P 72

Ymchwiliad i’r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Leonard Cheshire Disability

Response from: Leonard Cheshire Disability

Leonard Cheshire Disability
Cymru Wales

Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
Cardiff
CF99 1NA

1 September 2016

Dear Health, Social Care and Sport Committee,

Thank you for the opportunity to contribute to your consultation on priority issues for the Committee to consider during the 5th Assembly.

About Leonard Cheshire Disability

Leonard Cheshire Disability is the UK's leading charity supporting disabled people. We work for a society in which every person is equally valued.

We believe that disabled people should have the freedom to live their lives the way they choose, with the opportunity and support to live independently, contribute economically and participate fully in society.

Leonard Cheshire Disability provides a range of care and support services including residential care, supported living, homecare, day services and specialist care for adults with acquired brain injuries. This includes seven residential care services in Wales.

We also campaign to make care fair for everyone who needs it, including seeking an end to flying 15-minute care visits and sustainable long-term funding for social care.

Committee practices in the Fifth Assembly

Leonard Cheshire Disability welcomes the opportunity to engage with the Committee in this way. We have set out in the submission below a range of issues that we would recommend the committee examines over the course of its work.

In addition, and more importantly, we would urge the Committee to actively seek to include and engage with disabled people throughout its work. Whether the Committee is examining the integration of health and social services, or examining the health benefits of sport, it is important that the voices of disabled people are heard. In practical terms, we would be very happy to assist the Committee in taking this work forward, including supporting the committee to gather evidence from people who use our services.

Choice and control

The Committee has identified that a potential inquiry for it to undertake would be an examination of the integration of health and social care. We would welcome such an inquiry, but would recommend the committee reconstitutes it by looking at the inquiry from the perspective of a person receiving such care.

In May 2016, Leonard Cheshire Disability conducted a series of focus groups and in-depth interviews with disabled people across Wales in partnership with an independent qualitative research agency. One of the key findings from the research was the range of participants who expressed concerns to us that they still lacked control over their care.

Access to social care

Some participants felt that they lacked clear “signposts” to the services that were available to them. One participant with multiple sclerosis commented that “if you don’t know the system, you get nothing: you get lost.” They recommended that there should be “clearer pathways as to what you can access in the community.” In separate discussions two participants with differing conditions (arthritis and diabetes) advocated that “there should be signposting to services in GP surgeries.”

There was also a discussion about how much more difficult it is to get a social worker and support following discharge from hospital if you are working aged. One participant, who suffers with severe Arthritis, commented that:

> “you watch the hospital staff go from bed to bed of the elderly on the ward telling them what care has been organised for when they go home and I lie there being ignored - it is assumed as I’m in my late twenties that I can cope without formal care.”

Another participant talked about her feeling of abandonment by the social care system. She described how she after 6 weeks in hospital:

> ”I felt safe on the ward as I was being continuously checked and monitored, someone was helping me with physio and keeping me as active as was possible and then all of a sudden I was discharged and sent home to nothing.”

Personalisation

Others felt that the care they received was not sufficiently individualised, to recognise different people’s needs. We believe this can be rectified by commissioners providing funding for staff to take the time to read through individual care plans.

One participant with diabetes commented that: “there is a one size fits all approach to assessment and identifying equipment.” Another participant with Pompey Disease said that:

> “you can get wheelchairs, but there is no flexibility about wheelchair types. If you want an electric wheelchair you have to fund raise for that, I can’t use a self-propelling chair so if I didn’t buy my own I would have no freedom at all.”

Most participants felt that equipment provided to them was the cheapest and most basic available, rather than what was actually going to provide them with the most assistance, freedom and help to get on with their lives.

Support for unpaid carers

Support for families, friends and other informal carers was also a key issue in the research we conducted.

Many people with unmet care needs told us that they rely on informal care to get by. Others talked about the importance of friends and family for their holistic wellbeing, saying that they felt depressed, exhausted and inclined to stop engaging with the world altogether. However, they also reported that the provision of care created stress and tension on their relationships. Participants felt that the current social care system has not been sufficiently developed to support informal carers. One participant with fibromyalgia and arthritis commented that:

> “Your family are trying to manage their life as well as your life. The stress it puts on your family is extreme- you have to depend on others and you don’t want to.”

Other participants talked about the impact of their disability on others- about how their friends felt “guilty.” One participant suffering with psychosis said that “some relationships were not the same anymore as people interact differently with me since I’ve been ill.”

There was a general feeling of frustration that the system does not support informal carers and/or help with discussing your care needs with family and friends. There was also an overwhelming sense that not enough information about how to access support and advice was readily available. One participant with arthritis, diabetes and a heart condition commented that ‘if the information or support is out there I don’t know how to find it and my family haven’t been able to find it.’

It was suggested that information about services available to help friends and family support needed to be provided on many platforms, including online information; signposting and referral services being easily available via a general practitioner; and guidance booklets being given out at the point of diagnosis.

Taking a holistic approach to social care

A number of participants also suggested that insufficient consideration was given to the holistic needs of people receiving care. They said that a person was not looked at as a “whole package.” One said that the biggest negative impacts of their disability wasn’t the disability itself, but the way it affected their day to day life, stopping them from ever going away, having a social life or any ‘respite.’ The participant suffering with psychosis commented that sometimes a person didn’t need ‘care’ per se, but simply someone:

> “to help me go out. I don’t go out on my own… it would be nice to have someone neutral who could come out with me, someone who doesn’t see the disability, they see me.”

Another participant with multiple sclerosis suggested that newly disabled people should be given support in breaking the news of their disability to friends and family. They advocated that there should be help in putting complex medical diagnosis into a plain language form, to explain “to my kids why Mummy sometimes can’t play anymore.”

The National Living Wage

Leonard Cheshire Disability welcomes the introduction of the National Living Wage.

However, we are concerned about the challenges faced by the social care sector in finding the additional funds needed to meet wage increases at a time when local authority commissioners are squeezing care budgets and asking providers to do the same or more for less.

Across the UK, the social care sector is currently under significant financial pressure. Social care has seen funding reductions of £4.6 billion in real terms over the past five years, with further reductions of £0.5bn to come in 2015/16.[1] As a result of these severe funding pressures, most providers' fee levels are remaining static (and decreasing in real terms). This means that many providers now receive fees from local authorities which do not reflect the true cost of supporting people.

Sustainable funding for social care

We believe that over the next five years funding for social care will need to 'follow the legislation.' The Social Services and Wellbeing Act's person centred policies come at a time when social care across the UK is facing unprecedented financial challenges, with many providers receiving which don't reflect the true cost of supporting people. We believe funding has to be there to turn positive ideas into best practice. To ensure a sustainable care market, providing quality support for disabled people, facilitating them in fulfilling their potential, and living the lives that they choose.

We believe a more sustainable approach to funding would be to provide funding over five year terms. We would welcome the committee looking at the way in which commissioning for care is undertaken and see whether longer funder cycles may help improve efficiency and delivery of services.

We also believe that there are innovative solutions which could potentially be found in the 3rd sector to help statutory services better deliver their duties, and reduce wider budget pressures. For example, some of Leonard Cheshire's residential care homes in Wales include hydrotherapy pools and other equipment for delivering physiotherapy. At the moment, these are used exclusively by our residents. But, potentially, funding solutions could

---

[1] ADASS, Budget Survey, 2015.

be reached whereby they were used by a broader range of care recipients, relieving pressures on LHBs.

Issues impacting young disabled people

Leonard Cheshire Disability recently facilitated a group of disabled young people in visiting the National Assembly for Wales. During their visit, the young people suggested a number of other issues which the Committee might wish to consider. These included:

(a) Review of wheelchair services and funding

Disabled people talked about how getting access to the 'right' wheelchair has been challenging and raised concerns about ongoing maintenance and upkeep of their wheelchairs and access to services. People were clear about the need for improved funding for wheelchairs so that they can access chairs fit for their individual needs.

(b) Funding issues around social care

Various participants:

- had experienced lengthy delays in receiving social care funding (from application, to decision, to money received) and said that the process is too complicated and lengthy.
- hoped that the Social Services and Wellbeing Act would result in improvements related to social care funding, and asked that post-legislative scrutiny be conducted on the implementation of the Act.
- were concerned that there was not enough funding for 'social' hours (care packages meet basic physical needs but not enough funding is provided to enable people to experience social activities)
- were concerned about staff shortages (in that there was not enough funding to provide enough care staff to have prolonged interactions with care recipients)

Access to services for disabled people

Various participants spoke about the difficulties they have experienced in accessing services and finding community based programmes, particularly 'social' activities. Disabled people also told us that more needs to be done to make accessing services easier, including awareness raising that programmes and services exist.

Yours sincerely,
Rhian

Rhian Stangroom-Teel
Policy and Public Affairs Officer (Wales)
Leonard Cheshire Disability
Telephone: [redacted]
Email: [redacted]