Learning Disability Change Programme

A Plan For The Future

Some Services no matter where you live

be better at providing learning disability services

NHS

How can we make all NHS services better for people with learning disabilities

All working in the same way

we want to hear what you think

Bring this all together into a Report

NHS Report

Report on Service User Engagement Event
February 2013
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Learning Disability Services have come a long way since the closure of long-stay hospitals like Lennox Castle and Merchiston. The majority of healthcare is now being provided in the community. There is still a lot to do to address inequalities that people with learning disabilities face.

To do this, NHS Greater Glasgow & Clyde is reviewing all NHS Adult Learning Disability Services. These services are being reviewed because people with learning disabilities should be able to access good services which meet their needs no matter where they live in the Health Board area.

We have written ‘A Strategy for the Future’ which identifies a number of the challenges people with learning disabilities face. In the Strategy we say how we think our services need to change to make sure we address these. The Strategy says that learning disability specialist services should provide two things:

- Support to mainstream services to meet the needs of people with learning disability. Specialist services should work in partnership to build knowledge, capacity and competence.
- Direct healthcare when an individual requires specialist support because of their learning disability.

As we develop our plans it is really important that people with learning disabilities are involved in telling us what they think our services should do in the future. This report demonstrates how we are doing this in NHS Greater Glasgow & Clyde. People with learning disabilities from all over NHS Greater Glasgow & Clyde participated in an event held at the Beardmore Conference Centre in February 2013. This event was to hear what people thought of ‘A Strategy for the Future’ and tell us what else we needed to include to make sure future services are designed to make a difference and reduce the inequalities people face.

Thank you to all who participated in the event. This information will now be used to inform the next stages of developing better services.
Executive Summary

As part of our planning for the future, NHS Greater Glasgow and Clyde has decided that some changes need to be made to make sure that Adult Learning Disability Services meet the needs of people with a learning disability. We want to make sure that:

- No matter where people live you can get the same good services
- All staff who work in NHS Greater Glasgow and Clyde are better at understanding the needs of people with learning disabilities
- People can get specialist learning disability services when you need them
- We are clear about what these specialist services are and how best to provide them
- People with learning disabilities can get the same good services as everyone else when you go to hospital or health centres

The Agenda for the Day

An event was held to find out people with learning disabilities’ views about the Strategy. At the event we heard how to make services better and good examples of health care to be shared with the NHS.
The event was held in February 2013 and service users, carers and support workers came along from different groups:

- People First
- TAG from Glasgow, Clyde Coast and Dunbartonshire
- Scottish Consortium for Learning Disability
- The Good Life Group

Tom Kelly introduces the event

The Good Life Group (an action group of people with learning disabilities) performed three plays to show some of the problems people with learning disabilities face in accessing health care.

After each play, the audience discussed the problems and made suggestions for improvements. All the things they discussed, and the suggestions they made, are shown in this report.

The event was facilitated by:

- Tom Kelly – Learning Disability Change Programme Manager, NHS Greater Glasgow and Clyde
- Sally Swadel – Local Area Co-ordinator, West Dunbartonshire Learning Disability Services
- Sharon Symon – Speech & Language Therapist West Dunbartonshire Learning Disability Services
- Andy Miller, Scottish Consortium for Learning Disability.
- Linda McLaughlin – Facilitator, The Good Life Group
Play 1: We Do Things Differently Here!

The first play showed what might happen when a patient with learning disabilities, who needs physiotherapy, moves from one part of a health board area to another part. In her old area, a specialist learning disability physiotherapist came to her home, but in her new area she discovers that she has to go to the local health centre for it. When the patient gets this news, she’s upset and anxious.

After the play, discussion groups talked about the advantages and disadvantages of going to the health centre for services, and how it could be made easier.

Health Centre or Home-Based Services?

Some people preferred their services to be delivered at home because you feel more relaxed and able to talk in your own home.

However, others felt that getting services at home can make you less independent. Some thought that if you are able to go to the health centre, you should. It gives you more opportunity to get out and about, meet people, and feel part of the community.
Advantages and Disadvantages

The groups then talked about attending a health centre for services. People thought there were good and bad points in a number of different areas:

• Access
• Appointments
• Services, equipment and facilities
• Emotional and privacy issues
• Joined-up care.

Finding out the Physiotherapist doesn’t do home visits

Access

A lot of people thought that access to health centres could be a problem, because of difficulty with transport and physical access for people with mobility problems. It can also be confusing finding your way around unfamiliar buildings.
Appointments

People thought being able to make a set appointment time was generally a good thing, because it gives you more control over your day. Some thought that if you were going to a health centre for an appointment you may be able to use other services in the same place.

Some people felt that making an appointment was difficult because often the time you can call is restricted and often there’s only an answering machine. Also, you might not be able to get a suitable appointment time. There can be a long wait and appointments are often not long enough.

Drawing of discussion of Play 1
Services, Equipment and Facilities

Some people felt that there was a better range of services and equipment at a health centre, so you may get therapies there which can’t be delivered at home. They also thought that professionals could get access to information more quickly at the health centre and that you could get an overall health check there if you needed to.

Emotional and Privacy Issues

Some people felt that being in a professional environment made it easier to talk about personal things. However, nearly everybody agreed that reception areas are too open, so everybody knows your business, and crowded waiting rooms can make people feel anxious.

Joined-Up Care

Not everyone agreed about this.

Some people felt that there was more joined-up care in a health centre, because you could make an appointment with the same health professional each time, allowing a good relationship and a good understanding of needs to develop.

However, other people felt there was less joined-up care because you saw different people each time, staff were often part-time, which meant you had to repeat information, and there was a lack of familiarity with your individual needs.
Suggestions for Improvement

The groups made some general suggestions:

- You should be able to choose whether to get services at home or in a health centre.
- You don’t need special care just because you have a learning disability and should be able to get the same care as everyone else for routine health problems.
- It was important that health professionals listen to what people are saying.
- You should be left alone if specialist help is no longer needed, but be able to make contact easily if circumstances change.
- Hospitals and health centres should make sure they are sensitive to the needs of people with learning disabilities.

Deep in Discussion

The groups also made the following suggestions about how to make it easier for people with learning disabilities to use health centres:

Access

- Make physical access and signage better.
- Learning disability specialists should advise health centres on communication.
Appointments

- Make it possible to speak to a person (not an answering machine)
- Arrange better times to call for appointments
- Offer longer/double appointments
- Use email, text and the internet to make appointments and send reminders

Making our Voices Heard

Awareness and Attitude Training

- All staff must receive training in working with people with learning disabilities
- People with learning disabilities should train staff on attitudes

Joined-Up Care

- Get all staff into one building, so you don’t need to contact different places
- Ensure that staff work together to develop and use the same care plan

Resources

- Have support and advice available for people with learning disabilities – this could be provided by a person with learning disabilities
Play 2: Too Many Questions!

In the second play, a service user and carer are visited by a number of health professionals, one after the other, to carry out a needs-assessment. Each professional asks the same questions, and the service user and carer end up annoyed, frustrated and confused because of all the repetition.

After watching the play, the audience talked about what they’d seen.

How Would This Feel?

Lots of people said that all the questions would make them feel fed up, annoyed, irritated, confused and anxious. Some people also noticed that the questions were mostly directed to the carer, which they said would make them feel left out of the process of making decisions about their own care.

What Are The Problems?

You might not be able to answer properly, might not want to talk as much and might just stop co-operating. You might feel no-one had really tried to understand their needs before the visit, and you might actually feel worse after it instead of better.
Why Did It Happen?

People felt this might be because health professionals don’t get together often enough, and don’t share information.
Suggestions for Improvement

Better Communication and Information-Sharing:

- Health professionals should find out about your needs before they come
- There should be more reviews of your health, and everyone involved should attend
- There should be a computer system that everyone can access
- There could be joint visits, but one person should lead
- Health centres could use something like the Hospital Passport
- Everyone should be in the same building, so you don’t need to go all over the place to contact people
- Letters should use clear language, big fonts and pictures
- Health professionals should have a basic standard of training in dealing with people with learning disabilities
Preparing and involving the service user:

- Health professionals should ask for your permission to speak to carers
- Health professionals could put their photos on letters
- Someone should help you prepare for the meeting
- Health professionals should explain clearly (without using jargon) what will happen
- Health professionals should take time to listen to you
Play 3: Too Much Information!

The third play showed what happens when all the health professionals get in touch at the same time to feed back their advice. There is so much information to deal with, that the service user and the carer can’t cope.

The audience asked the service user and the carer how they felt about getting loads of information all at once, whether they had understood what everyone was asking them to do and which advice was the most important. Discussion groups then talked about their own feelings about the situation in the play, the problems it might cause and how it might be improved.

How Would This Feel?

Everyone agreed that getting lots of different advice would make you feel confused, anxious and unsure of what to do.

What Are The Problems?

People thought you wouldn’t know the most important thing to do, or which one to do first. They also thought there was too much telling and not enough discussion. All of this might mean a person would stop listening to any of the advice, which might be dangerous for their health.
Suggestions for Improvement

Producing an Action Plan

- Health professionals should work together to produce one Action Plan
- Have someone to manage things overall (e.g., care manager)
- Limit how many health professionals get involved
- Have more regular reviews

Talking about Action Plans

Communicating the Action Plan

- Action Plans should be explained face-to-face, so you can ask questions
- The most important service (for the person’s needs) should lead
- The most important points should be highlighted
- There could be joint visits with professionals working together
- Action Plans should use clear language, big fonts, pictures and photos
- Make a DVD explaining the Action Plan (especially exercises)
Ensuring You Understand Your Action Plan

- You should always have someone with you (e.g., parent, carer, support worker) to help them understand and remember the advice.
- Health professionals should ask if you can repeat the advice back, to check that you’ve understood.

Drawing of Discussion of Play 3
Conclusion and Next Stages

After the discussion groups had reported all their suggestions for improvement, everyone had a chance to talk about them.

Tom Kelly finished the day by thanking everyone for their involvement. He said the discussion points and suggestions from the groups would make a very valuable contribution to NHS Greater Glasgow and Clyde’s planning for change, and all the points people had made would be taken forward to the next stage of the plan process.

Report prepared by Linda McLaughlin and Sally Swadel
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