

Physical Disability Panels

Service users discuss their experiences of living with a physical disability and using adult social care services

June 2019

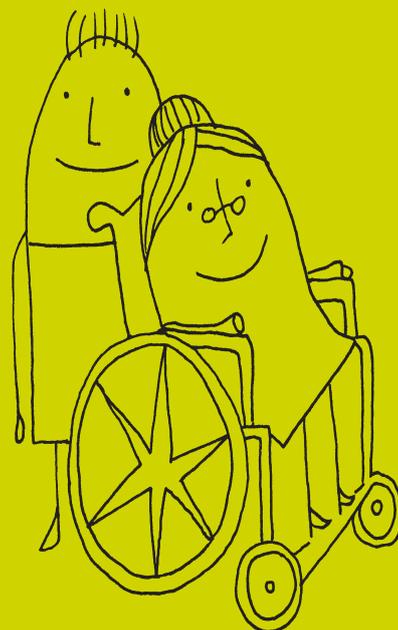
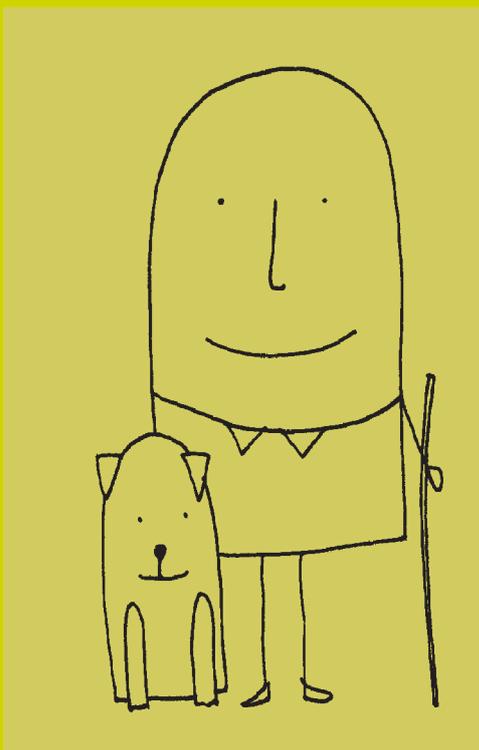


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Executive Summary

The purpose of this project has been to gather the views and perceptions of people who have either a physical and/or sensory disability and are aged 18-65 years in order to identify the key issues for them in accessing and using adult social care in Northern Ireland (NI). Information on the experiences of this particular group of individuals is limited; therefore, as part of the PCC's 2018/2019 business plan, it was decided that a scoping study should be undertaken with this particular group of individuals to inform the ongoing work on the reform of adult social care as demonstrated in the 'Power to People' Report.

The PCC's Personal and Public Involvement (PPI) team liaised with representatives from a variety of organisations that worked with adults with physical and/or sensory disabilities. Following consultation, a robust methodology was put in place to secure participation at a total of ten panels. The panel events were conducted at venues across the Province between June and October 2018. They included a total of 92 participants, made up of ten carers, 74 service users and eight staff who provided direct care for individuals on behalf of the organisations selected.

Domiciliary Care

In general, domiciliary care met the needs of the participants who used or knew someone who used the service. Two key issues were identified: inconsistency of care staff; and, the timing/duration of visits. In particular, participants reported that they would like more consistency of care in terms of having regular staff as opposed to many different staff, as well as having regular visiting times and an appropriate length of time for each visit. These are important issues to be considered by domiciliary care providers when designing and delivering person centred care.

Occupational Therapy (OT)

Some participants were in receipt of services from Occupational Therapy (OT); this service mainly involved assessments to enable panel participants to obtain equipment. Overall, participants were generally happy with the service they received from OT's and their assessment processes. However, the length of time they had to wait for equipment to arrive after the assessments had been conducted was reported to be too long.

Social Workers

Feedback was somewhat mixed with regard to participant experience of social workers. Whilst a few participants had no idea who their social worker was, or how to go about establishing contact if needed, others confirmed that they knew how to contact a social worker. Nonetheless, only a few people knew the name of their social worker. Participants who confirmed that they had contact indicated that their social worker had made them aware of certain things, which otherwise they would not have known. However, a few people stated that they would like to see their social worker being more pro-active in providing more information on what is available to them, rather than having to find out information for themselves.

Transport

The issue of transport within both rural and urban settings was raised by participants at most of the panels. Transport was identified as being pivotal in supporting people with physical and/or sensory disability to get to and from Day Centres or Resource Centres. Some participants described the difficulties they were currently experiencing in terms of buses not arriving on time, as well as having their payment methods changed; this further compounded the difficulty they encountered in successfully gaining access to transport. Some had reportedly lost access to their transport, making getting out and about extremely difficult for them. In contrast, those who currently had access to transport wanted to stress that they were happy with what was in place and hoped that this would continue in the future.

Family Carers

Many of the panel participants relied on family support and as a result did not access as much social care as they felt they would need to if they did not already have their family to rely upon. There was great appreciation amongst participants for the support of their families. It was felt there should be some form of legal recognition within Health and Social Care (HSC) of the level of family support in place, in order to offer family carers better support, both financially and socially. Particularly with regards to providing opportunities to give carers a much needed break.

Service Awareness/Access

There was a general lack of awareness amongst those with physical and/or sensory disabilities about what services were available to them. Most believed there were probably services available that they could be accessing but were not aware of them. Many felt that their social worker should be providing them with more information on services they could be accessing. Participants also felt there was a lack of services available with regard to physical disabilities and they reported feeling at a slight disadvantage compared to other disability groups.

Self Directed Support

Those who were currently using Self Directed Support (SDS), or had used it in the past, had mixed reactions to it; some liked it as it meant they had consistent carers and more flexible timings. However, others described it as “a hassle” and “more stressful” particularly when carers let them down. Some participants also reported having encountered difficulties in obtaining information, with some noting that the guidance they received was poor. Participants also highlighted the need for good management skills in order to facilitate the payments as the amount of administration involved was described as being too difficult for some. Some felt that for SDS to work properly it needs to be directed by the service user rather than by HSC Trusts.

Service User Input

Service User input was noted to have improved over the past number of years; panel participants felt it was important that this continues.

Additional Support

Sometimes the social care support offered to those with physical and/or sensory disabilities is not adequate to meet individual needs. The consensus, specifically amongst those who were visually impaired or wheelchair users, was that they wanted more support to help them be more independent and permit them to carry out what they perceived to be normal activities.

Technology

Most of the panel participants used different aspects of technology to support them in their daily lives. However, there was a limit to how much was provided to them free of charge; if anything further was required it was up to the person to pay for this themselves. This situation was often made more difficult because most of the equipment was reported to be expensive. The cost of equipment/technology was therefore a major barrier to people accessing it. It was believed that companies who make specialist chairs and other equipment specifically for those with disabilities were charging extortionate prices. This made it more difficult to get access to items on the NHS and even more difficult for individuals to purchase equipment themselves if they were not entitled to it on the NHS.

Education

Those who were visually impaired and/or wheelchair users were keen that others needed to know what it was like to live with visual impairments or use a wheelchair. They highlighted the importance of training to enable others to understand the difficulties that these particular groups of people face in their daily lives.

Care Workers

Domiciliary care, delivered by care workers, was highlighted as a vital service to enable people to move back home after a period in hospital. However, whilst participants felt that care workers received low pay they believed that enhanced pay would make for a better care system and would act as an incentive for care workers to stay in their role as opposed to moving on.

Support for Veterans

Due to issues with trust and sharing their service history, this group of individuals would like a central point of contact to receive care and long-term support.

1.0 Introduction

The International Classification of Functioning, Disability and Health (ICF) has defined disability as an umbrella term for impairment and restriction in activity and participation of daily living¹. This can then be further described as the individual's interaction with their given condition and their personal and environmental factors around them¹. Put more simply by the Equality Commission for Northern Ireland, disability is *"a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities"*².

As of 2018 about 15% of the world's population has a form of disability with around 110 million to 190 million adults having significant difficulties in functioning. It is also said that these rates will increase and continue to do so as a result of an ageing population and increases in chronic conditions³. In the future it is thought more of us will live longer lives despite ill health or disability. Conditions which in the past were thought to be untreatable are now being managed and younger disabled people can expect to live longer, more fulfilled lives than previous generations⁴.

1.1 Context in NI

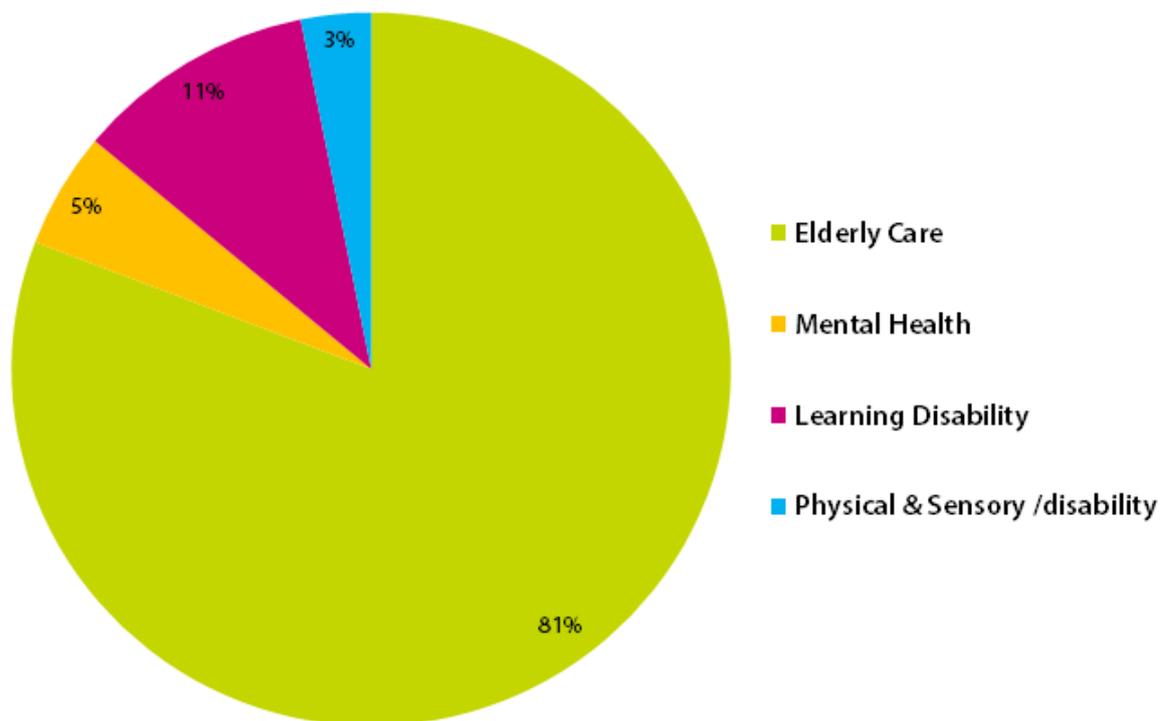
Regional and local statistics have previously confirmed that Northern Ireland (NI) is one of the most deprived areas within the UK with high levels of disability, poverty and unemployment⁵. In 2012, the National Audit Office combined data on various factors associated with health needs. These included population age, levels of disability and wealth. It found that NI had the greatest average need per person compared to the rest of the UK⁶.

The 'Power to People' report found that in NI in 2017, the rate of disability was 67% in those 85 and over compared to 5% among young adults⁶. The Department of Health (DOH) analysed several statistics in their Physical and Sensory Disability Strategy and Action Plan 2012-2015. Using statistics published by the Northern Ireland Statistics and Research Agency (NISRA) in 2007, they found that 18% of all people living in private households within NI have some degree of disability, with a further breakdown of 21% of adults and 6% of children living with a disability at that time. They also found a greater prevalence of disability in females (23%) compared to males (19%) and that the likelihood of disability increases with age⁷.

Recent data published by the DOH found that only a small proportion of the disabled population access Health and Social Care (HSC) services. The number of individuals in contact with the HSC over the past 5 years (2013/14 - 2017/18), with regards to their disability, has decreased for those that are physically disabled (-10%). In those with sensory disabilities i.e. visually impaired and hearing impaired, this has increased (+10% and +6% respectively)⁸.

As of June 2018, of the 11,781 care packages in Northern Ireland nursing and residential homes, over four fifths (81%) were in the Elderly Programme of Care (POC)⁸. This means that a large proportion of care packages currently available are invested in those over 65 years of age, with only 3% catering to those with physical and sensory disability⁸. (See **Figure 1**)

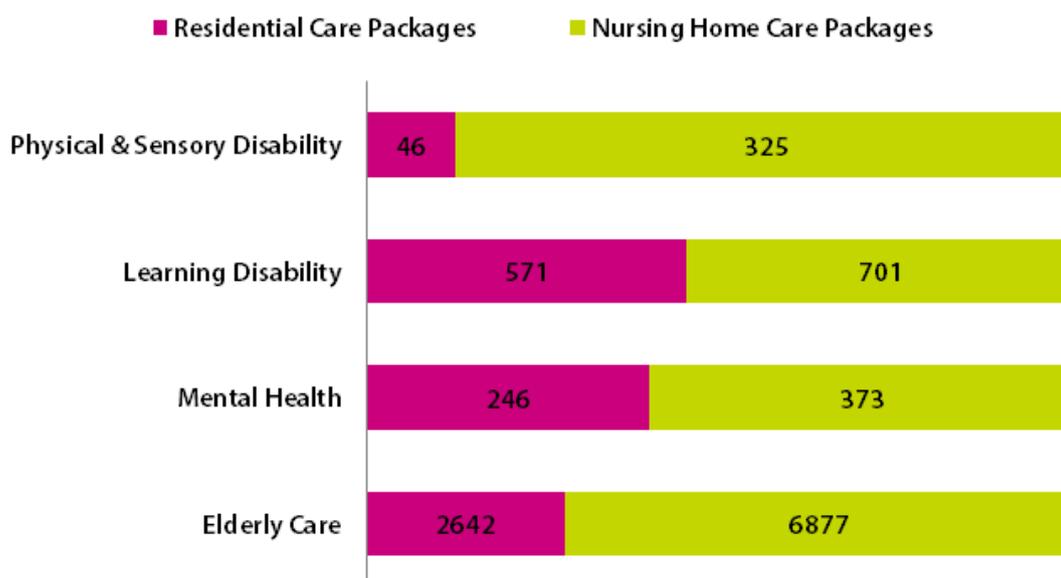
Figure 1: Programme of Care of residential and nursing home care packages in Northern Ireland 2018



Source: Department of Health, Statistics on Community Care for Adults in Northern Ireland 2017/2018.

This is further reflected in the DOH report of adult social care statistics which found that those with physical and sensory disabilities had by far the lowest uptake of care packages within both residential and nursing home settings. There were 46 residential care packages for those with a physical or sensory disability compared to 2,642 residential care packages for elderly care.

Figure 2: Care Type and Programme of Care in Northern Ireland 2018



Source: Department of Health, Statistics on Community Care for Adults in Northern Ireland 2017/2018

Domiciliary care statistics published by the Department of Health in December 2018 show that the HSC Trusts provided domiciliary care services to 23,409 clients, with 11% of those having a physical disability⁹. Further to this, there are 8,771 clients in NI receiving intensive (six or more visits and more than ten contact hours during the survey week) domiciliary care services, 12% of which were classified as having a physical disability⁹. Sensory disability was not referenced in this report; therefore, figures for those with a sensory disability using domiciliary care services in NI are not known.

Each year in Northern Ireland, HSC Trusts spend over £900m on adult social care, which includes services like day care, domiciliary care, residential care and nursing home care¹⁰. These services are vital to the many thousands of people and their families who receive them and will become important in the future with the rise of the ageing population. *“However, public knowledge and understanding of adult social care is limited: what it is, how to access it, who is eligible and how it is paid for”*¹⁰. As a result of this lack of knowledge and understanding, there is also a lack of knowledge of the challenges. This means the system needs to change to support the ever widening gap of what is available and what is needed¹⁰.

In order to address this, in December 2016 the then NI Health Minister appointed two leading experts in social care to form an expert advisory panel. The purpose of the panel was to provide an independent perspective on possible solutions to meet the challenges facing the adult care and support system in NI and to develop proposals to reform the system¹⁰.

The Expert Advisory Panel undertook extensive engagement in the form of a call for evidence, workshops, site visits and meetings as well as discussion with a Service User and Carer Reference Group. As a result of this engagement the ‘Power to People’ report was published in December 2017. It includes the panel’s 16 proposals on how to reform the adult care and support system in NI⁶.

The Reform Project Board and Project Team are currently developing an action plan based on the 16 proposals. This will outline the proposed way forward for the reform of adult social care and support, and will form the basis of an extensive public consultation in 2019⁶.

1.2 Our Aim

As shown in **Figures 1 and 2**, uptake of social care for those with a physical and sensory disability is much lower than other programmes of care. Information on the experiences of this particular group of individuals is also limited. Therefore, as part of the PCC’s 2018/2019 business plan, it was decided that a scoping study should be undertaken with this particular group of individuals to inform the ongoing work on the reform of adult social care as demonstrated in the ‘Power to People’ Report.

Our aim for this study was to engage with individuals who have either a physical or sensory disability and are aged between 18 and 65 years. The objective was to find out what the key issues are for them with regard to having a physical disability in health and social care.

The findings from this scoping study will be shared with key decision makers to help inform the future of adult social care services.

2.0 What we did

The PCC 2018/19 Business plan includes the following objective:

The Patient and Client Council will undertake a project that will inform the ongoing work to reform adult social care. This project will comprise of the following:

- a) A project to seek people's views on how to progress the findings in the report, 'Power to People', including social isolation and the funding of domiciliary care;
- b) A series of panels with physically disabled adults to inform the reform process;**
- c) A targeted social media campaign to capture views on Self Directed Support; and
- d) Work with the DoH to ensure the implementation plan is co-produced with service users and carers.

There are four specific elements to this objective; however, this report focuses specifically on **Part b**.

2.1 Overview of our approach

It was decided that facilitating panels* for adults with physical and sensory disabilities (aged 18 – 65 years) would be the best method to use to capture a wide range of views and experiences from a large number of people in a relatively short space of time.

A number of different organisations, which worked with adults with physical and sensory disabilities were contacted to set up a total of ten panels. These were conducted at venues across NI between June and October 2018. **Table 1** gives an overview of the organisations where panels were conducted, the Trust area they relate to, and the date of the visit.

Table 1: Overview of organisations by Trust area

Organisation	Trust Area	Date Visited
RNIB & Guide Dogs NI	Belfast	28th September 2018
Regional Veterans Group	Belfast	16th October 2018
Woodlands Day Centre	Belfast	18th October 2018
Cedar Foundation	Northern	19th September 2018
Omnibus Partnership	South Eastern	7th August 2018
Ardarragh Resource Centre	South Eastern	10th September 2018
Cedar Foundation	Southern	4th September 2018
Willowbank Resource Centre	Southern	26th September 2018
Millvale Resource Centre	Southern	19th June 2018
Wolves Wheelchair basketball Team	Western	6th September 2018

* A sample of people representative of a particular population who have agreed to take part in a group discussion. Participants who are unknown to each other are brought together, in a particular neutral location, for the specific purpose of discussing a particular topic or issue.

A total of **92** participants took part in the panels, including 10 carers, 74 service users and 8 staff who care for individuals at the organisations which we visited. **Table 2** below provides a breakdown of the number of carers and service users by gender at each panel.

Table 2: Overview of participants

Organisation	Carers		Service Users		Staff		Total
	Male	Female	Male	Female	Male	Female	
RNIB & Guide Dogs NI	-	-	4	5	-	-	9
Regional Veterans Group	1	1	3	-	-	1	6
Woodlands Day Centre	-	1	8	3	-	-	12
Cedar Foundation (Northern)	-	-	4	2	1	-	7
Omnibus Partnership	3	1	2	3	-	-	9
Ardarragh Resource Centre	-	-	5	5	2	-	12
Cedar Foundation (Southern)	-	-	4	4	-	1	9
Willowbank Resource Centre	-	-	5	2	-	1	8
Millvale Resource Centre	-	-	5	6	-	2	13
Wolves Wheelchair Basketball Team	1	2	3	1	-	-	7
Total	5	5	43	31	3	5	92

Table 3 outlines the number of carers, service users and staff which we spoke to in each Trust area.

Table 3: Breakdown of participants attending panels by HSC Trust area

Trust Area	Carers	Service Users	Staff	Total
Belfast	3	23	1	27
Northern	-	6	1	7
South Eastern	4	15	2	21
Southern	-	26	4	30
Western	3	4	-	7
Total	10	74	8	92

2.2 Context of the panels

There were two members of PCC staff at each panel. The panels consisted of an open discussion with the participants, which focused on their day-to-day experiences of living with a physical and/or sensory disability and using adult social care. It explored what the key issues are in health and social care for people living with a physical and/or sensory disability.

One of the aims of this scoping study (as outlined in **Section 1.2**) was that this project should inform the ongoing work on the reform of adult social care as demonstrated in the 'Power to People' report. Therefore, when developing the topic guide, the aforementioned report was taken into consideration and questions around self-directed support and wider support structures in particular were included in the topic guide specifically in response to proposals within the 'Power to People' report (see **Appendix 1** for full topic guide).

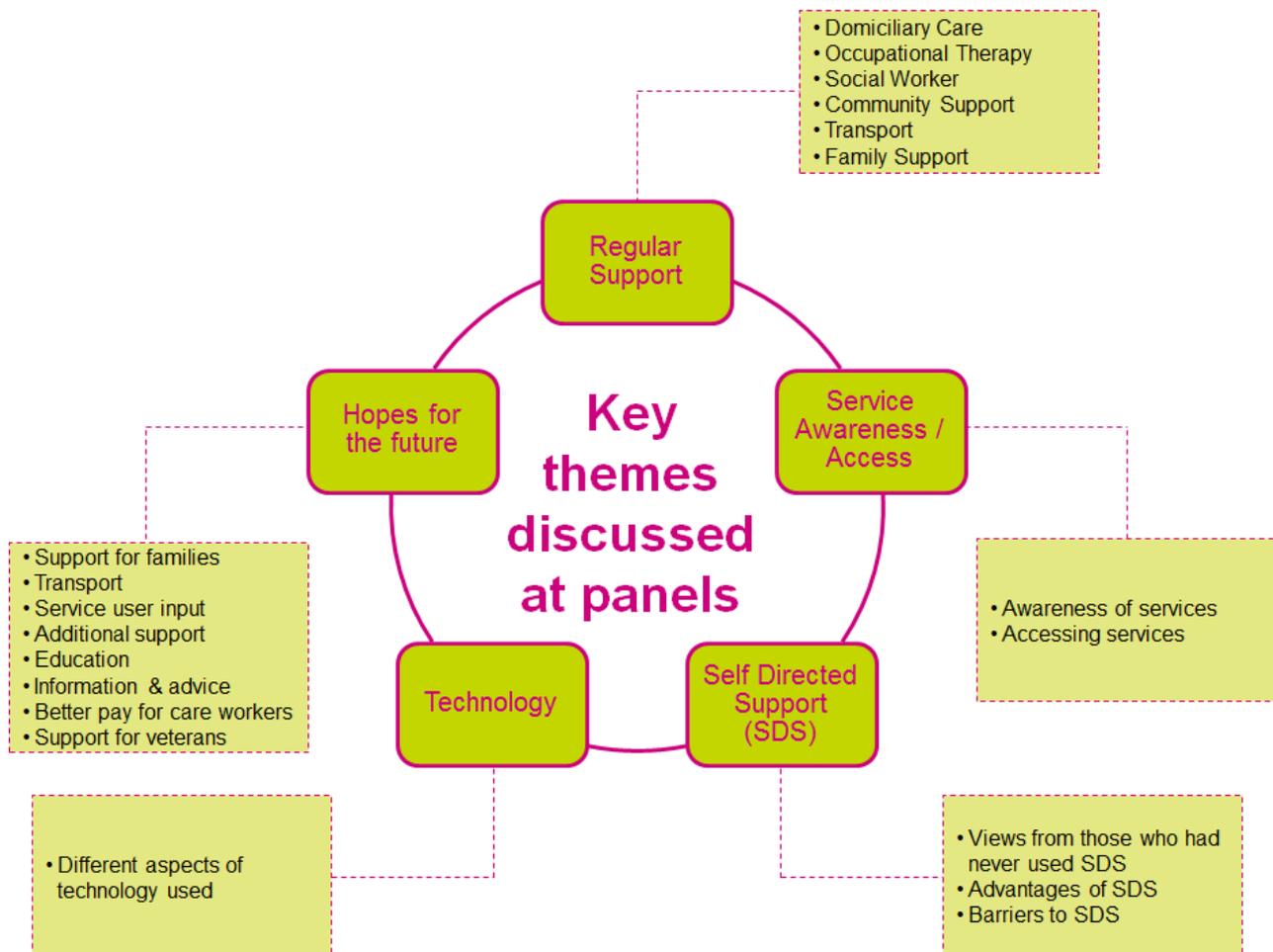
2.3 Reporting

This report aims to reflect the views and opinions of all panel participants on their experiences of living with a physical/sensory disability and the key issues these individuals face with regards to adult social care. It is important to note that whilst this report takes into consideration the views of the 92 participants consulted, it does not purport to be fully representative of the views of the wider population base living in Northern Ireland with a physical and/or sensory disability.

Such is the nature of qualitative research, the content of this report gives a synopsis of the type of issues which affect people living with a physical and/or sensory disability. Where points have been raised by people with issues relating to their specific disability, this has been noted in the report. Given the nature of the group discussions and nature of qualitative research, it has not been possible to assign numbers, percentages or weightings to quantify the numbers of people who raised specific issues.

The findings are detailed in the following chapters which focus on the key areas which emerged from the discussions at the panels. Each chapter provides an outline of the views provided by carers, service users and staff with regard to each of these areas. **Figure 3** provides an overview of the key themes discussed at the panels.

Figure 3: Overview of the key themes discussed at the panels



3.0 Regular Support

Proposal one set out in the 'Power to People' report outlines the value of social care and the need for transformational change. It also highlights the need for leadership responsibilities for the adult care and support system to be made more explicit¹⁰.

This chapter describes the support which those with physical and sensory disabilities receive on a regular basis and highlights the importance of the services obtained. Within the panels participants were asked to give an overview of the type of support they received on a day to day basis and the following areas of support highlighted in **Figure 4** were reported by the panel participants. These six elements of support are discussed in the remainder of this chapter.

Figure 4: Support used by participants on a regular basis



3.1 Domiciliary Care

Some of the panel participants were currently using domiciliary care services. A few had used the services in the past and were able to comment on their previous experiences. However, the majority of participants did not currently avail of domiciliary care.

Those who accessed domiciliary care generally had carers coming in either twice or four times a day. The carers helped them to get out of bed, washed and dressed them, gave them their meals, and then put them to bed again in the evening. In many cases, the care package was initiated by a Health and Social Care (HSC) Trust as a result of an individual being in hospital and needing a care package to go home.

Whilst not everyone accessed the domiciliary care services, many of those who did, had been in receipt of this care for many years. There were a number of issues which they raised with regards to the care received. Some participants reported that in their experience the care received in the past was much better. It was felt that the care received today was less about what people need and more about what the system pushed their way.

"The domiciliary care packages that they are working with now... [they are] just the very basics you know... get you up, get you dressed, get you a bite to eat and that's about it."

(Male, Service User)

A few people commented that whilst they did not want to have to receive domiciliary care services, they recognised the importance and value of this service. It allowed them to return home from hospital much quicker or relieved their loved ones of some of the workload.

“It means an awful lot to me, because if I didn’t have those ladies coming in to me, my husband would have to shower me.”

(Female, Service User)

“It’s either that [homecare] or you stay in hospital for a period of weeks and I think most people would rather be in their own homes.”

(Male, Service User)

Panel participants who accessed domiciliary care were generally happy with the care they received at home. Participant comments would suggest that whilst the service met their needs it is not designed around what they would like and improvement is needed in this area. For example, the service may meet service user needs with regards to getting an individual out of bed and washed and dressed every morning, however, they would like to be able to choose the time the carers arrive or at least know what time they are expected, as well as having consistent carers so they know who to expect.

The above example highlights two of the main concerns which arose throughout discussions with groups where domiciliary care was accessed; inconsistency of care staff and the timing of the visit. These issues are explored further in the next few paragraphs.

Inconsistency of care workers was an issue that was raised a number of times with regards to domiciliary care. Different carers were calling and the participants reported that they never knew who would be coming to see them each day. They indicated that they preferred to know who was coming rather than waiting to see who turned up. A few participants reported seeing a significant number of different carers in a short space of time.

“There’s no continuity, it could be anybody... I know it will be a pool of workers, but you don’t know out of ten workers who is coming in the morning.”

(Female, Service User)

“You don’t want just anybody coming in and helping you dress or get showered and when I had carers at the start anybody could have come in and you didn’t know who was coming in the door the next morning.”

(Female, Service User)

“It’s supposed to be a team of four carers, but I only had carers for six weeks and I had 22 carers.”

(Male, Service User)

The timing of the carers’ visits was also a common issue, with participants reporting that carers came at different times each day. This was mainly due to delays with other service users or being unable to

find the participant's home as carers no longer have set clients. This was an issue particularly for those participants who had to wait until the carer arrived before they could get out of bed, as they were never sure what time they would be getting up in the morning. Similarly, when it came to bedtime, participants reported that they were restricted to the times the carer came to put them to bed.

"The only thing that I didn't like is that you have to go by their times, so I was put to bed at 8pm in the evening for two years which isn't ideal. You are slotted in where it suits them and I understand that but... you're a young adult and you are put to your bed at 8pm every night. I'd a wee boy who was staying up later than I was."

(Female, Service User)

As well as the timing of the visits, the length of time the carers spent with participants was reported as not being adequate. A few panel participants reported that in the past visits would have lasted up to one hour. However, they felt that nowadays the visits are rushed and carers are given unrealistic timescales. Even though carers are given 30 minutes for each person, it seemed this did not include travel time. Therefore, the person being cared for does not receive the full 30 minutes. Panel participants recognised that this was not the fault of the care worker but the wider health care system and the budget allocated for domiciliary care services.

...the amount of time allocated to look after my needs... help me out of bed in the morning... for my hygiene needs, for my dressing needs and to get part of my breakfast is totally inadequate... it's not the domiciliary care workers fault nor is it the occupational therapists, it is the system that they are working under"

(Male, Service User)

"... even the actual times, you're given 15 minutes to get showered, that's you out of bed, into the shower out of the shower dried and back in bed, it is crazy like... you know you're lying in your bed 11 hours and then you're up and you're sling shot from the door, straight in and out like."

(Female, Service User)

One staff member who had previously been a care worker in the community, felt that there had been so many budget cuts it had left him/her incapable of completing his/her job.

"...the carers can no longer provide tasks for you, to do the likes of like your chores, like your washing because there wasn't time... so that is being slashed and cut and it's the carers then that have to take the flack for it because we can't provide the service."

(Female, Staff Member)

3.2 Occupational Therapy

Some participants were receiving services from Occupational Therapy; this service mainly involved assessments to enable panel participants to get equipment. Participants were generally happy with the Occupational Therapists (OT) and their assessment process. However, the length of time they had to wait for equipment after the assessment, was reported to be too long. For example, one person needed a hoist for the carers to get them out of bed. The hoist was not delivered for 13 weeks and the person was left in bed until the hoist arrived. Others reported long waits for equipment such as wheelchairs, which meant they either had to stay in hospital or come home and be immobile.

One person was extremely thankful for the help of the OT in their rehabilitation and for having been pointed in the direction of the Cedar Foundation. He/She felt that this had a major positive impact on recovery.

“When my mother was ready to come out of hospital, a wheelchair had been ordered for her but it wasn’t available. If we had not been able to get one from the Red Cross she would have been months in hospital.”

(Female, Service User)

“I was scared of coming out [of the house] now I’m on the table talking to people and I do believe personally if we hadn’t had the help from the OT from the start and the Cedar Foundation we would still be under the table and that help was just mighty, they got us help, work placements and training courses for us, got us socialising and different things and the difference it made has lifted our confidence up.”

(Male, Service User)

3.3 Social Worker

There was a mix of responses with regards to social workers. A few participants indicated that they had no idea who their social worker was or how to contact them if they needed one. Others knew how to contact a social worker when needed whilst only a few people reported that they knew the name of their social worker.

Those who had contact with their social worker indicated that the social worker had made them aware of certain things which otherwise they would not have known about. A member of staff at one of the resource centres stated that most people would come to them through a social worker’s recommendation. However, some participants felt that the social workers should be providing them with more information on services they could be accessing rather than having to find out for themselves.

“At that time my social worker identified what my needs were by speaking to me... the social worker, who was really good put me in the right direction and got other things set up... There is a major lack of knowing what to do

if something happens... and knowing what your rights are in respect of that. Therefore, people follow whoever takes them down a particular path. If that person doesn't know exactly what they are doing you are lost."

(Male, Service User)

On the whole, panel participants held similar views to the Expert Advisory Panel in the 'Power to People' report in which a proposal (number four) focuses on the concept of a social worker-led Community Navigator role, which should be available to every locality in NI¹⁰.

3.4 Community Support

One of the key themes that emerged throughout all ten panel discussions was the importance of the service provided. Specifically this included the support the service users all received from their different Day Centres, Resource Centres, Service User Groups (i.e. the different groups which we conducted the panels through). Those who attended Day Centres and Resources Centres generally did so on a regular basis with some attending up to five days a week whilst the majority were more likely to attend once or twice a week.

Some participants used these groups as a respite service to give their family members, who provide a lot of care, a break. However, the majority of participants used the services as an avenue to get out of the house, meet new people and take part in activities. It was highlighted by some participants that it was nice to be able to go somewhere where everyone else is in the same situation. In such a setting they felt comfortable talking to other participants as they understand what they are going through.

"...it is [Day Centre] more a home because we are knitted here together, it is more personal and each person knows each person."

(Male, Service User)

"Our heads would be fried without this kind of joint... it's kind of a way out for a bit... but then about five or six hours later it's back home to normality again, you know."

(Male, Service User)

"I'm actually learning how to do a lot of things, like woodwork, and learn different things every day, and see different things every day, whereas if you're sitting in the house, you're looking at the four walls. You are actually out meeting new people, and talking to people, it's brilliant, it's a good wee centre, I think very, very highly of it, you know."

(Male, Service User)

Most of the participants were extremely happy with the services provided and enjoyed the time they spent at the centres and the activities that they were involved in there. Some participants reported that when they had come to the service initially, they were very withdrawn, but as a result of peer support and different activities provided for them, they have gained more confidence.

“That’s the peer support training rubbing off, we wouldn’t have said boo to a goose, a lot of us have done it and it’s great.”

(Male, Service User)

“...the service that they give here [Day Centre] is tremendous... they couldn’t have helped me anymore, and I think very highly of them. If they can help you, then they will do that, they will actually go out of their way to do that, to help you.”

(Male, Service User)

3.5 Transport

Transport was a key issue discussed in many of the groups and one which impacted those living in both rural and urban locations. The participants who attended Day Centres or Resource Centres relied on community transport being available to them to get to these facilities. Most of those who were in attendance at the Day Centres used community transport to get there. According to panel participants, they are allotted a certain amount of community transport each week and once they have used their slots, they do not get anymore. Many of the participants could not use public transport and therefore relied heavily on the community service.

In one particular group, the service that was being used had changed their payment method. Previously when using the bus the person paid the bus driver £4.50; however, this was changed as the bus company felt the bus drivers were handling too much money. The new approach for those using the service is to purchase a postal order instead. This has caused a lot of problems for those using the service. It means they have to either remember to get the postal order, if they are physically capable of doing so, or rely on someone else to get the postal order for them. This was felt to take away some of their independence.

“A lot of them try to be extremely independent which is brilliant, but that takes away their independence because they are having to ask other people, ‘can you get that postal order for me?’”

(Female, Staff Member)

It was perceived by participants that part of the problem was that there was no competition for this particular bus company. Therefore participants believed the company could do what they wanted. Participants complained that buses were turning up either late or early and the driver is not allowed to get off the bus to help them. It was felt that those using the service either had to put up with it or not use it. One participant gave up using the service as he/she was being charged when the bus turned up early and he/she was not ready as the carers had not arrived and the bus would not wait.

“Like they would give you a time and then they didn’t turn up at that time. They would have come either half an hour earlier when my carers hadn’t been and I was getting charged then for that run even

***though I didn't get the run because they didn't wait. Away they went.
You know and then I got billed for a run that I didn't even book."***

(Female, Service User)

Transport was reported as an extremely important part of social care because without it participants are unable to leave the house and go to their various groups, Day Centres, Resource Centres etc. which in so doing, facilitated service users to engage socially.

3.6 Family Support

Family support was also seen as extremely important to panel participants. Many of those who did not receive social care support reported that they received most of their care and support from family members and relied heavily on them. Indeed, for some, they relied so much on family members, that if they did not have them to help out they would have needed to avail of adult social care services.

We spoke to a panel of veterans who explained that the wives of ex-military personnel are in essence their fulltime carers and they do not normally access social care services. Due to their background, they can have issues with trusting people and others knowing their history. In some cases the wives have had to give up employment to become fulltime carers for their husbands, but do not get carers allowance for this.

"Lots of the guys are cared for by their wives... speaking for myself and a couple of the other guys I know, their wife is basically their carer now who takes to do with all their medication and their basic hygiene... some guys wives have had to leave their jobs because they have got their husband who has got this condition... they won't apply for carers allowance because they don't even know if they can get it... and they can't put down they are caring for their husband because he is ex-military."

(Male, Service User)

Family carers are described as "vital partners for social care" in the 'Power to People' report and similarly to the panel participants, the report acknowledged the fact that the caring role can be difficult and lonely and carers feel out of sight, undervalued and neglected. The Expert Advisory Panel has proposed that the rights of carers are put on a legal footing and that a strategy to bring them into the heart of transformation of adult social care is adopted¹⁰.

4.0 Service awareness/access

Overall, there was a lack of awareness amongst panel participants about what services are available to them. There was a strong realisation that there were probably services available that they could be accessing but were not aware of. The remainder of this chapter explores these issues further.

4.1 Awareness of services

Most of the panel participants felt that there was a lack of awareness amongst those with physical and sensory disabilities about what services are available to them. They realised that there were probably services available that they could be accessing but are not aware of.

“It is access and knowledge, the communication is not there to let people know what services are available... They [Veterans] haven’t got a clue about who to turn to. It’s the same for benefits and the adult social care side, they don’t know who to approach to get these aids in their house or even what is available for them.”

(Male, Service User)

When asked where they would go to find out information about services, the most common reply was to speak to someone at the Day Centre/Resource Centre they attended (either a member of staff or other service users) or contact a social worker. Their reason for this was that this is where they had received information about services previously. A few of the participants suggested they would speak to an Occupational Therapist, the Citizens Advice Bureau (CAB), an MLA, or look on social media.

From the discussions it is clear that the majority of participants who attended Service User Groups, Resource/Day Centres received most of their information about services from this source. This was either from members of staff at different centres or through word of mouth from other service users or social media. Only for these services, participants would not have the knowledge of the range of services available to them.

“Only for these guys [Service User Group] I wouldn’t have known anything. I don’t know what I would have done.”

(Female, Service User)

“People access more information from organisations like Cedar, the MS society, you know what I mean there’s an awful lot of information from charitable organisations rather than statutory organisations and there needs to be some sort of central point you can go to for information.”

(Male, Service User)

“There’ll be several organisations but you’d be depending largely on your social worker to tell you exactly what she/he feels you’d be entitled to.”

(Male, Service User)

“We have found from this group... we would actually talk to each other and go ‘how did you get that?’ or ‘do you know about that?’”

(Male, Service User)

Whilst some people had received information from their social worker, it was felt that social workers should be providing more information on services and there should be a central point to go to for information. It was reported that there is no real clarity or clear route for people to tell them where to go for services. If people do not know what is available, they are not aware of what to ask for. Participants would like somewhere they can go to find out what is available to meet their needs.

A few people suggested that hospital staff and GPs should provide information on services, as this is generally the first port of call for many people. However, from their experiences it was felt that Trust employees do not always appear to have sufficient knowledge. Different information was reported by participants as being given to different people.

“Just having somebody to direct you on the right path as such.”

(Male, Service User)

“There is a major lack of knowing what to do if something happens. There is a major lack of knowing what your rights are in respect of that. Therefore, people follow whoever takes them down a particular path. If that person doesn’t know exactly what they are doing you are lost.”

(Male, Service User)

When the issue of making a complaint was raised, the consensus in one group was that people would be afraid to make a complaint about the service they receive in case it affected their care. However, other panel participants said they would talk to either their GP, care worker, social worker, local politician or a member of staff at the Resource Centre/ Day Centre they attended.

“I have a problem at the minute and I don’t know what way to deal with it, to go to the team leader or to go to my social worker because this one girl I’m afraid of her getting back to me and taking it out on me and reporting me.”

(Female, Service User)

“If you’ve any problems or you think somethings gonna worry you, all you have to do is ask one of the members of staff here [Day Centre].”

(Male, Service User)

4.2 Accessing services

A comment that was raised in a few of the panel discussions was that there was a lack of services available with regard to physical disabilities and participants felt at a slight disadvantage compared to other disability groups.

“For us in physical disability the services, like we want to live as normal a life as possible... That’s why we are here playing sport, doing things that everybody else would see as normal... Those type of services don’t really exist, so we have relied on other agents like DSNI (Disability Sport Northern Ireland) to set this [the basketball group] up, like the Trust isn’t setting up those types of services, whereas say you had a brain injury there are services for that or autism. It’s quite specialised if you know what I mean, they look at certain pockets and I know everything is money, that’s obviously a driver but I think we are sort of left to find our own way... and try to get through it you know.”

(Male, Service User)

A perception noted in one group was that services for those with learning disabilities are much better than the services for those with physical disabilities. For example, it was suggested that there is supported living accommodation for those with learning disabilities but nothing similar for people with physical disabilities.

“Learning disability seems to be the big winner and physical disability just seems to stay quiet because they are just happy they have got something.”

(Female, Service User)

A few panel participants felt that support could be accessed quicker if the person is in hospital. Home support was more likely to be provided in this scenario to allow the person to go home and “free up a bed”. It was believed that accessing care and support at home was more difficult under other circumstances; this was particularly noted by the panel of blind or visually impaired participants. This particular group of individuals had found it hard to access the support they needed and felt the assessments were difficult and made them feel humiliated.

“I think it is very hard to get help with social care. It was an ongoing five year battle and a hard battle I can tell you, but after five years I have won and have been awarded four hours of help.”

(Female, Service User)

The panel of users who were either blind or had sight impairments were in agreement that they were not aware of what they were entitled to and that there was no-one to provide them with the information they needed. One person in the group reported that a senior social worker had told him/her that in his/her experience “blind and partially sighted people were at the back of the pecking order.” There was general

agreement across the group on a view that if you are not aware of any social workers or professionals who could provide you with information, they were just left in limbo. This group of service users reported that they were a very independent group of individuals and liked to do as much as they could themselves without asking for help. However, they felt this had a negative impact on them when it came to receiving support.

“You are not told about the team, their services, I don’t know much about access but you really really have to batter down doors to actually find out what you can get.”

(Female, Service User)

“I feel that the more independent you are and the more you try to do for yourself, the less help you are going to get. Whereas, if you sit back and do nothing and don’t even try, basically the impression I get is that you will get help... when you try to get help it isn’t there and it should be there.”

(Female, Service User)

The panel of blind/visually impaired participants felt that in their experience they had to be persistent to get any help or support. Two participants said that they would not have the confidence to raise an issue if they had one. This was cited as being due to mental health and confidence issues and the other because of his/her previous experience of having had a long battle to get support, they would be nervous about raising concerns now. One person said the only reason they had got the help they needed was because they contacted their local MLA.

One group of people we spoke to was a group of veterans who had very specific issues with regards to accessing social care. The panel reported that they attend a Defence Medical Rehabilitation Unit in England. However, once they are discharged and they return to NI, that support ends. With regards to accessing social care the veterans expressed significant concerns centred on trust. They indicated that they find it difficult to trust individuals with their medical and career history. They feel they cannot disclose the whole story, making it difficult for health professionals to understand fully the extent of their problems. Many of these veterans indicated that they were unwilling to access care from their GP.

“We are behind the ball before we even start because we haven’t been able to disclose what is wrong with us, how it happened etc. So we are not getting the benefits probably that we are entitled to.”

(Male, Service User)

“Trust is a very big thing with some of the veterans and it is a massive thing for all of us that served here in Northern Ireland.”

(Male, Service User)

Those veterans who could use care at home often do not access it as they are reluctant to have people who are not known to them (‘strangers’ as described by the veterans) coming into their home. They reported that they often have military memorabilia, pictures of them in uniform and they do not want carers to come in and see that. They do not trust people, especially strangers coming in; therefore, in these cases most of the care is provided by their partner.

5.0 Self Directed Support

The 'Power to People' report promotes a "person-centred vision for adult care services" and the Expert Advisory Panel proposes that "models of Self Directed Support (SDS) become the norm in order to empower citizens with effective demand"¹⁰. Self Directed Support enables individuals to choose how their support is provided and gives them as much control as they want over their Personal Budget¹¹. An individual's personal budget can be:

- ▶ Taken as a Direct Payment;
- ▶ A Managed Budget (the Trust holds the budget, but the individual is in control of how it is spent);
- ▶ The Trust can arrange a service; or
- ▶ You can choose a mixture of these options.

The introduction of Self Directed Support means that once a Trust agrees that an individual needs social care support they can work together with their key worker to agree how care is provided, that best meets their assessed needs. The aim of Self Directed Support is to promote independence by offering more flexibility on how services are provided to people who are assessed as being eligible for social care support¹¹.

Based on the information provided by panel participants it would seem that a significant amount of work remains to be delivered if progress is to be achieved with regard to this particular proposal. Although some people had heard of direct payments, only a few participants had heard of SDS, had tried it, or were currently using it.

5.1 Views from those who had never used Self Directed Support

Self Directed Support was explained to all panel participants. A few of those who had never heard about it before felt that it sounded like a good idea as it meant they were in control and they did not have to rely on the HSC Trusts.

One aspect, which participants particularly liked, was that they would be able to arrange the times that their carer would arrive, as some people did not like that they were tied to the times the carers called. This was the case especially for morning calls to get them out of bed and evening calls to put them to bed; in some instances, people were being put to bed as early as 6.30pm.

"I think it would be a real good idea because when the Trusts do it for you as such, you're set to them times... if you are in control of that, it means you can say bring somebody in at ten or half ten, eleven, if you organise that for somebody to come in... you're not just set to them times."

(Male, Service User)

They also felt that using SDS meant there would be consistency of carers and they could be more flexible with timings and possibly be able to spend a little more time and not be as rushed. However, they did

raise concerns about what would happen if the carer failed to turn up and the subsequent consequences. The point was also raised that for SDS to work properly, it needs to be directed by the service user rather than Trusts.

5.2 Advantages of using Self Directed Support

One person had accessed SDS approximately six years ago and had found that it had made a huge difference. He/she received help at the outset to get it up and running but commented that they liked how they knew who was coming every morning. They also liked how they were able to build up a relationship with that person as opposed to different people from agencies coming every day.

“Once it is up and running it is just night and day the difference to how you’re able to manage and you’re aware who is coming and they’re coming at your request as opposed to at somebody else’s rota.”

(Male, Service User)

“The only way you get to choose who comes into your home is by employing somebody and with all of the difficulties that brings.”

(Male, Service User)

This person also reported that at the beginning when SDS was introduced it was thought that the package was more advantageous to encourage people to take it up and then a few years later, it was reassessed and the package was reduced. This meant that a lot of activities were stopped because of the lack of a helper, such as swimming and other exercise programmes. They stated that these exercise programmes had helped them a lot and their health had improved over the years.

This person’s support was broken down by hours and he/she reported that if he/she had hours left over that they had not used they could use them for some kind of social activity. Alternatively, if they wanted to go out at night they could get someone to go along and help them.

Another advantage of SDS noted by a few participants was that they liked that their carer was coming at a time that suited the service user and not working from a rota. Therefore, they were able to pick and choose when they received their support.

“They [carers] come when I want and go when I want them to. It gives me better day to day things, so if I want to go out on a Tuesday, I tell them I’m going out, so that means they are off the rest of the week or if I want them in the house for six hours, they come in for six hours... So it’s great, I definitely can’t fault it at all.”

(Female, Service User)

“Managing budgets is good because I think you have more control over it but at the end of the day it’s about the continuity of care that you have the same people coming in and out.”

(Male, Service User)

5.3 Barriers to Self Directed Support

Many of those who had heard of SDS prior to attending the panel or had previously/currently used it were not as positive about it. One person had been made aware of SDS through their social worker. They used it for two and a half years and stated that it was “a hassle” and “a lot of stress” and as a result had gone back to using the services provided by the Trust.

Another person indicated that they had been “put on SDS” and that they found it very difficult to get information and felt that the guidance received was very poor. This was similar to findings in a PCC report which was recently completed on SDS and explored the experiences of those who had used SDS or direct payments. Within this report, service users and carers highlighted that the biggest issue by far with SDS was around information, or the lack thereof, given to them about SDS and how it works¹².

Similarly to those who had never used SDS, those who had tried it in the past or were currently using it felt that the system needs to be “more fluid” and the Trust needs to give people more control. By offering SDS and direct payments, participants reported that people think they are in control, but a lot of the control still lies with the Trust.

“I think there is a fear within Trust authorities to let people take control of their own lives... with direct payments you are in control but the Trust is trying to wrestle some of that control from you a lot of the time. So there is not that control that people think they are getting.”

(Male, Service User)

SDS was reported to sound attractive at the outset. However, when delving deeper into the different elements associated with it service users are often “put off”. A few panel participants felt that you need to be organised to be able to manage the payments. For example, to be able to use SDS the person must be able to manage their own finances, pay the carer’s national insurance and employer’s liability. However, one participant reported there is help available to put all this in place. Another participant also stated that “it’s straightforward once it’s set up, it’s just at the start it’s a bit of a hullabaloo because there are things to be filled in”.

“When it was first talked about to me I thought that sounds great, until my daughter started explaining things to me... I can’t manage my own bank account, my daughter takes care of my bank... the more she talked the more barriers sort of came up... It is just going to be too hard, too confusing.”

(Female, Service User)

“I know a guy... who has a carer 24/7 and he employs a driver, the problem is you have to be switched on enough to manage that... there are a lot of people that would overwhelm, even the thought of it. So it is easier just to get someone else to do it.”

(Male, Service User)

“It would only be suitable for people that are fairly competent.”

(Male, Service User)

Participants believed the Trusts were pushing SDS but felt there was no real input from service users to guide the implementation. One group suggested that there should be a panel of service users working with the Trust and providing their views and experiences on SDS and direct payments.

“There is no panel of SDS users... there is no panel working with the Trust to iron out problems. The Trust is not sitting down and talking with the people that are actually using the service. The Trust is just going in there and saying this is what you have got”

(Male, Service User)

A few of the panel participants reported that from their perspective SDS had been used inappropriately and in some instances was perceived by participants as a potential threat i.e. *“if you don't like domiciliary care then you are going to have to have SDS”*. These particular individuals were reluctant to speak out as they were scared of losing their care and therefore they did not want to complain any further.

One of the biggest disadvantages of SDS noted by a few of the participants was that if carers failed to turn up at any stage in the day or were sick, then the onus was on the person receiving the care to find an alternative person to provide their care that day. By contrast, for those who had care provided by Trust/ Agency staff, the onus was on the Trust/Agency to sort out any staffing issues on behalf of the service user.

“If a carer is on holidays, phones in sick, or an emergency has happened, [Name] is just left there, whereas... if you have the package with some agency or with the Trust privately... it's their responsibility.”

(Female, Staff Member)

Another barrier reported with regards to SDS was the difficulty surrounding recruiting carers. The issue mainly regarded getting someone suitable who they felt they could trust. For this reason one person indicated that he/she used a mixture of Trust carers and direct payments and found this worked well.

The recruitment process was found to be difficult as panel participants were often unsure about who to speak to. A few people had used the Centre for Independent Living to recruit carers. However, they reported that they had encountered candidates who either were not suitable or when interviews were organised the person did not turn up. It was felt that it was made more difficult for those who needed to recruit someone for a small number of hours.

“I use a mixture of Trust and direct payment and it's grand, it works well enough for me but it's not easy to get people... I certainly wouldn't take it on for my whole package. It's too big a package and I definitely couldn't

cover it and I wouldn't want to be in the position where you get a phone call in the morning from the carer to say they can't come and you've to get somebody else... you know if it's the Trust it's up to them."

(Female, Service User)

Those who were blind/visually impaired also noted that information on SDS should be made accessible for this group for example, audio information. The recruitment process was also an issue for those who lived in more remote rural locations as they found it was difficult to get someone to call with them four times a day.

The risk to carers was also reported by a few of the panel participants. For example, it was felt that the direct payments scheme could not offer domiciliary care workers the same terms and conditions as the Trusts, for example, time and a half on Sundays. Another disadvantage for carers was that if the person they are caring for becomes unwell and has to go into hospital, the carer will automatically lose that income for the period of time they are in hospital.

"Carers don't find that it will be of benefit to them... if [person they are caring for] takes ill and remains in hospital for three weeks I will automatically lose that source of income. I can't afford to wait three weeks for [name] to come out to restart her package. I may possibly have to move on which means when [name] gets out of hospital she has already lost one of her carers."

(Female, Staff Member)

Those who were blind/visually impaired had slightly different issues regarding SDS. In particular, this group reported difficulties in obtaining SDS, with one person reporting they fought for five years to get it. However, when these service users eventually got SDS, they found that they did not have control over the hours that were provided to them. For example, they were given support in the home, which was not always what they needed, as they wanted support outside the home, i.e. to go into town and get help with basic tasks such as shopping.

"They make it so difficult for you to get it... if you are going through assessment after assessment; you end up physically in tears because of the assessments, because of the humiliation. You end up totally, physically and mentally worn down."

(Female, Service User)

"We can't get it [SDS] to go out... it is the little things, like getting the dogs out for a free run, shopping for clothes, socialising... living our lives like sighted people do."

(Female, Service User)

"The theory behind self directed payments, Self Directed Support is great, brilliant. It doesn't happen though."

(Female, Service User)

6.0 Technology

Most of the panel participants we spoke to used different aspects of technology to support them in their daily lives. However, there was a limit to how much was provided to them free of charge. If anything further was needed, it was up to the person to pay for this themselves, with most of the equipment required reported to be expensive. Some people reported that getting the technology they required had been difficult and that they had to fight to get what they needed.

It was reported that technology plays a big part in the lives of those who are severely disabled. One person who had a serious accident in the past had use of a specialist laptop whilst in hospital to support communication. This laptop allowed the person to communicate by looking at letters on the laptop, which were then typed on the screen and read out. This was the only method of communication and after seven and a half months in hospital they were sent home without this and unable to communicate, which they found extremely difficult.

"I had that whenever I was in hospital because all I could do was move my eyes, so that's how I got to speak to people with a laptop and you had to look at the letters and when you looked at the letters it typed it on the screen and it read it out for you so you were able to say what you wanted. It was great but then when I got out of hospital I wasn't able to take it with me."

(Female, Service User)

This technology was used to develop the care plan in hospital; however, once the person was at home communication with carers was almost impossible (or extremely challenging). The situation was aggravated further by a number of different carers being involved in the delivery of the care.

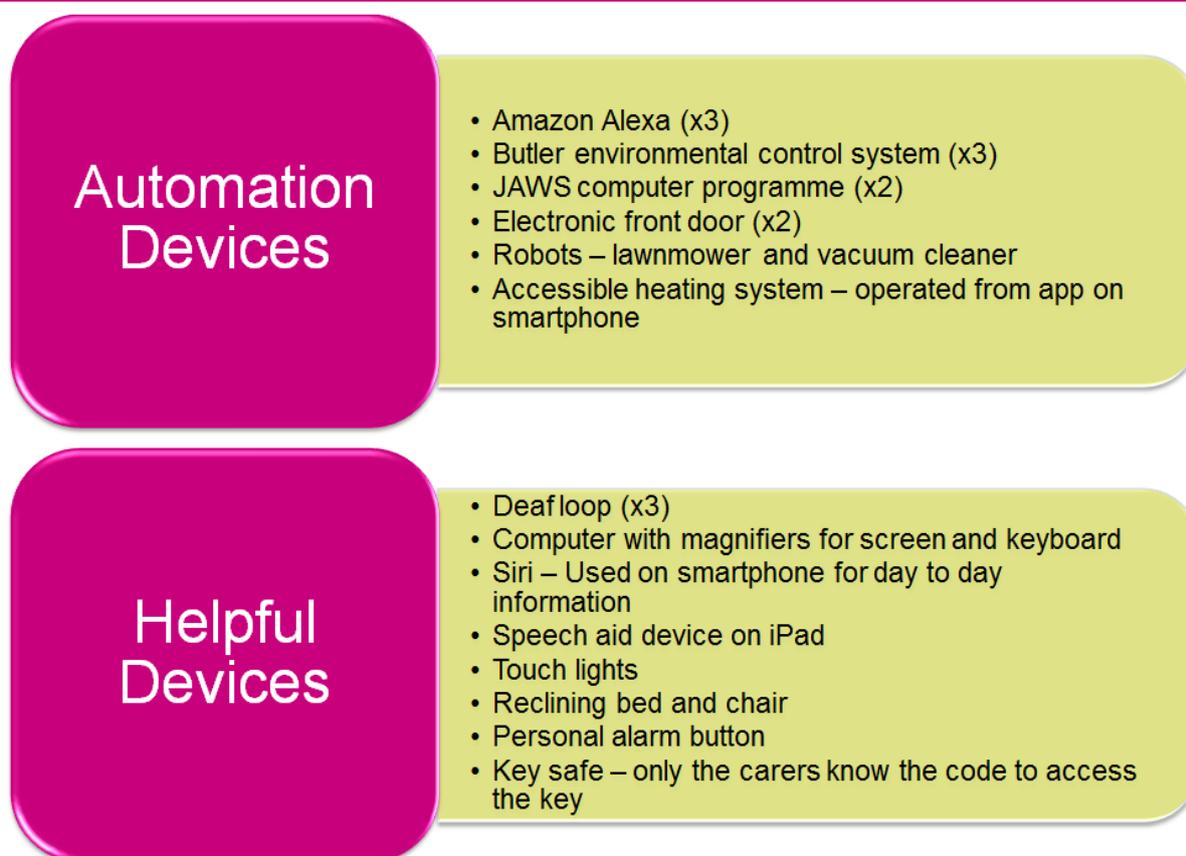
The same person also had used an electric wheelchair in hospital; however, this was reported as having been removed on discharge. It seems that the individual went from being able to communicate and being able to move around to having no voice and being immobile.

"The first night I was home I thought, 'take me back to hospital'; they took away my wheelchair, they took away my laptop, I can't speak, I can't move, what am I going to do here now?... having that power and that feeling of being able to interact, being able to speak again, it is a great feeling. But then for that to be taken away from you, so I'd say technology is a big advantage to disabled people."

(Female, Service User)

Figure 5 on the next page shows the different types of technology which panel participants indicated that they used in their daily lives.

Figure 5: Overview of the technology used in daily lives of those with physical and sensory disabilities



The most commonly used devices included the deaf loop, Amazon Alexa (used for home automation and to provide information, for example, weather) and the Butler environmental control system (voice activated electronic control system used to control heating, open curtains, operate the TV). These were followed by the JAWS computer programme, which reads out loud whatever is written on the computer screen and an electronic front door which closed automatically when the person left the house.

One person, who was blind, stated that *“everything in my house is assisted technology. Everything either talks or is in large print. I have no social worker, I have no support worker and I use assisted technology in work.”*

LCD displays and touchscreen technology were noted as being particularly difficult for those who are partially sighted. Furthermore, the cost of equipment/technology was a major barrier to people accessing it. It was believed that companies who make specialist chairs and other equipment, specifically for those with disabilities, were charging extortionate prices. This made it more difficult to get access to items on the NHS and even more difficult for individuals to purchase equipment themselves if they were not entitled to it on the NHS.

“I do think we could use a lot of technology, but I do think people are holding the service to ransom and charging extortionate prices for equipment to do with disability. These chairs are all £3,000 each we are sitting in.”

(Male, Service User)

7.0 Hopes for the future

Panel participants were asked what they thought the priorities should be and their hopes for the future in adult social care services for people with a physical and sensory disability. **Figure 6** below outlines the key areas highlighted as priorities in adult social care services.

Figure 6: Key areas highlighted as priorities in adult social care services



7.1 Support for families

More support for families of those with a disability was noted by two of the panels as something that is needed in the future. One of these groups focused on respite services as an issue, especially for younger people. It was reported that young people are sometimes forced to go to nursing homes for elderly people because they are so physically disabled and there are no respite services available for them. Participants reported that in the past, respite services were more readily available. However, due to NHS cutbacks it was felt that there currently is not the same availability. The other panel did not specifically mention respite but felt there was a need to recognise the hard work of the family carers. A service should be provided for them to relax and have a break from their caring responsibilities.

"I think people like your husband or wife, or family of the person who's had the accident or injury, they are the ones that do all the work and don't get any thanks for it. They are left out and I think a wee thing for them would be good just to get together or a wee pamper day."

(Male, Service User)

7.2 Transport

Transport was mentioned in at least four of the panels as being something participants would like to be made more readily available. In the past, a few of the panel participants had been able to avail of community transport services to take them to sports centres, church, hospital appointments, work placements and other places. However, cuts were cited as the reason that transport was no longer available, which meant that those affected could no longer go to places they had previously gone.

One panel participant discussed an easybus service that they had used in the past to get out and about. However, this service was removed, which meant, in an area with 54 disabled dwellings, there was no transport available.

Throughout the panels the importance of being able to get out and about and not sitting at home all day was raised regularly. Transport was deemed as important to enable people to get to the Day Centres, Resource Centres etc.

“Help with transport, getting out and about as the other participant said, she feels quite isolated, and it’s very important that nobody is just stuck at home and you can’t get out and have a social life.”

(Female, Service User)

“I can’t get community transport, even to take me to Craigavon Hospital... I was totally housebound and was expected to make my own way up to the Royal by public transport where there is no public transport and it is dangerous for me just trying to get trains and stuff.”

(Female, Service User)

A few of the panel participants, who were wheelchair users, had to book taxis days in advance if they needed to go somewhere; there was never a certainty that they would turn up when they were meant to. One person was also paying £40 per journey for a taxi with disabled access. Therefore, it was felt that more accessible transport in the community would be beneficial.

7.3 Service user input

One person reported that the Trusts paid more attention now to service users’ views than they did 20 years ago. He/she believed this was a great improvement and felt it was really important that service users’ views were taken on board and that this needs to continue.

“If you want to find out what it is like to have problems with eyesight or hearing loss... ask somebody that deals with it rather than going looking in a book or reading about it... they’ll soon tell you very fast.”

(Male, Service User)

“There are so little opportunities for disabled people to input into things that are designed for them which is never really correctly designed but it can be done and all it really takes is a bit of preplanning.”

(Male, Service User)

The ‘Power to People’ report provides reassurance that this will continue in the future. Proposal 13 focuses on *“a whole-systems approach to facilitating joint working between commissioners, health services and care providers, which includes a clear mechanism for involving people receiving services and carers within all the HSC Trusts”*⁶.

7.4 Additional Support

Those who were blind/visually impaired highlighted that they often did not need help in the home. Nonetheless, they needed more help when they went out and about trying to do activities that most people would take for granted such as shopping, going to the bank, walking the dog, socialising etc. As a result, the visually impaired panel reported that in the future they would like more support to help them carry out normal day to day activities outside the home and that this support should also be available through SDS.

“That extra help would be nice, sometimes you want to be doing something or going to the shops... you get fed up being stuck at home and the things you want to do you can’t. With a mental health condition it makes it worse.”

(Female, Service User)

“You should be allowed to spend your hours on what matters to you and for the things you need in your life and in your own home.”

(Female, Service User)

A panel of wheelchair users also wanted additional support to help them become more independent and be able to get out and about.

“We are not seen as a group that needs care immediately. We want to be independent and so we are sort of falling between the stones. And nobody is really looking after us.”

(Male, Service User)

One person gave the example of going grocery shopping and often having to wait quite a long time for a member of staff to assist them. However, participants felt that if they had their own assistant to go to the shop with them they could get what they wanted much quicker. These individuals often required help with cleaning and gardening but had to pay privately for someone to do this for them. One person

commented that people living in the Northern Trust area can get help with cleaning but not in the Belfast Trust; however, they were unsure as to the accuracy of this.

Another couple had asked for help at home to cook dinners as the lady had arthritis in her hands and her husband was unsteady on his feet. However, they were told to have frozen ready meals instead. This was disappointing for the couple as they liked to have home cooked meals.

7.5 Education

Another issue raised by the panel participants who were blind/partially sighted was the need for education. Four of the panel participants were involved in delivering training to help raise awareness of what it is like to be blind/partially sighted. The panel felt there needs to be more education and training to raise awareness amongst professionals as well as the general public. They also felt that organisations need to work together to raise awareness in communities rather than working in silos.

“We know what impacts us on a day to day basis. We know what the challenges are. They are never going to understand, unless it comes from us and I think that is one of the most important things.”

(Female, Service User)

“I also deliver visual awareness training, on numerous occasions people have said to me that it meant so much more to them as able bodied people that it is actually being delivered by the people themselves that have the active disability.”

(Male, Service User)

This issue was also raised by a group of wheelchair users. They were keen that others needed to know what it was like to be a wheelchair user. They felt that if able-bodied people had to spend a day in a wheelchair they would understand the challenges faced on a daily basis and changes might take place.

Both panels felt that it would be good for children to be educated on what it is like to be blind/visually impaired and/or a wheelchair user. This would help to normalise their situations rather than having children staring and not understanding why that person is in a wheelchair.

“We should be treated fairly and as equally as anybody else, just because we are disabled doesn’t mean we are different.”

(Male, Service User)

7.6 Information and advice

Panel participants would like to be provided with information and advice on what is available to help and support them. They suggested a central organisation which people could access to find out about any services that are applicable to them. It was also felt that organisations need to work together to ensure all those with disabilities are provided with the same amount of information and advice.

“Various charities, Trusts, organisations, whoever they are should work together to provide an overall supportive network, with services in place for disabled people whatever the disability.”

(Female, Service User)

“Social care has to be fully inclusive, it has to give the opportunities to be able to do things just the same as anybody else... it has to be inclusive and it has to be accessible.”

(Male, Service User)

7.7 Better pay for care workers

Some of the panel participants believed that the care delivery would be much better if carers were paid more. Better pay was seen to act as an incentive to get people into the jobs and encourage them to stay rather than move on. With regards to Self Directed Support, staff retention and recruitment was reported as a major difficulty when it came to employing care workers. Participants highlighted that the system was profit driven. If care workers were paid more than the minimum wage then they would be more inclined to stay in their role as a care worker instead of moving on to a better paid position.

“Why are the Trusts paying so little for a service that actually keeps people going... The care workers, they are the people that actually keep you up and running. They won’t pay people the money they are entitled to. The money and the price is a major factor.”

(Male, Service User)

7.8 Support for veterans

Participants from the veteran group felt there needed to be a central point of contact specifically for them; somewhere they could go to receive care and not have to worry about their service history or who would see what they did in the past. They also felt there was a need for a post to be put in place in Northern Ireland similar to an ex-military navy doctor, who the veterans would trust and go to. The need for long term support for these individuals was also highlighted, particularly as, they are dealing with issues from the atrocities and horrors they have seen. They felt there is no quick fix of being diagnosed and given tablets.

“I do think it is harder in Northern Ireland than England because of that trust... we need a point to go through, a centre or whatever it is so that when we go in the door we know we are safe... we just want to feel secure when we are talking about it. You know that really shouldn’t be a big deal!”

(Male, Service User)

8.0 Conclusion

The purpose of this scoping study is to focus on what is important to those who participated as panel members, with regards to adult social care services for service users who have either a physical and/or sensory disability. The panels provided an insight into some of the key issues in the day to day lives of those with physical and sensory disabilities. Participants used a number of different elements of support in their daily lives ranging from domiciliary care, support from occupational therapists and social workers, community support, transport and family support. Each of these areas of support were seen as important to the panel members and highlighted the significance of adult social care in their lives. However, community support, transport and family support were three of the areas that were extremely important to them. With the majority of participants valuing the input of the community organisations in their daily lives to give them a purpose, a change of scenery and many reporting how attending had helped with their confidence.

Domiciliary care was noted in this report as a vital service and participants highlighted that generally their needs are being met by this service. However, it was believed that improvement is needed to make services like domiciliary care more patient-centred. Participants told us that whilst the service provided met their physical needs it does not focus on them as an individual person and what their specific needs and wants are. It seems that there needs to be an even greater focus on patient centred care with services being tailored to meet individual needs.

With regards to awareness and access to services, it was clear that there is a lack of awareness amongst those with physical and sensory disabilities about what services are available to them and whilst they realised there were probably services available that they could be accessing, they were not aware of them. This group relies heavily on information provided to them from others about available services.

Self Directed Support is proposed in the 'Power to People' report as *"becoming the norm in order to empower citizens with effective demand"*¹⁰. However, this study found that very few of the panel participants had heard of Self Directed Support or were using it/had used it in the past.

Most of the panel participants used different aspects of technology to support them in their daily lives. In particular technology was highlighted as playing a big part in the lives of those severely disabled or blind/visually impaired. However, equipment was noted as being expensive with a limited amount provided for free by the NHS.

The remainder of this chapter summarises the key learning points from the report and key recommendations. It is important to note that these recommendations are based solely on what panel participants would like to see in the future with regards to adult social care services. These are issues which were reported as being important to the panel participants and therefore should be given consideration by the appropriate organisations responsible for each area of learning.

8.1 Learning points and recommendations

The following learning points were identified through completing this piece of work:

- ▶ **Learning point 1: Domiciliary care** – In general, domiciliary care met the needs of the participants who used/knew someone who used the service. However, whilst the service met their needs it was clear from the comments that this is not necessarily designed around what the patient wants, therefore, improvement is needed in this area. There were two key areas where issues arose, namely inconsistency of care staff and the timings of the visits. Timings of visits are not planned with the service user in mind and as a result the length of visits can be unrealistic. Participants would therefore, like more consistency of care i.e. regular staff as opposed to many different staff, as well as regular visiting times and an appropriate length of time for each visit.

Recommendation: There should be more consistency of staff for those receiving domiciliary care and timings of visits should be reviewed to ensure they are adequate to not only meet service user needs but to provide them with a service that is more person centred.

- ▶ **Learning point 2: Transport** - This issue was raised at most of the panels and was a key element of support for participants, and impacted on those living in both rural and urban locations. Transport was seen as vital to enable panel participants to get to and from Day Centres or Resource Centres. Currently some participants are having issues with transport, for example buses not arriving on time and changing their payment methods which makes it more difficult. Others had reportedly lost their access to transport, making getting out and about extremely difficult. Those who currently had access to transport wanted to stress that they were happy with what was in place and hoped that this would continue in the future.

Recommendation: Community transport should be available to everyone and consistent in its timings and payments. No differentiation should be made between services provided for rural or urban residents; everyone in Northern Ireland should have equal access.

- ▶ **Learning point 3: Family Carers** - Many of the panel participants relied on family support and as a result did not access as much social care as they would otherwise have needed. There was great appreciation amongst participants for the support of their family and it was felt this should be recognised within HSC and opportunities should be provided to give carers a much needed break/ respite.

Recommendation: In line with the 'Power to People' proposals, the rights of family carers should be recognised legally in order to offer them better support, both financially and socially. There needs to be better access to respite services for carers as well as recognition and reward for their hard work.

- ▶ **Learning point 4: Service awareness/access** - There was a general lack of awareness amongst those with physical and sensory disabilities about what services were available to them. Most believed there were probably services available that they could be accessing but were not aware of. Those who were aware of their social worker or knew how to contact him/her felt that the social worker should be providing them with more information on such services. A few participants were unaware that they were entitled to social work services and therefore did not have access to a social worker. Panel participants also felt there was a lack of services available with regard to physical disabilities and they felt at a slight disadvantage compared to other disability groups.

Recommendation: There should be a central point/organisation (one stop shop) where people can find out what services are available for them to meet their specific needs.

- ▶ **Learning point 5: Self Directed Support** – Those who were currently using SDS, or had used it in the past, had mixed reactions to it. Some liked it as it meant they had consistent carers and more flexible timings. However, others found it to be “*a hassle*”, “*a lot of stress*”, particularly when carers “*let them down*” and it was then up to them to find a replacement. It was also reported as being difficult to get information and the guidance they received was poor. Panel participants felt that there is a need for good management skills in order to facilitate payments and the administration involved was found to be too difficult for some. This is in line with findings from a previous report by the PCC which focused specifically on Self Directed Support and direct payments¹².

Recommendation: There is a need for the HSC Trusts to improve their assistance to service users to find replacement support especially with regards to being let down by their carer.

Recommendation: There needs to be better information provided around Self Directed Support to enable service users to make an informed decision. This information needs to be clear and concise to make the process as easy as possible for those wishing to take it on. This information also needs to be available in audio format for those who are visually impaired.

Recommendation: Where service users are happy to take on SDS they should be supported and guided through the process. However, SDS should not be forced on individuals who do not feel comfortable with it.

Recommendation: The PCC have recently produced a report on Self Directed Support which looked at service users experience of using SDS and direct payments¹². One of the recommendations made in the report on SDS, can also be reinforced in this report. The SDS report recommended the need for Health and Social Care Trusts alongside the Health and Social Care Board to co-produce a training package with recipients of Self Directed Support to ensure that new applicants feel confident to successfully utilise Self Directed Support. This could be delivered as an e-learning package; however alternative delivery modes would require consideration to support those who cannot access/do not have access to a computer/the internet.

- ▶ **Learning point 6: Service user input** – Service user input was noted to have improved over the past number of years; panel participants reported this to be a great improvement and felt it was important that this continues.

Recommendation: Service user views should continue to be taken on board in the future.

- ▶ **Learning point 7: Additional Support** – Sometimes the social care support offered to those with physical and sensory disabilities is not adequate to meet individual needs. Specifically, those who were visually impaired or wheelchair users wanted more support to help them “*be more independent*” and allow them to “*carry out normal activities*”.

Recommendation: There should be alternative support available for those who need it, especially visually impaired or wheelchair users, who would like more help outside the home. There needs to be and an understanding that domiciliary care is not the only type of support people with physical and sensory disabilities need.

- ▶ **Learning point 8: Education** – Those who were visually impaired or wheelchair users were keen that others needed to know what it was like to live with visual impairments and/or using a wheelchair. They highlighted the importance of training to enable others to understand the difficulties that these particular groups of people face in their daily lives.

Recommendation: More education for professionals and the general public on the daily challenges of living with a physical or sensory disability. These awareness sessions should be delivered by those with a physical or sensory disability i.e. experts by experience so as to enable a more profound impact.

- ▶ **Learning point 9: Care workers** – Participants highlighted that domiciliary care, provided by care workers, was a vital service which helped to get people out of hospital and back into their own home. However, it was felt that care workers had low pay which resulted in high staff attrition. In line with the 'Power to People' report⁶ participants felt that better pay for care workers would make for a better care system and would act as an incentive for care workers to stay in their role as opposed to moving on.

Recommendation: In line with proposal six in the 'Power to People' report⁶, there should be better pay and conditions across the social care workforce.

- ▶ **Learning point 10: Support for veterans** – Due to the issues with trust and sharing their history, this group would like a central point of contact to receive care and long term support.

Recommendation: The needs of this unique group should be further explored and the possibility of a specific healthcare professional they could trust and go to for care/support should be considered. For example, an ex-military doctor or someone in a similar situation to them who understands their past. Military Support Associations for example, the Reserve Forces and Cadets Association (RFCA) and the Ministry of Defence (MOD) should be made aware of these specific needs.

6.0 References

1. World Health Organisation. 2018. *The International Classification of Functioning, Disability and Health, 2018*. [Online] Available from: <https://www.who.int/classifications/icf/en/> [Accessed 06.12.18]
2. Equality Commission of Northern Ireland. *Definition of Disability*, 1995. [Online] Available from: <https://www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/DefinitionofDisability07.pdf> [Accessed 06.12.18]
3. World Health Organisation. 2018. *Disability and Health*. [Online] Available from: <http://www.who.int/en/news-room/fact-sheets/detail/disability-and-health>. [Accessed 06.12.18]
4. The Kings Fund. 2013. *Integrated care in Northern Ireland, Scotland and Wales Lessons for England*. [Online] Available from: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/integrated-care-in-northern-ireland-scotland-and-wales-kingsfund-jul13.pdf [Accessed 06.12.18]
5. National Audit Office. 2012. *Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland*. [Online] Available from: <https://www.nao.org.uk/wp-content/uploads/2012/06/1213192.pdf> [Accessed 07.12.18]
6. Department of Health. 2017. *Power to People: Proposals to reboot adult care and support in NI. Expert Advisory Panel on Adult Social Care and Support*. [Online] Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-full-report.PDF> [Accessed 07.12.18]
7. Department of Health. 2012. *Social Services and Public Safety. Physical and Sensory Disability Strategy and Action Plan 2012-2015*. [Online] Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/disability-strategy-2012-2015.pdf> [Accessed 06.12.18]
8. Department of Health. 2018. *Statistics on Community Care for Adults in Northern Ireland 2017/18*. [Online] Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/health/cc-adults-ni-17-18.pdf> [Accessed 06.12.18]
9. Department of Health. 2018. *Domiciliary Care Services for Adults in Northern Ireland 2018*. [Online] Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/health/dcs-adults-ni-18.pdf> [Accessed 30.11.18]
10. Department of Health. 2017. *Power to People: Proposals to reboot adult care and support in NI. Executive Summary* [Online] Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-executive-summary.PDF> [Accessed 30.11.18]
11. Health and Social Care Board. 2019. *Self Directed Support*. [Online] Available from: <http://www.hscboard.hscni.net/sds/> [Accessed 16.04.19]
12. Patient and Client Council. 2019. *Our experience of self-directed support. Service users and carers share their views*. [Online] Available from: http://www.patientclientcouncil.hscni.net/uploads/research/1749_eEklVf.pdf [Accessed 18.2.19]

Appendix 1 – Topic Guide for Panels

Topic Guide: Reform of Adult Social Care

Physical and Sensory Disability Panels

Notes below to be used as a guide:

- Introduce yourself and thank the group for allowing you the opportunity to meet with them.
- Introduce the Patient and Client Council as a Health and Social Care organisation that provides a powerful, independent voice for patients, clients, carers and communities on health and social care issues. The Patient and Client Council is funded by the Department of Health.
- What the Patient and Client Council does:
 - Listens and acts on people's views;
 - Encourages people to get involved;
 - Helps people make a complaint and
 - Promotes advice and information.

State the purpose of this project

The Patient and Client Council are conducting a series of panels with adult whom have physically and or sensory disability to inform the ongoing work on the reform of adult social care as demonstrated in the 'Power to the People' report. As part of this we want to hear from service users aged between 18 and 65 years old on what the key issues are for people living with a physical disability in health and social care. The findings from this work will be shared with key decision makers.

Explain the format of the Panel

The discussion will focus on a number of questions in relation to your experience of living with a physical disability and using social care services. The discussion will last approximately 45-60 minutes.

Suggest a few basic rules – respect everyone’s views, only one person should speak at a time, remind all there are no right or wrong answers. It is important to hear YOUR views/opinions, and finally ask them all to remain focused on the topic/question.

Have comment cards at hand should people wish to raise individual complaints.

Recording

Ask the group if they are happy to have the discussion taped to assist with capturing all of the discussion. Emphasise that the transcript will be anonymised so that no one can be identified.

If someone would prefer not to be taped please respect this and ensure full written notes are captured. You may need to emphasis briefly that we are focusing on experience of social care and support NOT healthcare

***Capture group demographics**

What services/support are people currently accessing

Could I ask each of you to describe what a typical day is like for yourself? In particular we are interested in hearing if any of you have support from adult social care and support services on a day to day basis.

(Allow people time to discuss their routine and any services/support they may be receiving)

- What type of care do you receive?
- How long have you been receiving this support?
- Who initiated it? Did you ask for help, did someone request it on your behalf or did a health or social care professional suggest commencing support?
 - Did you feel that you received the support at the right time for you?
- How would you rate the standard of care you receive?
- Do you feel like you have choice over the care and/or support you receive? e.g. If you receive domiciliary care are you given a choice of when the care workers arrive, when you have breakfast or when you are put to bed?

Awareness of services/support and how to access

Do you feel that you have a good awareness of the range of services available within social care for people with physical disabilities?

- Are you aware of any differences in services between Trusts?

Can you describe how you would go about trying to access a service?

- Has anyone ever self-referred for social care services? How did you go about this?

Self-directed support

Proposal Two

The Expert Advisory Panel proposes that models of self directed support become the norm in order to empower citizens with effective demand. Further priority should be given to how Self Directed Support funds could be used as catalysts to create and shape a diverse market of care and support provision, and we propose that mechanisms to stimulate such models are facilitated as a matter of priority.

Q: Does anyone use self-directed support?

- Is anyone familiar with the types of self-directed support available?

Self-directed support enables individuals to choose how their support is provided and gives them as much control as they want over their Personal Budget.

An individual's personal budget can be:

- *Taken as a Direct Payment,*
- *A Managed Budget (where the Trust holds the budget, but the individual is in control of how it is spent),*
- *The Trust can arrange a service, or*
- *You can choose a mixture of these options*

The introduction of Self Directed Support means that once a Trust agrees that an individual needs social care support they can work together with their key worker to agree how care is provided, that best meets their assessed needs.

If the person you care for needs help to organise their support they can ask the Trust, family members or a friend to help with this.

The aim of Self Directed Support is to promote independence by offering more flexibility on how services are provided to people who are assessed as being eligible for social care support.

- What is your opinion on these arrangements?
- What do you think are the advantages and disadvantages of:
 - Direct payments
 - A managed budget

Technology

Do you use technology in your day to day life?

- How do you think technology could be used to enhance the lives of people living with a disability?
“Assistive technologies refer to devices and equipment that compensate for sensory, physical/mobility, and cognitive impairments. They include;
- Voice recognition software
- text telephones
- accessible keyboards
- speech recognition software
- intelligent electric magnifiers
- reading lenses,
- Other devices which help the user to drive a car or to participate in sports, and memory aids on smart phones or tablets.

These technologies also include robots, for example those which help people with physical disabilities to carry out daily life activities or to recover or maintain some capacity.

Wider support structures

How could your families, friends and your wider communities be facilitated to support people with disabilities?

- Think of various settings – Education, workplace, Churches, sporting and leisure activities

Proposal Four

The Expert Advisory Panel proposes that neighbourhood based, preventative and citizen-focused community support models are encouraged and enabled. This should include the concept of a social worker-led Community Navigator role with such models available to every locality in Northern Ireland.

Proposal Nine

The Expert Advisory Panel proposes that the Department of Health should ensure that charging arrangements should be based on the principle that where a person can afford to contribute to the cost of a service they should do so. This principle should be applied consistently and equitably across all adult social care models.

How to raise an issue

If you experienced an issue regarding social care and support services, how do you think you would go about raising this?

- Has anyone ever raised an issue/concern or a complaint about adult social care and support?
- Who did you complain to?
- How did you feel the process was managed?
- Were you happy with the outcome?

Summary

In summary, what do you think the priorities should be in adult social care and support services for people with physical or sensory disabilities?

- **What are your hopes for the future?**
- **How can we ensure people with disabilities have optimal wellbeing and quality of life?**

Remember you can contact us by

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