

Patient and Client Council

What Matters To Me?

Service users' and carers' views on learning disability services

November 2015

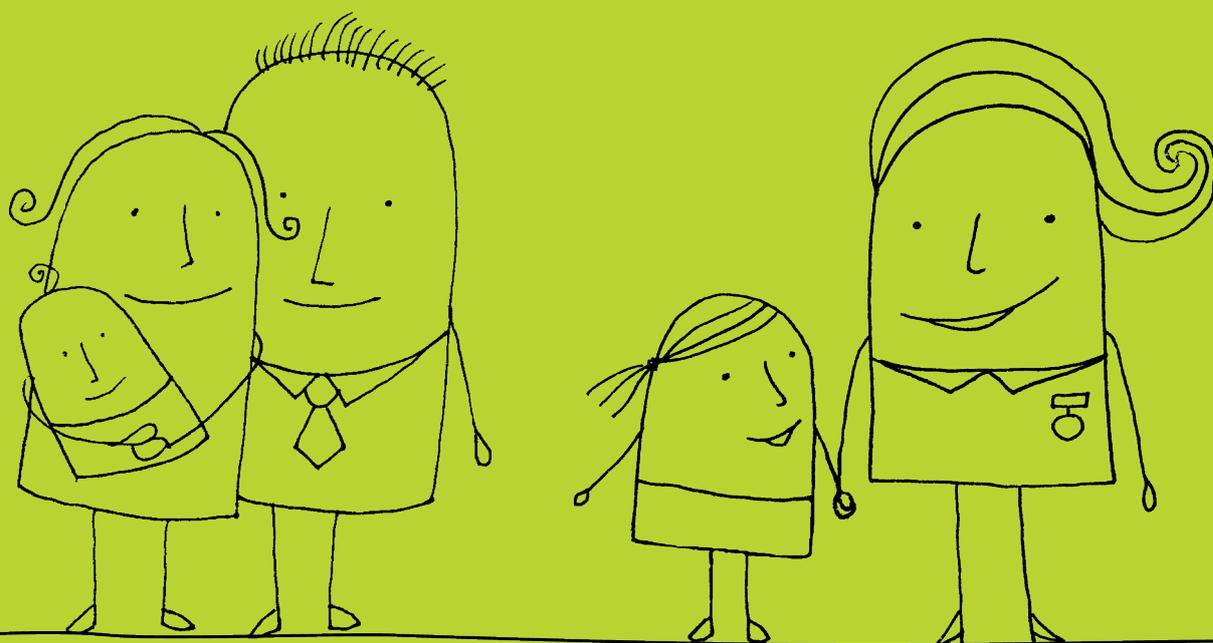


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Foreword

Dear Reader,

It's important for people with a learning disability to lead independent lives and be part of their community. Having a job, socialising with others and learning new things are some of the things that are important for our future. But, to be given this opportunity, we may need some support.

Through this report, people with a learning disability have shared with us their views on what's important to them. It's necessary that these views are heard and that we work together because we need to be part of any decision making that impacts on our lives.

Learn from us and we can help make services better for everyone!

A handwritten signature in black ink that reads "Gerard McWilliams". The signature is written in a cursive style and is centered within a light grey rectangular box.

Gerard McWilliams

Personal and Public Involvement Officer

Gerard is a Personal and Public Involvement Officer in the Patient and Client Council. This involves engaging with the public to ensure they are involved in Health and Social Care. As part of his role, he works with the Bamford Monitoring Group. Gerard is also a learning disability service user.

Executive Summary

Background

This project was developed with guidance from members of the Bamford Monitoring Group to explore service users and carer's current views and experiences of learning disability services. The specific objectives of the project were to:

- ▶ Engage with learning disability service users and carers to provide an opportunity for people to give their views on learning disability services;
- ▶ To understand the views of service users and carers about what they feel is working well and not working well in learning disability services; and
- ▶ To establish the key issues service users and carers have with learning disability services.

What we did

Throughout 2014 and 2015, Personal and Public Involvement (PPI) Officers from the Patient and Client Council (PCC) carried out focus groups across Northern Ireland with learning disability service user groups. These focus groups asked participants about what was working well/ not working well and what they would like to change within learning disability services. This piece of work aimed to give service users an opportunity to express their views on learning disability services. In total the project spoke to 48 service users and 24 carers across 11 focus groups.

Key findings - service users

Service users highlighted six key areas which were specifically relevant to them. These included:

- ▶ views on day opportunities;
- ▶ supported housing;
- ▶ respite (short break) services;
- ▶ further education;
- ▶ training and work; and
- ▶ HSC staff in learning disability support services.

There were things that worked well and did not work well in the discussions with services users about their learning disability services. They reported how day services were important to them and choice, flexibility, and independence were key aspects to day services which worked well.

Whilst many service users reported positive experiences of staff they also reported that staff did not always understand their particular needs. Respite was also an area which service users talked about positively and identified it as something they enjoyed however a few expressed frustration with limited access to these services.

Key findings - carers

Carers highlighted five key areas as being specifically relevant to them and the person they care for. These included:

- ▶ respite (short break) services;
- ▶ transition from child to adult services;
- ▶ HSC staff;
- ▶ joined up working; and
- ▶ information.

Carer participants were generally more negative than service users about learning disability services.

Carers highlighted that respite was important to them but there is a need for improved availability and access to these services. They also reported that it was important to have good communication with HSC staff and that they should listen to carers opinions and value their expertise more. Carers also identified an information gap with regards to services which are available, reporting that they are unaware of opportunities available in their local area. Some relied on support groups as their method of hearing about services which they could avail of.

Whilst not specific to one particular area, carers often noted throughout discussions that they were concerned about the future of service provision due to potential budget cuts and funding issues in the future.

Conclusions and next steps

The themes and key issues raised by people in this report will come as no surprise to decision makers as similar messages have been highlighted in various projects undertaken in the past by the Bamford Monitoring Group and the Patient and Client Council.

The Patient and Client Council and the Bamford Monitoring Group will continue to review the issues raised in this report and will seek to influence decision makers and professionals working in Health and Social Care so that learning disability services are provided in ways that best suit the needs of the people who use them.

1.0 Background and purpose

The Patient and Client Council provides a powerful, independent voice for people. We have four main duties. They are to:

- ▶ listen and act on people's views;
- ▶ encourage people to get involved;
- ▶ help people make a complaint; and
- ▶ promote advice and information.

1.1 Why we developed this project

Improvements to learning disability services have been documented in recent years, but it is recognised that more needs to happen.¹ This project was developed, with guidance from members of the Bamford Monitoring Group, to explore service users and carers current views and experiences of learning disability services. In particular, this project sought to give service users an opportunity to have their say / express their views on learning disability services. The specific objectives of the project were to:

- ▶ Engage with learning disability service users and their carers to provide an opportunity for people to give their views on learning disability services;
- ▶ To understand the views of service users and carers about what they feel is working well and not working well in learning disability services; and
- ▶ To establish the key issues service users and carers have with learning disability services.

1.2 The Bamford Monitoring Group

In 2002 the Department of Health, Social Services and Public Safety (DHSSPS) carried out an independent review of mental health and learning disability law, policy and service provision. It was called the Bamford Review of Mental Health and Learning Disability, now known as the 'Bamford Review'.²

Between June 2005 and August 2007 the review produced a series of 10 reports that made over 700 recommendations to improve mental health and learning disability services. It represented a far reaching vision for reform and modernisation of mental health and learning disability services in Northern Ireland. The Equal Lives report focused on reviewing policy and services for people with a learning disability.³

The Bamford Monitoring Group has been set up by the Patient and Client Council to monitor how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.

The role of the group is to find out from people with mental health needs, learning disabilities, parents, carers, family members and communities whether any changes to the services they use are making a positive difference to them.

1.3 What do we mean by learning disability services?

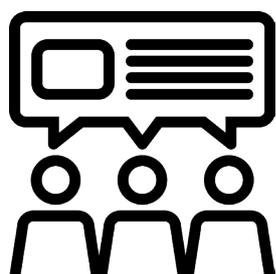
Learning disability services are any services designed for and provided to people with a learning disability and / or their families and carers. When talking about health and social care learning disability services, often people are referring to support services. These are services which support people to live as independently as possible. The services and support provided will depend on individual circumstances and require an assessment of individual needs. These services can include assessment and treatment, community living, respite and day opportunities and will be provided by local Health and Social Care (HSC) Trusts.

Learning disability services can be wider than Health and Social Care support services however. They can include services provided, for instance, by the community and voluntary sector relating to supporting people with education, employment and training, therapeutic services, leisure services and social activities.

2.0 What we did

This was a qualitative project which aimed to capture an in-depth understanding of views on learning disability services from a small number of service users and carers. Throughout 2014 and 2015, Personal and Public Involvement (PPI) Officers from the Patient and Client Council carried out focus groups across Northern Ireland with learning disability service user groups. Focus groups were designed to give service users an opportunity to share their views on learning disability services. Focus groups with service users included a short role play, facilitated by PPI Officers, to set the scene and to explain what we wanted to talk about. Discussions also took place with carers to gain an insight into their views on learning disability services. **Figure 2.1** summarises the key questions that participants were asked about.

Figure 2.1: Summary of what participants were asked



- ▶ What is working well in learning disability services?
- ▶ What is not working well in learning disability services?
- ▶ What would you like to change in learning disability services?

The main focus of discussions was learning disability services relating to Health and Social Care. However, given the wide and varied nature of the lives of people with a learning disability, the provision of learning disability services are not just the responsibility of Health and Social Care, but also other government departments and agency partners such as in areas relating to education, employment and learning. Therefore, during discussions, participants in this study were free to discuss any learning disability services which were important to them.

In total 48 service users and 24 carers took part in the project across 11 focus groups. **Table 2.1** provides an overview of the learning disability service user and carer groups the PCC visited across Northern Ireland.

Table 2.1: Outline of learning disability service user and carer groups visited by the PCC

Groups visited	
Mencap	Solas Support Group
Now Project, Hub Group	Autism NI
Strule Buzz Group	Downs Syndrome Association Support Group
Learning Disability Service User Advocacy Group	Carers Forum
Positive Futures (x2)	Share Carers Group

It is recognised that the views of the people that we talked to as part of this study may not reflect all those people who use learning disability services. For instance, further work would need to take place to fully reflect the views and experiences of services users / carers in relation to services for people with severe or profound disabilities, including those with challenging behaviours.

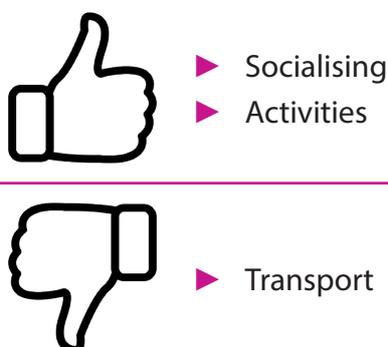
Given the nature of the group discussions it has not always been possible to assign specific numbers to the qualitative data outlined in this report. However, as a general guide the following definitions will give the reader an indication of the frequency of occurrence during group discussions:

When we say:	We mean:
"few"	10% of the people or less;
"some"	11 to 25% of the people;
"many"	26 to 50% of the people;
"the majority"	51 to 75% of the people; and
"most"	76%+ of the people.

3.0 Our findings

3.1 Views on day opportunities

Most service users talked about the importance of day centres and day services to them. The participants that we talked to used the terms 'day centre' and 'day service' interchangeably. Activities that service users talked about in relation to day opportunities related to social and leisure opportunities. A number of aspects of these services which worked well were highlighted by participants in relation to socialising and the activities that they provided. Issues in relation to transport were highlighted as not working so well within these services. Carers did not have any views on day opportunities, however discussions relating to respite services (see **section 3.3**) highlighted issues with services including those which provided day opportunities for learning disability service users.



Some participants identified the positive social impact that attending day centres / services had on their lives; in particular, this provided service users with the opportunity to have a break from being at home and the chance to participate in a range of social activities for their own fun and enjoyment, such as shopping, games, day trips and computer activities.

"Shopping. A whole lot of people go shopping like their parents do."
(Male service user, age not given)

However, some participants did express concern about the lack of suitable transportation available to attend day centres / services. For instance, one person provided an example where a day centre / service they attended moved location, which resulted in people being unable to afford to travel to this location. In turn, this prevented their continued participation in this organisation.

“They (organisation) moved to an industrial estate and how do they expect anyone on benefits to get down there because we’re on benefits, we can’t afford taxis every five minutes.”

(Male service user, 25-34 years old)

Many others who regularly used day centres / services believed that more accessible and suitable transportation was necessary to enable people to take part in activities.

“They have a small bus and it’s not for wheelchairs, it’s not wheelchair friendly. And they want me to ask about it, but I’m not (going to) ask in case they take the bus away.”

(Female service user, age not given)

It was clear that many service users really valued the day centre / service opportunities they had. It was in this context that one participant expressed a feeling of disappointment if their time in the day centre was ever reduced.

“I would be cross if they cut my days down here at the centre.”

(Female service user, age not given)

3.2 Supported housing

Supported housing was an important area for many service users that we talked to in this study, however was not discussed by carers as they had either no experience of using these type of services or did not anticipate that they would do so in the near future. A few people identified the positive impact of support and independence that these services provided and therefore felt that supported housing was working well for them. However, others noted that they would like supported housing in the future but that this was not currently available to them.



- ▶ Independence
- ▶ Support when required



- ▶ Not all people can get this



A few people spoke positively about their supported housing arrangements and highlighted that they are successfully living independently in the community.

"I live at home, in a housing executive house and everything is fine."

(Male service user, age not given)

"I'm in supported living, well was in a supported living service and I live now with an organisation called Positive Futures since 2002 and I lived at home before that. I think that's working well."

(Male service user, 25-34 years old)

One person highlighted the positive support an organisation provided, which enabled them to increase their independence which is something they really valued.

"Positive Futures has given me independence which is very important. With the help of Positive Futures I am able to arrange my own appointments and order heating oil for the house."

(Male service user, 35-44 years old)

Some participants noted that they would like supported housing to allow them to live more independently in the future.

"I would like to achieve independence and have my own house...I would like to learn how to look after myself and live like every other citizen in this country."

(Male service user, 18-24 years old)

"I would like to live in my own home; the staff are trying to help me which is good."

(Female service user, 45-54 years old)

"I would like more independence and less support. I would like to live on my own and be able to talk to someone if I needed it."

(Male service user, 35-44 years old)

3.3 Respite (short break) services

Respite services can mean different things to different people, but are generally understood to be any sort of help and support that enables a person caring for somebody else to get a break. Carers identified respite as an area which worked well within learning disability services and despite these services being focused on helping carers to have a break, many service user participants talked about the positive experiences of respite services for themselves also. Accessing these services however was raised as something which was not working well for a few participants.



- ▶ Enjoyment
- ▶ Break from caring duties
- ▶ Quality of care



- ▶ Not always able to access respite services
- ▶ Lack of time at respite
- ▶ Inability to plan ahead to use respite
- ▶ Unsuitability of respite to needs



Many participants highlighted the positive role respite had in learning disability services for them, identifying it as something which they enjoyed.

"I have had respite a while ago, it was good."

(Male service user, 35-44 years old)

"I go once a month every Friday and come back on Monday. The staff take you out for a drink if you want."

(Female service user, age not given)

However, a few participants expressed frustration with accessing respite services.

"I haven't been able to get respite in two years...I miss this."

(Female service user, 65 years old or over)

"More opportunities for respite because, I know money is tight, but surely they could scrape some money together to take us away."

(Male service user, 25-34 years old)

"I was to get it last year, but for me going into hospital, I couldn't get away and they only give you an exact date when you can go."

(Male service user, 25-34 years old)



Many carers recognised respite as an important service which gave them a break from their caring duties and time for themselves, which is something they really valued. However, carers also believed that respite was an important service for the person they cared for, identifying that the person enjoys going to respite, in particular, the activities they took part in when they were there, such as day trips, games and computer activities.

"We get four hours respite per week, which is a godsend."

(Male carer, 35-44 years old)

"It is working well for me and I use it once a month and we meet with carers and it does seem to be working and I've been using it for about a year."

(Female carer, age not given)

"For both of us, it was like a holiday."

(Carer, 55-64 years old)

Carers spoke about the positive role of staff and the high quality facilities which contributed to the enjoyment of the person they cared for during their time at respite.

"They are brilliant staff and my daughter loves going there."

(Male carer, 45-54 years old)

"Our older parents are getting to use it and it does seem to be working well."

(Female carer, age not given)

"You'd be hard pushed to find anything better in Northern Ireland. It is state of the art."

(Female carer, age not given)

Whilst carers valued respite as a service, problems remain within the practicalities of how the service is provided. It was believed that longer hours of respite were necessary to ensure that carers could get the most out of this service. For some, respite may be the only time they have a break from their caring role. One participant highlighted that they would benefit from longer hours of respite.

"They arrive any time from 9 o'clock or 11 o'clock and then they're leaving from 2:30pm...It doesn't give the carer any time."

(Female carer, age not given)

Some participants also identified access to respite as a major problem and that the respite capacity is not big enough to meet demand.

"I would like more but I don't think we can get more."

(Male carer, 35-44 years old)

"We've six beds – it's not a lot."

(Female carer, age not given)

"It's state of the art...but it's too small!"

(Female carer, age not given)

Interestingly, some participants in a Carers' Forum noted how they themselves prioritised need by ensuring that older parent carers receive respite before younger parent carers.

"Younger parents step back and let our older parents get the use of the facility because we are all going to be in that position and we think they need it more than we need it."

(Female carer, age not given)

For some, access to respite was only gained due to an emergency situation and others highlighted that they planned to use respite in advance but were not successful and felt like they had to fight to get access to the service.

"The first thing we got was respite and this was because of an emergency."

(Carer, 55-64 years old)

"I gave social services one year's notice that we were going away for two weeks. They had a year to find us respite for that fortnight and they did nothing."

(Carer, 55-64 years old)

"Half the time you are fighting for it."

(Female carer, 45-54 years old)

Furthermore, others expressed frustrations over the unsuitability of respite to their needs.

"I can't get it because my girl has additional medical needs. There is only one place children can go to here and if they have additional medical needs, they won't do medication."

(Carer, 45-54 years old)

This means that some carers may not be able to avail of respite, despite the fact they would like to and this may mean it may be difficult to get a break from their caring duties.

"The people who need it the most can't access respite."
(Carer, 55-64 years old)

3.4 Further education

A key theme which emerged from findings was the importance of further education for service users. Some service users talked about how day services helped to provide these services; others noted that they were supported with a move into further education. Many participants reported positive experiences of further education, indicating that they were provided with opportunities to learn new things, helped them to build their confidence, provided opportunities for social interaction and helped them to develop and progress. However some participants felt that there was a lack of suitable classes for them and/or appropriate support to help them in further education.



- ▶ Opportunity to learn
- ▶ Helped build confidence
- ▶ Social interaction
- ▶ Opportunity to progress



- ▶ Lack of suitable classes
- ▶ Lack of support in education
- ▶ Unequal opportunities



Many people identified further education as something which is working well in learning disability services. Participants talked about the support that they received to enter into further education and how this had given them an opportunity to learn new things.

"I attend a literacy class, it is very good and at my level. It's also free as it's community based."

(Male service user, 35-44 years old)

"I go to tech to do two courses. I love the tech and love the courses."

(Female service user, 35-44 years old)

However, some people also expressed frustration with their educational opportunities, in particular, with the lack of suitable classes which were aimed at their level.

"I was at tech but they didn't have courses at my level."

(Male service user, 35-44 years old)

As a result, some participants felt there should be more appropriate courses available to people. Indeed, some people talked more widely about the educational system, particularly with the teaching methods used and the lack of support available for them.

"I would like to learn how to read and spell because I want to be an actor but I can't because I can't read. Classes that teach me in different ways would be good."

(Male service user, 18-24 years old)

"I started a course and I was told that I would have an assistant to help me, but when I turned up to start, I was told that, due to cutbacks, that I couldn't have an assistant. The teacher tried his best to help me as best he could, and I battled on and got my level one. But I don't feel like I can carry on to level 2. It's just too hard and I need help. Maybe more help."

(Female service user, 55-64 years old)

Whilst some people called for more suitable courses at their level, others suggested that there should be no differentiation between learning disability and mainstream courses.

"I think there should be more course opportunities. We should have the right to go to any course with anybody else that has a disability or not."

(Male service user, 25-34 years old)

"In the college, there's no provision for people who want to do mainstream courses, like in the college you're sent to the step centre to do your written work and that's not right; you're supposed to be integrated with other students."

(Male service user, 25-34 years old)

These examples highlight that some people felt there are problems within further education for people with a learning disability. As well as developing skills and learning new things, some service users talked about how further education opportunities can promote social interaction and help to build their confidence.

"I went to night classes in literacy and numeracy, the essential skills course. It helped build up my confidence."

(Male service user, 18-24 years old)

3.5 Transition from child to adult services

As service users move between different health care services, they will find significant differences in the expectations, style and culture of these services, while their own care needs will be evolving at the same time.⁴ The transition period from child to adult services was an area which many carers highlighted as not working well.



- ▶ Lack of rights when person cared for reaches adult age
- ▶ Practical issues with transition
- ▶ Uncertainty regarding transition
- ▶ Impact of transition on service user



A key problem identified by some carers was a perception that they were not involved enough in the health and social care decisions and conversations about the person they care for when they reach adult age. This was an issue raised in particular by parent carers (carers looking after their children). This can prove a difficult period, especially in relation to the impact this move to adulthood has for the carer, in particular, in terms of who can make decisions. Once service users transition to adult services, this means that they can now do things on their own, which in turn leaves carers in a difficult position when, for instance, dealing with professionals. An example stated by one participant identified practical issues with filling out forms, as professionals want to speak directly to the service user. This in turn can result in added stress and pressure on carers who may feel that their views are not taken into consideration.

"You can't discuss and they won't discuss on the phone with you."

(Female carer, 45-54 years old)

"Now that my daughter is over age they won't take evidence off us, they say they need to speak to her and I say it would be great if you could because she doesn't talk."

(Male carer, 45-54 years old)

"He is 19 and because he is an adult he can go now and he can do things. It is just a mess because you can't go in with that 18 year old anymore."

(Female carer, 45-54 years old)

The transition to adult services may not only impact on the service user, but as these examples show, may prove difficult for the carer. Carers may have spent their life looking after the person they care for. This sudden transition means carers may have to relinquish control which can prove difficult. Uncertainty regarding the transition period from child to adult services was a key theme which emerged.

“There are all these questions that we need answered; even the good staff that we talk to don’t know the answers.”

(Male carer, 45-54 years old)

One carer also identified how, when service users turn 18, they are no longer able to avail of certain day opportunities. This can pose a problem, particularly if service users are settled and comfortable in these services. In some instances, adult day services may not be geared towards, or are suitable, for them either.

“She went there until she was 18 and then after that there you don’t get into the day centre.”

(Female carer, 55-64 years old)

As a result, this sudden change to adult services may be a difficult transition stage for service users. One carer expressed concerns in relation to the length of the transition period.

“My daughter is very autistic with severe learning difficulties, she will need a long transition from child services to adult services and it is just not happening at the minute.”

(Male carer, 45-54 years old)

A few carers talked about how, given the needs of the people they looked after, the transition to adult services should be progressive and there should be gradual change in provision to alleviate stress for everyone involved.

3.6 Training and work

Job and training services that enable people with a learning disability to find paid employment was an important area for service user participants. Service users highlighted a number of areas which were working well and also not working well. Positive experiences within the workplace were highlighted by service users, however many issues in relation to a lack of general opportunities were highlighted, in particular, as not currently working well.



- ▶ Work experience
- ▶ Social interaction
- ▶ Supportive colleagues
- ▶ Independence
- ▶ Financial benefits



- ▶ Lack of job options
- ▶ Lack of training opportunities
- ▶ Lack of paid employment opportunities



Services which support training and work opportunities were important to many learning disability service user participants. In particular, people valued opportunities to gain work experience.

"I got a work placement, part time with Mencap. I enjoy that."

(Female service user, 25-34 years old)

Training and work opportunities helped to enhance people's skills and knowledge, and also provided people with a chance to socialise and get to know other people.

"I was doing a good thing in the college educating young people about people with learning disabilities."

(Male service user, 25-34 years old)

However, many participants indicated that they were unhappy with the lack of job options available to them. Indeed, some people believed that it was difficult to get a suitable job and expressed frustration with their lack of options. In this context, participants wanted more options for work placements and jobs.

"There are no jobs for me to find."

(Male service user, 18-24 years old)

"I am trying to get a job. There should be more opportunities for jobs and for those who have experience."

(Male service user, 18-24 years old)

Some participants expressed frustration with the lack of training opportunities and paid employment for learning disability service users.

"I volunteer in a care home. I have been there for five years but because I am a volunteer, I don't get properly trained and I don't get paid."

(Male service user, 35-44 years old)

"I'm a volunteer and I don't get paid and I would love to get paid work, part time, and get some money."

(Male service user, 25-34 years old)

However, some participants noted positive experiences of working. In particular, support from work colleagues was viewed as being important. Some participants also noted how they enjoyed being part of a team.

"The staff that support us are brilliant."

(Female service user, 35-44 years old)

"I work in the council, this is office based. I think it is good, they make me part of the team – I go to the Christmas dinners."

(Male service user, 35-44 years old)

For some, work opportunities have also provided them with independence, in particular, financial independence.

"I am very independent with my money and medication."

(Female service user, 35-44 years old)

3.7 HSC staff in learning disability support services

Participants also talked about issues within services in relation to HSC staff. Most participants, both service users and carers, felt that staff were supportive and helpful when they needed them, being approachable and friendly and helping to provide good continuity in any care that they required.

However, there were some issues in relation to HSC staff that participants felt were not working well for them. Some service users felt that staff do not always listen to them, or involve them in decisions about their care/ their dependents care and that staff did not provide them with information that they wanted in an accessible format.



- ▶ Approachable and friendly staff
- ▶ Continuity in the care and support provided
- ▶ Staff treating people with respect
- ▶ Staff listen to carers views and communicating with them



- ▶ Staff do not listen to service users or involve them in their care
- ▶ Staff do not listen to carers views or the person they care for
- ▶ Delivery of information in accessible formats
- ▶ Poor communication between staff and carers



Most participants identified the positive role of staff. In particular, people really valued staff that were approachable and friendly.

"The staff, they take me out."

(Female service user, age not given)

"My carers have been a great help to me, my parents have been very pleased for me."

(Female service user, 35-44 years old)

"I think the hospital was so wonderful, because they brought me a TV down and the services were really good in it...and the diabetic nurses in the health centre were so wonderful."

(Male service user, age not given)

Another participant identified the importance of continuity in care. The importance of working with the same staff was noted. It was felt that this allowed people to build up a relationship with staff, who they feel comfortable with.

"It is important that the staff I work with stay the same as I built up a relationship."
(Male service user, 35-44 years old)

Additionally, some people also identified the positive impact of staff who made them feel valued by treating them with respect and as equals. They emphasised the importance of having understanding, patient staff who took the time to interact with people at a suitable level.

"The doctor talks to my face and not down at me. He treated me as a human and not somebody who is stupid."
(Female service user, 55-64 years old)

"I think that one of the advantages is that most of them can understand you, like very well, the people who are from the learning disability area, the workforce – they would understand you and they would try and help you out as much as possible, for me that's one of the advantages."
(Male service user, 18-24 years old)

However a few people highlighted their frustration that staff do not listen to them or take their views into consideration.

"She just doesn't listen to me. If they could understand that a person that had a learning disability would tend to put on weight because of the drugs they're taking, I know I'm taking a lot more drugs than a person with just learning disability but you go into that place and you're sitting out there and your hands start to swell up and you think here we go today again, (staff are) patronising again. I go in there and I'm happy, it's like being knocked off a cliff, she knocks all the, everything I've achieved, the wind out of your sails."
(Male service user, 25-34 years old)

One participant noted how staff can sometimes take a dominating role which, at times, does not give people enough involvement in their care.

"I was in hospital in 2003 and I did not like it all, it was very controlling and I thought the staff were too pushy and I can understand that they're probably off their feet and there's challenging behaviour and all that there, but sometimes, it didn't happen to me a lot, but I'd tend to find they'd talk to them as children."
(Female service user, 55-64 years old)

As a result, some people stressed that they would like to have a greater say in decisions that affected them, rather than having decisions made for them.

“Having a say in decisions about yourself.”

(Male service user, 25-34 years old)

“People should have the opportunity to make their own decisions.”

(Male service user, 18-24 years old)

One participant highlighted the benefit of working with staff who ensured they did not impose upon their life, but rather, understood their needs and when they wanted support and when they did not.

“I have a social worker who hardly comes near me. That’s a great thing, because the last one I had she never left my door...I can get him if I wanted him but that’s the good thing about my social worker. I don’t like people telling me what to do and being in my face, yes I have disabilities and I have illnesses but I don’t like people in my face. It’s nice in the shadows and they’re there when I need them but I don’t, I have disabilities and that there, but I expect to be treated like anyone else who goes to the health service.”

(Male service user, 25-34 years old)

Some participants stressed that staff need to be adequately trained to work alongside learning disability service users in a respectful manner, providing information in accessible formats to ensure they understand and help people make their own decisions.

“When the new doctors are coming out of university, part of their courses should be based around learning disability so they know what they’re dealing with before they’re coming out.”

(Male service user, 25-34 years old)

“None of these big hard words, I don’t know where they’re getting these words out of. Some of the medication they have, you don’t remember it. You have to spell it out to order your prescription.”

(Male service user, 25-34 years old)

“Staff working well, give people the right information. Do not patronise them and break down information. Have information in accessible formats for them.”

(Male service user, 18-24 years old)



Some carer participants identified the importance of building a good relationship with staff who listened to their views. Indeed, many carers felt that effective communication between staff and carers was essential within learning disability services. It was vital to have an open relationship with staff, where carers' views were listened to and valued. An example of good practice identified by some carers was when staff listened to their opinion and valued their expertise showing how simple, effective collaboration between staff and carers can alleviate pressures and contribute to more efficient and effective learning disability services.

"The staff were excellent but they were guided by us."

(Female carer, 45-54 years old)

"Staff couldn't have been any better, but led by me. To be fair they did look to me and say: can you guide us on this? It was great but that is not the norm."

(Female carer, 45-54 years old)

However, other participants highlighted that this was not always the case and expressed frustration that their views were not always taken on board and they were sometimes perceived as complainers.

"I didn't get met with much sympathy. In fact at the end they made me out to be a complainer...I explained that she had autism and they just made no allowance for it...I didn't feel that the health care was particularly sympathetic."

(Female carer, 25-34 years old)

"The bottom line is your sister has no speech; she has no voice so you should be listened to."

(Female carer, 45-54 years old)

One carer spoke about their frustration with the diagnosis process.

"We waited 13 years for a diagnosis of Autism, even though me and my partner knew. It means the child loses out on services he could have had all those years, and there's the 13 years of stress and anxiety on the family... Why, when the parents know there is a problem, do you have to wait?"

(Male carer, 35-44 years old)

Carers not having their views listened to can result in frustration, stress and anxiety for them, conveying how poor communication between professionals and carers can also impact negatively on the carer themselves.

"Carers views seem to fall on deaf ears a lot of the time."

(Male carer, 35-44 years old)

"They don't listen to you...They (staff) don't understand and don't want to understand."

(Female carer, 55-64 years old)

"It is down to someone's opinion and you know they aren't seeing the meltdowns... how do we go about getting it through?...You feel like bashing your head against the wall and you feel like: aahhh!"

(Female carer, 35-44 years old)

In some cases, it is fundamental that carers' views are considered and listened to by professionals, particularly when service users are unable to express their own views, as illustrated by some participants.

"The professionals need to listen to the parents and acknowledge that help is needed."

(Male carer, 35-44 years old)

"You know sometimes I get cross because we are caring for people with disabilities, yes they are our children but it affects our whole lives and has huge implications on our relationships with our husbands, our wives, our children and our friend...They should think well these are the experts."

(Female carer, 45-54 years old)

These examples show that simple, effective collaboration between staff and carers can alleviate pressures and contribute to more efficient and effective learning disability services. Some participants believe they are providing a vital role as a carer which saves the government money and as a result, some carers felt that there needs to be more effective communication with professionals, who should value their knowledge and expertise as carers.

"If they worked with us and it was supportive and preventative then it would save them money, instead of going back and back and back."

(Male carer, 45-54 years old)

However, other participants did identify the positive role HSC staff played in learning disability services. Some carers talked about how much they valued the support they received in their role as a carer. This included support from HSC staff offered to families, as well as support offered to the person with a learning disability. For instance, some carers identified the positive role of day centre staff.

“Day centre staff do a very good job; I personally would be lost without it...There’s a couple of staff who are very good and very supportive.”

(Female carer, age not given)

“Staff in the local day centre, the manager, he runs it very well and he’s very approachable and if there’s any problems you can go to him and discuss it.”

(Female carer, age not given)

This gave carers a break from their caring responsibilities. Indeed, knowing their loved one is in a safe, local environment enables carers to make the most of their free time.

Furthermore, some carers also highlighted the positive role of caring and understanding staff who help make things easier for both carer and service user.

“She would look up anything for you. She is really good.”

(Female carer, age not given)

“In the days of the learning disability nurse when I first started with the peg feeding I would be on the phone all the time and they were out like a shot. Every day, they were brilliant.”

(Male carer, age not given)

3.8 Joined up working

Joined up working was identified by some carers as something which was not working well within learning disability services.



- ▶ Lack of joined up working
- ▶ Carers have to repeat information
- ▶ Impact of this on service users
- ▶ Impact on care



Some carers expressed frustrations with a perceived lack of joined up, collaborative working between services and staff. Many carers indicated that they felt frustrated having to constantly repeat information, which they felt professionals should already be aware of from colleagues.

"You're passed from pillar to post."
(Female carer, 35-44 years old)

"You feel like you're starting over again with every new person that comes to work with your child."
(Male carer, 35-44 years old)

"There are so many departments not working together, they are working in isolation and there doesn't seem to be any joined-up working....Everybody just sees their wee bit and if you don't fit in that bit or this bit then you are just sort of left."
(Male carer, 45-54 years old)

These examples highlight that basic collaboration and joined up working is something which some carers felt is lacking between HSC staff and services. Some people believed that staff and services were not communicating with each other and this causes more problems for carers. For instance, one carer highlighted how a lack of joined up working led to problems with diagnosis.

“One person came to talk to get background details of our son, then a few weeks later someone different comes out and asks the same questions! I felt like saying, do you not talk to each other if you are on the same team? Nobody seems to talk to each other...It has taken all four members of the disability team to come out and see the family on separate occasions over the best part of a year...So you feel like you’re starting over again with every new person that comes to work with your child.”

(Male carer, 35-44 years old)

One carer suggested that there needs to be a more collaborative approach within learning disability services.

“We need a more collaborative approach to care.”

(Female carer, age not given)

3.9 Information

Information within learning disability services was also recognised as a key theme for carer participants, with many identifying the negative impact a lack of information had for them.



▶ Information from support groups



▶ Lack of information

▶ Negative impact of a lack of information that carers need



Many carers stated that they needed more information about a range of learning disability services which are available to them. Generally speaking, carers felt information was not easily accessible and it was left to them to source their own information.

“You just get steered in different directions and names thrown at you – he/she may help you. At the end of the day it is a long waiting list that you are on.”

(Female carer, 45-54 years old)

"Nobody has come to me, I have found everything out myself... this should be set down and coordinated for you, you shouldn't have to phone here and there and find out things from word of mouth."

(Female carer, 25-34 years old)

Some carers highlighted that other carers were their main source of information, in particular, through support groups they attended. They highlighted that attending support groups allowed them to meet with other carers who are going through similar experiences as them. It is in this context that carers were able to share their knowledge with other carers. For some carers, support from these groups and other carers may have proved vital, particularly for those participants who felt that they lacked information about learning disability services.

"We go to a few support groups. It is good to get feedback from other parents, you pick up different tips or advice on treatments, knowledge of events and stuff."

(Male carer, 35-44 years old)

"It is talking to other parents. Coming to groups like this and finding out what is out there."

(Carer, 45-54 years old)

As a result, one carer suggested that there should be more local support groups, for both carers and service users.

"I love the groups like this one, (I'd like) more support groups, better community support. There are not enough groups in the one area for different age ranges. I have to drive all over to get my kids to their clubs. Maybe if there was one venue, but had separate clubs for different age ranges?"

(Male carer, 35-44 years old)

It was evident that participants were unhappy with the lack of recognised Health and Social Care information available to them, with other carers acting as a main source of information. One participant discussed feeling in the dark following the birth of their child due to a lack of information provided. The participant described getting their initial diagnosis and being given some support leaflets, but after this, they were left to source their own information.

"They just give you this diagnosis and send you home and all you have is Google."

(Female carer, age not given)

In some cases, a lack of information can prove detrimental to the wellbeing of the person they care for. For instance, one carer stated that they were given an initial leaflet when their child was born and this was all the information they were provided with.

"I was given leaflets on Down's syndrome eight years ago when my daughter was born and that was it."

(Female carer, 35-44 years old)

Some carers noted that they would like a way to access local and relevant information. It was felt that this could help to alleviate some of the stress and pressure they face as carers.

"If you had a single website which listed all the services you would need, like where you could get funding or all the treatments you could try. A central point where you could get information. People don't know enough things that are out there."

(Female carer, 35-44 years old)

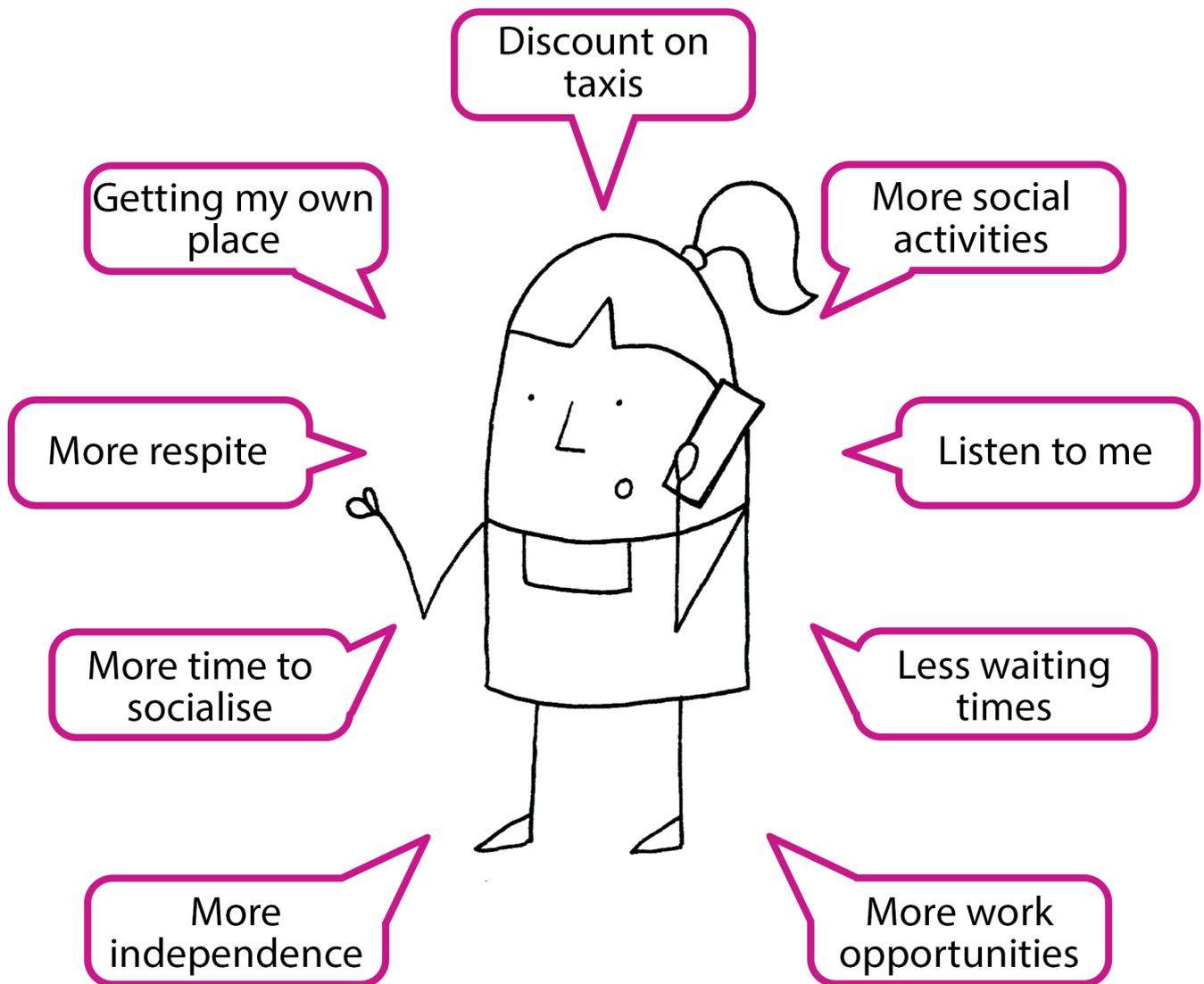
"You could have templates. Time is very precious so you could have templates of letters on the website – right I put her name in and we will send that off."

(Female carer, 45-54 years old)

3.10 Service users' priorities for change

As part of focus group discussions, service user participants were asked to name one thing they would change within learning disability services which would really make a difference to them. A summary of responses are detailed below in **Figure 3.1**.

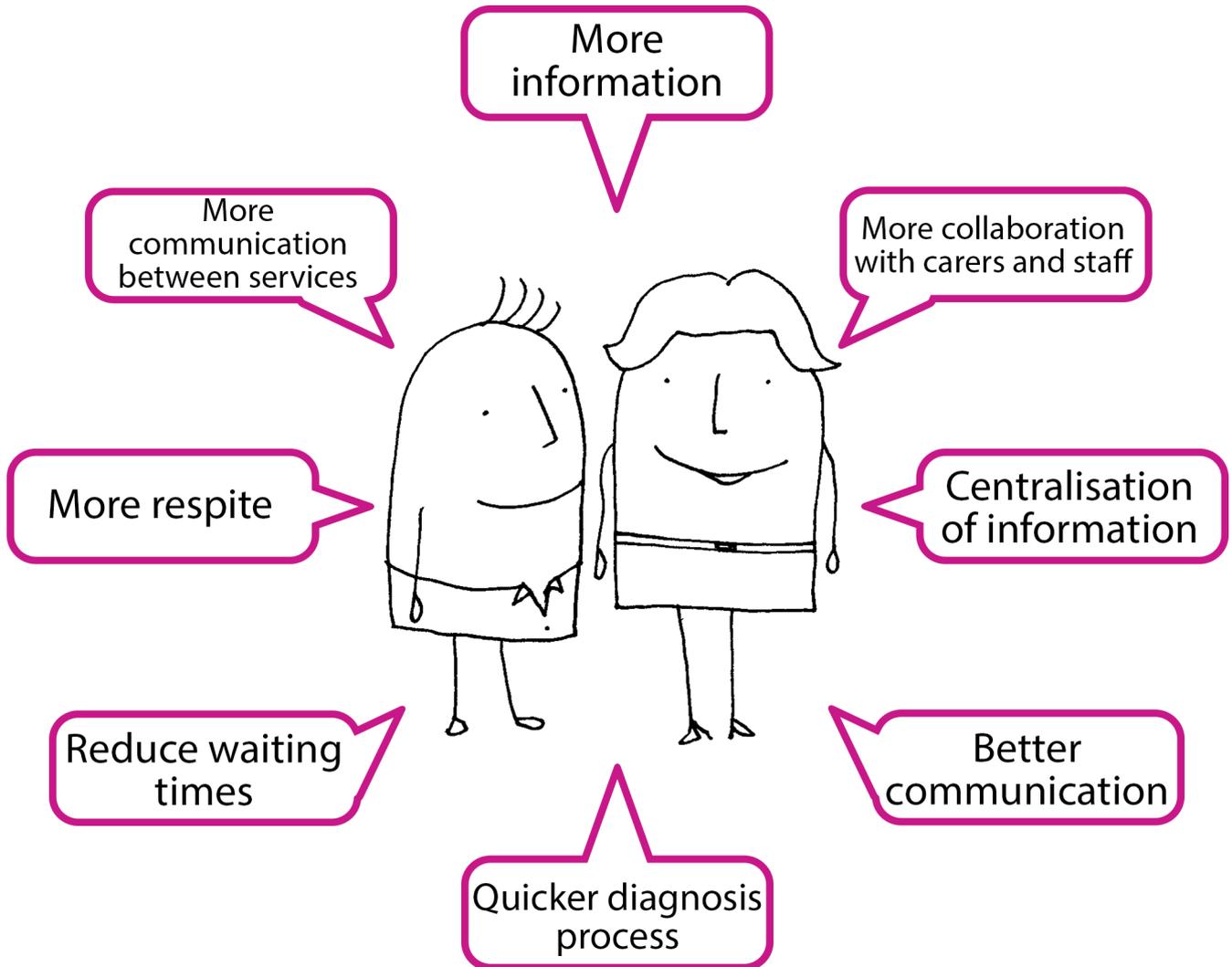
Figure 3.1: Service users' priorities for change



3.11 Carers' priorities for change

As part of focus group discussions, PPI officers also asked carers to name one thing they would change within learning disability services, which would really make a difference to them and the person they cared for. A summary of the responses given are detailed below in **Figure 3.2**.

Figure 3.2: Carers' priorities for change



4.0 Conclusion and next steps

This study of the views of 48 people with learning disabilities and 24 carers continues to highlight issues which really matter to people. The issues highlighted in this report are consistent with what people have told us elsewhere, namely the 'The People's Priorities'⁵ and 'My Day, My Way'.⁶ People want to see accessible and appropriate learning disability services that support service users to live as independently as possible. In this report, the people that we talked to also highlighted the importance of staff and coordinated ways of working. Whilst most participants in this study reported positive experiences of staff within learning disability services, service users in particular felt that staff did not always understand their particular needs. Carers also felt that services could work in a more joined up way, highlighting their frustration of having to constantly repeat information, which they felt professionals should already be aware of.

Service user participants also reported how day opportunities were important to them. Similar to what was found in the Bamford Monitoring Group report on day opportunities for people with a learning disability, 'My Day, My Way',⁶ choice, flexibility and independence were key aspects to day services which worked well. It is also clear from this report that people with a learning disability really value having a variety of activities to do during the week, be that college, work, volunteering, social enterprise schemes, day centres or clubs. The findings of this study support the observations made in 'Transforming Your Care'⁷ that learning disability services require community based, multi-agency, integrated approaches to fully meet the needs of those who use them.

A clear message in this study was that for people with a learning disability, family members and carers, respite and short break services are important to them and not working as well as they should. Availability and improved access to services were highlighted as issues for the people that we talked to. As with day services, respite/short breaks should be more flexible and able to meet the needs of all services users and their carers, as well as enabling individuals to be able to have more choice of respite services.

An information resource for people with a learning disability continues to be identified as a priority across the Patient and Client Council's reports in this area of care. There appears to be an 'information gap' as regards both day services and respite services - on many occasions, people with a learning disability, their carers and family members reported that they were simply unaware of the opportunities available in their local area.

The Patient and Client Council and the Bamford Monitoring Group would like to thank those that took part in this study. We will continue to review the issues raised in this report and will seek to influence decision makers and professionals working in Health and Social Care so that learning disability services are provided in ways that best suit the needs of the people who use them.

The Patient and Client Council therefore recommends that:

- ▶ The Health and Social Care Board should continue to implement fully the recommendations of 'My Day, My Way' with regards to day opportunities;
- ▶ The Health and Social Care Board should further develop and expand the provision of flexible respite services regionally;
- ▶ A regional Healthcare Passport should be adopted by all HSC Trusts; and
- ▶ The Health and Social Care Board should develop a single information resource for learning disability services including a directory of day services and respite services across Northern Ireland.

Appendix 1: References

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Appendix 2: Participant demographics

Demographics	Service users	Carers
Trust area		
Belfast HSCT Area	17	3
Northern HSCT Area	7	6
South Eastern HSCT Area	13	11
Southern HSCT Area	5	4
Western HSCT Area	6	0
Gender		
Male	26	4
Female	19	20
Not recorded	3	0
Age		
18-24 years	12	1
25-34 years	4	2
35-44 years	8	6
45-54 years	5	3
55-64 years	2	1
65 years old or over	2	0
Not recorded	15	11
TOTAL	48	24

Appendix 3: Topic guides

Topic guide - Service users

Section	Question / Action	Time (indicative)
Introductory Questions	<p>What do we mean when we use the word 'services'? Can anyone name a health and social care service for me?</p> <p>We want to hear from you about the services you use or have used in the past 12 months.</p> <p><i>Refer to drama and the services mentioned in it, if needed.</i></p> <p><i>If participants are still not clear – use prompt cards (as a last resort).</i></p>	10 mins
What is working well in learning disability services?	<p>What is working well in learning disability services?</p> <p>Please record the service(s) and what the person likes about the service e.g. college- I get to learn new things.</p> <p>Tell us what is good and why?</p> <p>If the person is still unsure about this question the following prompts may be useful:</p> <p>What do you do during the week? Do you work? Do you go to college? What do you look forward to most in the week?</p> <p>Record the services they mention and why they like them.</p> <p>Prompt the following options if needed: Day centres, college, job, social clubs, day opportunities, supported living, respite, resettlement from hospital.</p>	15 mins
What is not working well in learning disability services?	<p>What is not working well in learning disability services?</p> <p>Please record the service(s) and what the person does not like about the service e.g. day centre, I only go two days and I would rather go four days.</p> <p>Tell us what is not working well and why?</p> <p>Are you happy with your week?</p> <p>Is there anything you would like to do more of?</p>	15 mins

	<p>Is there anything you would like to do less of?</p> <p>Is there anything new that you would like to try? What is stopping you from doing this?</p> <p>Prompt the following options if needed: Day centres, respite, transport, college, resettlement, lack of information, work.</p>	
Tell us one thing you would change	<p>If you could change one thing about learning disability services what would it be?</p> <p>It could be anything- put down whatever you think would make your life better.</p>	10 mins
List of Priorities	Summarise priorities emerging from discussion	10 mins
Finally:	<p>Anything else people would like to add.</p> <p>THANK AND CLOSE</p>	10 mins

Topic guide - Carers

Section	Question / Action	Time (indicative)
Introductory Questions	<p>What do we mean when we use the word 'services'? Can anyone name a health and social care service for me?</p> <p>We want to hear from you about the services you use or have used in the past 12 months.</p>	10mins
What is working well in learning disability services?	<p>What service(s) are working well in learning disability services?</p> <p>Please record the service(s) and what the person likes about the service e.g. Respite - I get some rest time.</p> <p>Tell us what is good and why?</p> <p>If the person is still unsure about this question the following prompts may be useful:</p> <ul style="list-style-type: none"> ▶ As a carer, what services help you to cope? ▶ What does the person you care for do during the week? ▶ Do they work? ▶ Do they go to college? <p>Record the services they mention and why they like them.</p> <p>Prompt the following options if needed: Day opportunities, college, job, social clubs, day opportunities, supported living, respite, resettlement from hospital.</p>	15 mins

<p>What is not working well in learning disability services?</p>	<p>What is not working well in learning disability services?</p> <p>Please record the service(s) and what the person does not like about the service e.g. day centre, they are not open long enough for my son/daughter.</p> <p>Tell us what is not working well and why?</p> <p>Is there another service that would help you cope better as a carer? Is there anything stopping you from getting this service?</p> <p>Is there any service you would like more of?</p> <p>Is there any service you would like less of?</p> <p>Prompt the following options if needed: Day opportunities, respite, transport, college, resettlement, lack of information, work.</p>	<p>15 mins</p>
<p>Tell us one thing you would change</p>	<p>If you could change one thing about learning disability services what would it be?</p> <p>It could be anything- put down whatever you think would make your life, as a carer better.</p> <p>Link back to question above (something they don't like about the services) if required.</p>	<p>10 mins</p>
<p>List of Priorities</p>	<p>Summarise priorities emerging from discussion.</p>	<p>10 mins</p>
<p>Finally:</p>	<p>Anything else people would like to add.</p> <p>Any key points they would like to say to key decision makers in health and social care.</p> <p>THANK AND CLOSE</p>	<p>10 mins</p>

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