your life. You shouldn't have to do things if you choose not to.

There is not enough information about how to get into education and how to get support.

*I would like a paid job. I tried to work as a chef in Belfast but got bullied and picked on.*

I have to have my breaks on my own and do my jobs on my own so it's hard to make friends.

People in Scotland with a disability travel for free on buses - why not here?

The government need to do something about benefits, I should be able to work more than 4 hours and get a real wage.

One of the best things is that we moved from the country in to the Playhouse in Derry City which is much better.

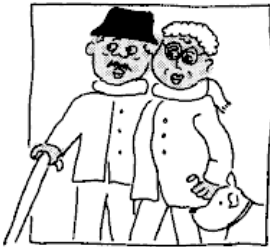
Those with a learning disability are not children. We do not want to be treated as children.

I am ready to work but doors are always closed in my face because I have epilepsy and learning disability. People don't want to know. Employers can't be bothered to have people with learning disability.

We have a  
dream  
about...

# Friendships

At a lot of the meetings people talked about how important it was for them to have friends. They told us that it was hard making friends. For many people their only friends are relatives or staff members.



Some of the people we talked to told us they would like to have a boyfriend or girlfriend. For some people who did have boyfriends or girlfriends the staff were not very helpful. In 2 of the groups people said that staff were nosey and interfered with their relationships.

In most of the groups people felt that they have a right to have relationships with people from the opposite sex.

In some cases restrictions were put on people by staff about whom they should meet and where they should go. In many cases people relied on staff to transport them to meetings and so they had a lot of control over their relationships.

At 3 of the groups people said they had not got enough education about relationships. In particular as mentioned people did not get enough information about contraceptives and relationships with members of the opposite sex.

## Some comments from the meetings about having friendships...

I have to rely on my parents to collect me and bring me to my friends' houses. I wish I could go by myself.

My friends would be my family at home and then there are friends when I go to work, but I only see them at work

I never thought about living with my partner.


I used to live at home but when my parents died I moved to (*residential home*). I never thought about living on my own or with my boyfriend, J.

People with a learning disability have the right to have a relationship with someone who doesn't have a learning disability.

People with a learning disability should have the choice to have a relationship and get married if they want to.

I don't want to get married... the woman takes all the money!

I have a woman.  
Someday I might get married



We have a dream about...

# Support from staff

At all of the group sessions people wanted to talk about the support they get from the staff who are paid to work with them. People said that having good staff and the right type and amount of support was very important.



A lot of people talked about how good their staff were and the support that they got from them. Good staff are those who:

- Listen well
- Know what they are supposed to do
- Understand about people having fits and what to do in an emergency
- Know a lot about learning disability.

At each of the meetings some people told us about bad staff who had worked with them.

These staff:

- Did not listen or try to understand the person's point of view
- Had a bad attitude about learning disability and thought people with learning disabilities were like children
- Did not give people control over their lives
- Always thought that they knew best
- Ignored people they were supposed to be helping or talked about them behind their backs



- Passed judgement on people as if they were the experts
- Did not take the time to explain what they were talking about.

Many people said that staff have to be taught how to give the right support and how to work properly with people with a learning disability.

Some people told us the Review should make sure that people with a learning disability are involved in picking staff and offering them jobs.

In 3 of the small groups there were people who had been involved in Person Centred Planning (PCP). For each of these people PCP was a very good way of working. They thought that PCP made it easier for them to tell the staff what they wanted and how they should get support.



At one of the meetings a person explained that Person Centred Planning means putting the person with the learning disability right in the middle of all the work that goes on.

The person with a learning disability is given a chance to invite whoever they want to their PCP meeting. They are also given a chance to be honest and relaxed about saying what their dreams are and the help they need to make their dreams to come true.

## Some comments from the meetings about having support from staff...

My social worker helps me at the moment with money and all.

My support is just right - I am always busy, can cook my own dinner and manage my own money.

My food is cooked for me. I would not like to cook

Sometimes my carers forget to lock the fridge.

They do the right things, bring me to the movies and help me with the shopping.

Some staff are bossy.

Staff don't stick around - I have to ask them where are you and where are you going? I want staff to stay around me but they do not, so I feel unsupported.


Staff need to be on the same wavelength as me - not like I am a social worker so I am better than you - people need to be down along side you - not be snobby - I don't like staff to be like some uppish nennie

Organisation give too much guidance which I can't stand. I want to learn my mistakes myself

*Staff in the centres are fine. I wouldn't say a bad word about them*

If I could I feel I would change my staff and pick new ones.

You know years ago we had to expect bad behaviour from staff. But when you complain - people are often too afraid to report incidents in case you get bullied from that member of staff - it has happened you know.

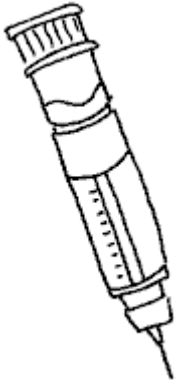


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# Help when we are sick

In the small groups many people told us good stories about what had happened when they went into hospital or became sick.

The most important thing was that the nurses and doctors took time to listen to people. When this happened people thought that they were treated well.



Several people who had epilepsy told us that many doctors did not really understand how to treat them. Time and again people told us that the doctors and nurses need to get special training so that they understand learning disability.

If people had to go into hospital it was very important that their family and friends were able to with them if that is what the person wants. Sometimes this was not allowed and the nurses did not really understand what the people needed.



People told us over and over that they do not like it when doctors talk about them rather than to them. If parents and staff are there the doctors or nurses sometimes just ignore the person with the learning disability as if they are invisible.

## Some comments from the meetings about help when we are sick...

*Sometimes doctors and nurses don't listen to me or understand me.*

Doctors don't listen to anything I say. The doctor should first of all listen to me, **not my parents.**

I would be better going to the doctor myself because doctors tend not to talk to me - they only talk to my parents.

Doctors see the learning disability before they see the person.

It is better if you can visit your own doctor because he will know and understand you.

I think doctors should be especially interested in people with learning disabilities.


I hate having to repeat information for example telling the doctor about myself again and again instead of them taking the time to read my notes.

I felt very ill because of the way my parents treated me, I had no support, I ended up being admitted to hospital.

Reform the Mental Health Act so staff have to inform you of your rights when you go into hospital

Doctors don't talk to us but to the people who come with us. They should talk to us

People are locked up in hospital. That should not happen. They have no contact with their family and friends



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# What the Review should do

We have listened very, very carefully to all the things that people have told us over the last few months. We hope that everyone in the Review will read this report carefully and make sure that they listen to what people have said.

We would want the Review to especially make sure that the following dreams come true:



Everybody should have a choice where they live and if they want to stay in their local area then they should be supported to.



If people want to live on their own or with friends they should get the help they need to do that.



All staff who work with people with a learning disability should get special training so that they understand how to respect people and know what to do to support people with a learning disability.



Any time people are making decisions about services or support they should have to listen to people with a learning disability.



We hope that the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.



People with disabilities should have the same opportunities as people without a disability.

# What next?

The Equal Lives Group will continue to meet every month until the Review is finished.

We will meet with people from the Review to give them advice on what they need to put in their report.



If you have something that you want us to tell the Review you can ring us free and leave a message by phoning 0800 328 4260.

Or you might want to talk to us directly - ring

Siobhan Wylie 028 9032 5835

Paul Roberts 028 9147 5720

If you can get the use of a computer you can also keep up to date with what is going on in the Review by going to [www.rmhdni.gov.uk](http://www.rmhdni.gov.uk)