

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?

Yes No

We held four consultation events with people who use our services, their families and support workers about the findings of the report. There was widespread agreement that the report did not reflect the reality the lives of people with learning disabilities.

Not only did people tell us that they felt there had been little or no improvement in the provision of services and life chances of people with learning disabilities, but that things had become significantly worse over the past decade and that cuts in services across the board seemed to be disproportionately impacting on disabled people.

Whether in relation to education, employment, accessing day services or healthcare, there was general agreement that disabled people were being let down by a lack of appropriate services or by the inability to access those that did exist due to cuts in other services – for example in local authority funded transport that enabled people to travel to day services.

We also found evidence of a postcode lottery element in the provision of services for people with learning disabilities, and family members often having to take up the slack to the detriment of their own quality of life and employment opportunities. In one of our focus groups in the Highlands two mothers explained about their inability to hold down jobs due to having to be on hand to provide care for their children, or to drive them to and from day services due to the withdrawal of transport that was funded by the local authority.

“I was told by a social worker that I should have checked out what was available and should not expect the same amount of service.”

- Family member in the Highland Council area following a move from West Lothian

People talked to us about their frustration at not feeling heard or understood and how this could sometimes impact on their independence.

In addition, disabled people told us that they did not feel that their needs were a priority. They expressed a feeling that they were bearing the brunt of the economic downturn and that their benefits and services were seen as an easy option for the government to take, although it was unclear at times what specific branch or branches of government they felt this applied to.

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?*

NHS Learning Disability Champions

NHS Dumfries and Galloway asked UCI (User and Carer Involvement) to carry out a survey looking at the experiences of people with learning disabilities of local NHS services. The result of this work was that a new course was developed with University of West of Scotland. The purpose of the course is to help people who already work in the NHS better understand the needs of people with learning disabilities and more able to make any contact they have with the NHS, a more positive experience. A number of nurses and ancillary workers attended the first course in 2011 and a second course is planned for 2012.

While we recognise this is a positive step and appreciate it is still relatively new, we still heard from our respondents about disabled patients being treated in an unacceptable manner and as yet there is no sense that a coherent national strategy is in place.

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

It is clear that there is a postcode lottery element in relation to the provision of support and services.

We have found evidence that people with learning disabilities and their families experience vastly different levels of support, depending on the local authority area that they live in.

One family that we met with in the Highland Council area, expressed dismay at the much-reduced level of support they were receiving since moving from West Lothian for a 28 year old family member with Downs Syndrome and learning disabilities (see case study below).

We also found evidence of this in a supported living unit, in which two of the residents were being funded from different local authorities. This resulted in one resident receiving many more hours of one-to-one support from his local authority, while the other had his hours of support reviewed and reduced. As well as impacting on his ability to pursue interests and activities that contribute to his social wellbeing - the reduction in supported hours means that he has to use his allocated hours to attend medical appointments and his college course, leaving little left over for social pursuits – the change has led to a problems in the dynamic of the house.

A lack of ring fencing means that the funding for social work varies from authority to authority.

CASE STUDY:

We spoke to a family of three that had recently re-located from West Lothian local authority area to the Highland Council area. They have a daughter (aged 28) who has Downs Syndrome and a learning disability and who, despite being assessed by the local authority as needing 24/7 care, has received funding for only 15 hours of support per week, with no provision for transport to or from day services.

The family received no support when they initially moved to the area, as they were required to undergo complete re-assessment for a social work funding, despite telling the local authority that West Lothian Council had already fully assessed their needs and could provide the necessary documentation. When they were finally assessed, the support that they were offered fell well short of what they had received in West Lothian.

As a result her parents had to rearrange their working hours. Their daughter attends a day service three days a week, but on the other days she has to go with her Dad to his job. This can result in her being woken in the very early hours of the morning, when he receives a call-out, or having to wait in his van when he is working on jobs where she is not allowed on-site. There have been occasions when, due to the nature of her parents' jobs, and the long distances that her Dad often has to travel, she has been unable to

attend a day service and has had to go to work with him instead, as he could not guarantee that he would be back in Inverness in time to collect her.

Good Practice – Organisations

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

Break Away is a collaborative project between Leonard Cheshire Disability and City of Edinburgh Council (CEC) respite project held within the Local Area Co-ordination Team which supports the ethos of Self Directed Support (SDS). Break Away currently offers a respite service to individuals aged 16 – 65 who have a disability and who already have a CEC allocation of respite. Break Away supports individuals and their families to manage an Individual Service Fund by facilitating the planning and brokerage of short breaks and social events.

The Break Away ethos is to support individuals and their families to take an informed and active part in how they use their respite:

- To make informed decisions and choices
- Turn their ideas into action
- Take advantage of the break opportunities available to them in Scotland and outside of Scotland.
- Have the confidence and knowledge to take their place as active citizens in their communities- locally and nationally.

This partnership came about at the end of 2011 due to the Leonard Cheshire Disability Granton Road respite unit being identified for closure. Families who had previously accessed that respite service, identified through consultation with CEC Break Away project and Leonard Cheshire Disability that they wanted the staff support to continue to be provided by Leonard Cheshire Disability and the accommodation, for the time being, to be near to the Granton area of Edinburgh to enable a smooth transition.

Leonard Cheshire Disability has taken a lead role alongside the Break Away team to meet the respite requirements identified by individuals and their families. Some of the key areas identified were that individuals would be supported to build friendships, independence and take part in social activities, and that the service would be flexible to how families need to use their respite. Break Away, with Leonard Cheshire Disability, have worked to be outcomes focused in the development of this new respite option and meet the service needs that families have said are important to them.

The supported breaks which have been offered through our joint working, so far, have been based at Western Harbor holiday apartments, a respite option which has been opened up to all families who use Break Away. The Leonard Cheshire Disability staff team have creatively supported individuals to have breaks which have been meaningful to them, which in turn has

meant that carers/family have enjoyed their respite.

These supported breaks have emphasised developing independence skills: making sure everyone is actively involved in activities, domestic duties and decision making. Friendships have been encouraged and developed through these shared breaks, resulting in lasting relationships.

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

Please provide any comments and/or examples here

N/A

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

- Training for all healthcare staff, across all levels of the NHS
- Truly accessible services
- Healthcare that addresses medical problems, while also recognising additional needs, such as assistance with meals, taking medication and toileting
- Emergency care plans for disabled people with severe and complex needs so that they are not left isolated should anything happen to family carers

While the report points to some improvements in healthcare, it is our experience that people with severe learning disabilities or complex needs are repeatedly let down when it comes to healthcare, whether they are seeking treatment or screening for illnesses.

Specialist services are not always accessible, for example, one woman who attended hospital for a mammogram was told that the screening could not be carried out due to inaccessible equipment.

There were concerns that a lack of awareness meant that things were often poorly explained, or not explained at all. People with learning disabilities expressed frustration that time wasn't taken to make things clearer for them.

“It wasn't explained to me very well. I just feel sometimes people don't understand what I'm trying to say. I try to understand what they're trying to say to me but they don't understand that I can only take in so much at a time.”

- Middle-aged man with a learning disability talking about a hospital visit

Another person who uses a Leonard Cheshire Disability service spoke about how she is unable to keep appointments, and depends on support workers to remind her to keep them. She said that it would be helpful, for example, if her GP's surgery had a system whereby they could call her and remind her about appointments, but acknowledged that most surgeries

would not be willing to offer this.

An additional related concern was the difficulty in ensuring that there would be support in place for people with learning disabilities, should anything happen to the family members who supported them. Parents spoke of the lack of security about what would happen to their children should they themselves suddenly be unable to care for them, and a lack of awareness amongst social workers and medical professionals about an individual's right to dignity, with inappropriate care being suggested.

CASE STUDIES

In May 2012 a person who uses a Leonard Cheshire Disability service attended a CT scan following a referral from his psychiatrist – his behaviour had changed and his daily living skills were worsening. He was accompanied by Leonard Cheshire Disability staff and the Community Learning Disability Nurse. On arrival for the scan he was chatty but fairly relaxed. The first response from the radiographer was to say that, "there is no point trying this if he is not going to stay still."

Leonard Cheshire Disability staff responded by lying the man onto the bed to see if he would relax once lying down. The other NHS member of staff present said, "Well we might as well give it a go." The man lay down, was still chatting but stayed still. The straps were attached across the man's body and head. The Leonard Cheshire Disability staff members were asked if it would be better if they stayed whilst the scan took place. It was decided that they would see if he would settle without any staff distraction/presence and the support staff were moved to a side room with a window so they could observe what was happening.

The radiographer had to reattach a strap as the patient had moved and then tried to do the scan, and then moved again before the scan was finished. Leonard Cheshire Disability staff then suggested one of them stood near the patient so that he could focus on a person he knew, which was agreed.

The remaining Leonard Cheshire Disability member of staff then overheard the radiographer say to a colleague who had just entered the room, "This is pointless, he will not keep still," to which the colleague replied, "get him off the bed, there is no point, this is a waste of time". Leonard Cheshire Disability staff reported that they were in the CT room for around five minutes at most.

The same man was an in-patient at the regional general hospital because of a corneal abscess. Our staff members visited twice daily and on many occasions found the patient's medication still in a pot at the bedside or in his bed evidencing he was being given no support to take his prescribed medications.

On another occasion he was an in-patient at the regional general hospital due to pneumonia. He was nursed in a single room and again our staff visited twice daily.

A red mark was observed on the man's face, which staff questioned but it

was two days later before the ward confirmed that he had fallen.

Meals were regularly found untouched in front of the patient suggesting the ward staff were not supporting him to eat. Leonard Cheshire Disability staff began to visit outside of regular visiting hours so they could support him with his meals.

The individual who we were supporting has no awareness of the lack of support offered or the staff attitudes displayed in the above situations and has no family connections. On both in-patient stays his Health Passport accompanied him, which clearly explains all his support needs, but doesn't seem to have been noted.

In another case, a 30 year old man with complex learning and physical disabilities moved to a Leonard Cheshire Disability service one year ago having lived with his parents all his life. He has to have all his food pureed and has had Speech and Language Therapy input all his life. He has a history of experiencing episodes of malnutrition and/or dehydration due to his refusal to eat or drink, which sometimes requires admission to hospital. He has an adapted set of supports for his bed and wheelchair to ensure correct positioning.

In 2012 the man required in-patient admission as he was not eating and his weight had fallen to around 32kg. For the first two weeks of his admission Leonard Cheshire Disability staff visited him four times a day to deliver direct support with toileting, washing, dressing, giving medication and mealtimes.

During this time Leonard Cheshire Disability staff had to point out on more than one occasion that the oral medication left for the patient was incorrect.

The social work department officer, on learning of the direct support input from Leonard Cheshire Disability staff, immediately instructed it was to stop as the NHS staff should provide it. We subsequently learned that the parents took over the direct support provision.

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

- Meaningful courses that have practical and useful outcomes
- Transitional support from school to further and higher education
- Real options in terms of the courses available

Education was seen as important among those that we spoke to, not least because it provided people with social interaction as well as stimulation. However some people said that they felt as though the educational opportunities available to them were, at best, tokenistic. The parents of people with learning disabilities spoke about courses that offered little in the way of genuine life skills, or qualifications for future employment opportunities. One young woman, for example, received a certificate for playing the bongo drums. There was an overall sense that few courses had options at their conclusion and that education provision for people with learning disabilities had not been fully thought through.

However, we also heard positive feedback, in particular from two men, who attended a nearby college several times a week and enjoyed the courses on offer, some of which related to life skills. They got a lot from the ability to socialise with people and learn about things that were of interest to them.

The lack of transitional support for people with learning disabilities leaving education was highlighted as a significant problem. While there was a consensus that there was good support generally for school-age children, the same was not said about education after the age of eighteen.

“She left school last year and we were dumped from a great height”.

- Parent of a young person with a learning disability

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

It is our experience that the terms “learning disability” and “people with learning disabilities” can be problematic, as well as having their uses, as people with learning disabilities are not a homogenous group, and require different levels and types of support in order to live their lives independently.

Many of the people with learning disabilities that Leonard Cheshire Disability supports depend on assistance from families and other carers without whom they would be unable to live independently. However, all too often too great a burden is placed on family carers, leaving no time or support to balance work and other commitments with their caring responsibilities.

In addition, we found that the educational opportunities made available to people with learning disabilities left them unqualified for employment, which in turn presents difficulties in relation to supporting oneself.

Of the people that we spoke to, a lack of clear information and rules being consistently applied was highlighted as a problem.

Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

- Greater support for employers who take on members of staff who have learning disabilities in order that they can offer adequate support in the workplace
- A recognition that, for some people, there may be a number of reasons why a person is not able to work, and for other opportunities to be open to them without jeopardising benefits
- A recognition that the Work Capability Assessment for Employment and Support Allowance is failing people with learning disabilities

While talking about this consultation with people who use our services, it became clear that the fear of having benefits stopped or cut is a major issue for many disabled people. People spoke about their concern that volunteering could send a message that they were fit to work and should be earning money rather than receiving benefits.

One person in particular repeatedly spoke of her anxiety on days when her benefits were due to be paid, and her fear that they might not be in her bank account.

There is a lack of appropriate employment opportunities for people with learning disabilities. However, one person who used our services had a positive experience. He was assisted by the company Real Jobs, who found him a placement with The Body Shop. Although he only worked once a week for a few hours, he was able to retain all of his benefits and enjoyed going to do his job. Key to this was that he felt that his manager supported him.

“My manager understands me. If I’ve got any problems, I say.”

- Man with learning disability, 51

“[She] would love to have a job, but she needs constant care so she has no way of getting to a place of work on her own.”

- Parent of a person with a learning disability

Future Priorities

Q.10 What other future priorities do we need to focus on? (Please list these in order of importance with the most important first)

Advocates

While compiling this response, Leonard Cheshire Disability made a

concerted effort to engage with the people who use our services, their friends and families and our support workers.

We were reminded of the difficulties that can arise when trying to involve people with learning disabilities in process that involve them, particularly where an individual has a severe learning disability and/or complex needs.

There is a clear need for greater advocacy on behalf of people with learning disabilities so that their needs can be better understood.

Social Work

Some of the people using our services had experienced problems when interacting with social work departments. While some people reported more positive experiences, there were concerns that there was often a lack of communication, a lack of clarity about what information was being held by social work departments and a sense that information about an individual was often being sent to other agencies, but not the family itself. In instances where this occurred, it could cause additional stress in an already difficult situation.

Respite care and day centres

One thing that arose from our discussions with disabled people and their families was a lack of appropriate, high-quality services for young adults. We heard that young people were often forced with no or little alternative to services that were designed for older people, and therefore had a lack of physical activities and few activities other than watching television. The parent of one young person noted that if her son was unhappy when at some centres or on respite weekends, there was a knock-on effect in terms of her own happiness.

“If [he] was away and wasn’t happy I wasn’t happy the whole time that he was away.”

- Mother of a young adult with physical and learning disabilities.