

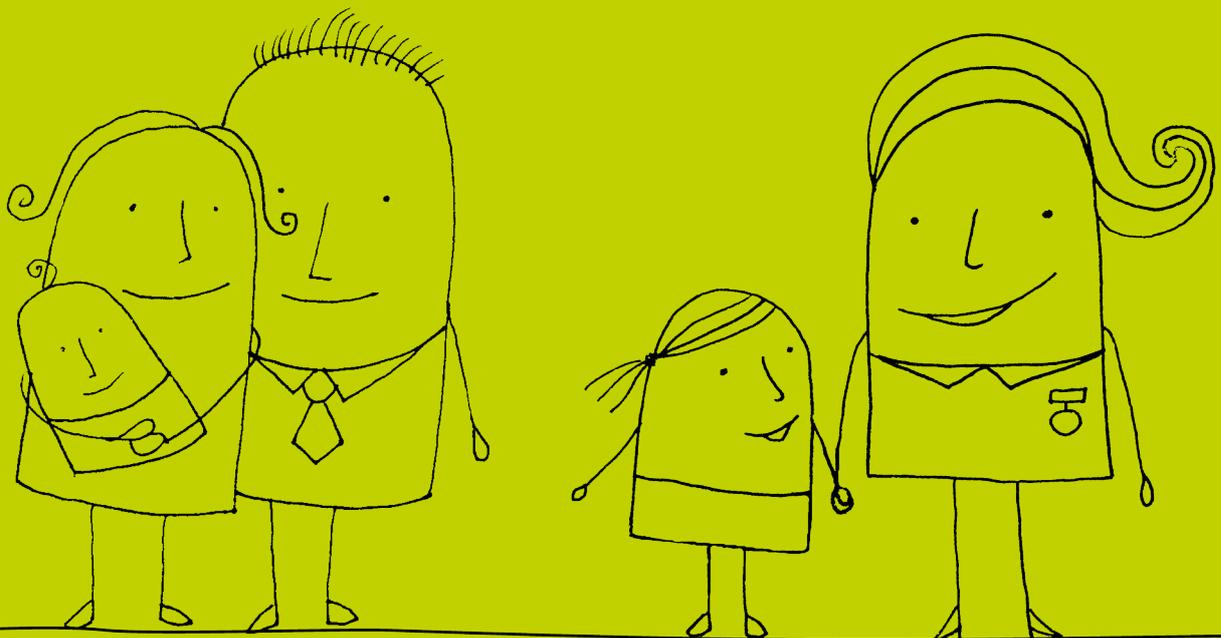
Patient and Client Council

Your voice in health and social care

# Our experiences of self-directed support

Service users and carers share their views.

February 2019





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# 1.0 Introduction

In June 2015, the Health and Social Care Board (HSC Board) announced the launch of self-directed support (SDS) across Northern Ireland.<sup>1</sup> Self-directed support is a term used to describe the ways in which social care services and support can be offered to individuals and families.<sup>2</sup> SDS is advertised as giving greater control to the person who needs social care and to those close to them to ensure they can shape the support they need to suit their lives.<sup>3</sup> The aim of self-directed support is to give people freedom of choice to allow individuals to obtain the type of support they want, where they want it and when.<sup>2</sup> For example, arranging support staff to visit at a time that suits the service user, or enabling them to employ their own personal assistant.<sup>4</sup> It is intended to support independent living by giving people more choice control and flexibility over their own care.<sup>5,6</sup>

Self-directed support is intended to support people to be equal citizens with both rights and responsibilities.<sup>2</sup> It is intended as a way to overcome the problem of institutionalisation and help people with disabilities and older people enjoy full citizenship and inclusion.<sup>3</sup> This will enable them to enjoy a good life, as a member of the community.<sup>3</sup> This was noted in a pilot scheme run by the Southern Health and Social Care Trust where participants reported having higher levels of satisfaction and a greater quality of life as a result of using self-directed support.<sup>1</sup>

People who have opted for self-directed support are allocated a personal budget from their local HSC Trust to support their assessed need for social care.

A personal budget can be:

- ▶ Taken as a Direct Payment (a cash payment).
- ▶ A managed budget (where the Trust holds the budget, but the person is in control of how it is spent).
- ▶ The Trust can arrange a service directly.
- ▶ Service users can also choose a mixture of all three of the different types of Self Directed Support.<sup>5</sup>

Before beginning self-directed support the service user has a support plan written which describes an individual's desired personal goals (outcomes) and details how these goals will be achieved through the involvement of a variety of people, services and supports both paid and unpaid. The purpose of a Support Plan is to reflect what is important to and for the individual to enhance the quality of their life and can be used to outline essential care and support needs. It highlights how a personal budget will be used to meet the assessed needs and achieve agreed individual goals.<sup>4</sup>

The Health and Social Care Trusts are in the process of rolling out Self Directed Support in Northern Ireland but progress has been acknowledged to have been slow.<sup>12</sup>

A number of concerns about Self Directed Support were raised in the Power to people report. These include the level of personal budget, limited brokerage support and perceived administrative burden.<sup>12</sup>

These may be considered as barriers to the slow uptake of self-directed support. More specifically, statistics (Table 1) provided by the Department of Health reflect numbers of those who take up Direct Payments. The table indicates a steady rise in the number of direct payments paid out and suggests that this will continue to rise.<sup>13</sup>

**Table 1: Direct payments paid by end of September 2016, 2017 and 2018**

HSC Trust	30th Sept 2016	30th Sept 2017	30th Sept 2018
Belfast HSC Trust	578	715	802
Northern HSC Trust	692	771	857
South Eastern HSC Trust	784	921	1,056
Southern HSC Trust	763	769	825
Western HSC Trust	615	829	1,276
<b>Total</b>	<b>3,432</b>	<b>4,005</b>	<b>4,816</b>

## 1.1 Aims and Objectives

Adult social care services in Northern Ireland are currently undergoing a reform process. Informing this reform of services is the 2017 Expert Advisory Panel Report: 'Power to People: proposals to reboot adult care and support in NI'.<sup>12</sup> Amongst the sixteen proposals contained within the report, proposal two states:

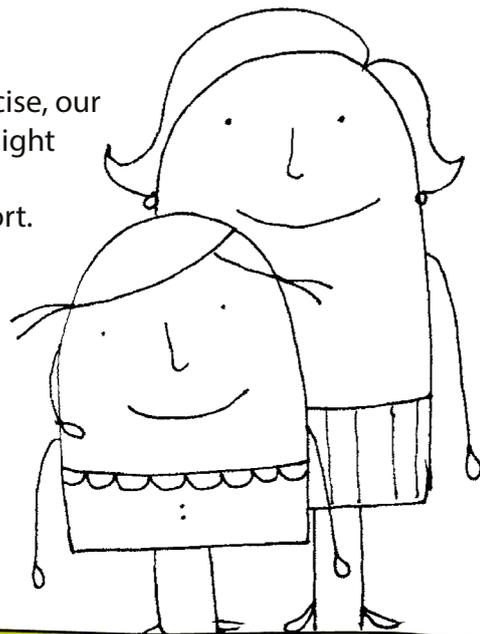
**Proposal Two:**

*"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."*

Given the prominence that is placed on self-directed support within the report, and that it appears to be the direction of travel for the provision of social care services, the Patient and Client Council felt it necessary to conduct an information gathering exercise to determine people's views and experiences.

The information obtained through this exercise and contained within this report will feed into the wider reform agenda and help to improve and develop services based on what people have said.

Given that this is a small-scale information gathering exercise, our aim is not to make specific recommendations, but to highlight key points and areas that we feel should be worked on to improve the overall user experience of self-directed support.



## 1.2 Methodology

For this information gathering exercise it was originally envisaged that we would carry out a one-hour 'Twitter Chat' to obtain people's views and experiences of self-directed support and/or direct payments. This would then be supplemented with a series of telephone interviews where people's experiences could be discussed at greater length. This approach was decided on as it was felt that people in receipt of self-directed support have busy lives and may find it difficult to attend traditional engagement events, such as focus groups. Additionally, we were aware that many carers use social media as a means of sharing and finding out information on services available to them.

The Twitter Chat was scheduled for 7:00pm on Wednesday 12<sup>th</sup> September 2018 and was advertised through the following channels:

- ▶ The Patient and Client Council's social media channels.
- ▶ The Patient and Client Council Blog.
- ▶ The Patient and Client Council Membership Scheme Newsletter - UPDATES.
- ▶ The newsletter of the Centre for Independent Living.
- ▶ Carers Coordinators in the South Eastern, Southern, Western and Northern HSC Trusts.
- ▶ Through related Community and Voluntary groups.

However, on the night of the event, not enough people joined the Twitter Chat to merit a productive conversation. As a result, those who joined were offered the opportunity to take part in a telephone interview at a later date instead.

Following on from the Twitter Chat, a slightly different approach was taken and it was decided we would engage with people associated with a user group for Direct Payments on Facebook. Therefore, the key themes and issues discussed in this report are borne from the following:

- ▶ A discussion with a small group of self-directed support users on the Direct Payment User Group NI Facebook page.
- ▶ A series of nine telephone interviews with carers and service users in receipt of self-directed support.
- ▶ Feedback on self-directed support from two focus groups conducted by the Patient and Client Council on Carers Assessments.

**Important Note:** Whilst we engaged with people on the subject of self-directed support, the overwhelming majority of people's experiences, both positive and negative, related to direct payments which forms one part of the self-directed support package.

## 2.0 Our findings

There was a range of both positive and negative views around self-directed support. Findings have been grouped into seven main themes taken from the engagement with service users and carers.

### 2.1 Benefits of self-directed support

The vast majority of people we spoke to were keen to share the benefits of using self-directed support. In particular, almost all appreciated and lauded the flexibility that it affords them. Nine respondents who indicated they used direct payments to employ personal assistants (PA's) told us they felt less constrained by the rotas of a traditional care agency and more in control of how they manage their day-to-day life. Three individuals reported that they really valued being able to get out and do social activities, such as shopping, swimming or going to the cinema with support from their personal assistant. For families with more than one child it has allowed parents to be able to spend more quality time with their other children.

***“The positive aspect is that I can employ whoever I like, whenever I like to do whatever I want them to do. I am not at the mercy of somebody in a health trust with a big rota...”***

*Female Carer*

***“Yes I do have freedom of choice, but it's more than that. It's about being able to actually decide for myself exactly what's happening.”***

*Male Service User*

***“We all got a quality of life as a family, we could spend precious time with our other children as they had missed out on us as parents. Giving [my son] independence was unimaginable, he gained so much in every aspect of life.”***

*Female Carer*

Nine participants told us they were able to hire personal assistants that are best suited to the person they are supporting. One participant talked about wanting to ensure their son's PA was a similar age - not an 'old' person. Three people told us that they employed friends or people they already knew, which they preferred over hiring someone they did not know.

***“It's my house they're coming into. I'm picking people not just for their abilities to do the job. Someone I can work with and someone who I am prepared to let into my home space and to work with me in the most intimate of circumstances.”***

*Male Service User*

Additionally, participants told us that some people with particular conditions, such as autism, do not like change or do not cope well with it. Employing a single personal assistant, rather than using a care agency also allowed for consistency in their care.

Six participants told us that self-directed support has enabled the people that they care for to be able to live busy, active lives. They also said that SDS has given their loved ones independence and allowed them to plan for the future - helping to avoid institutional care.

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***“When I think of other adults in learning disability and them institutionalised and you know parents can’t look after them and here I am sitting with a care package coming in, providing [my son’s] care, managing and being in control of his life and giving him and fighting for his independence every day of the week.”***

*Female Carer*

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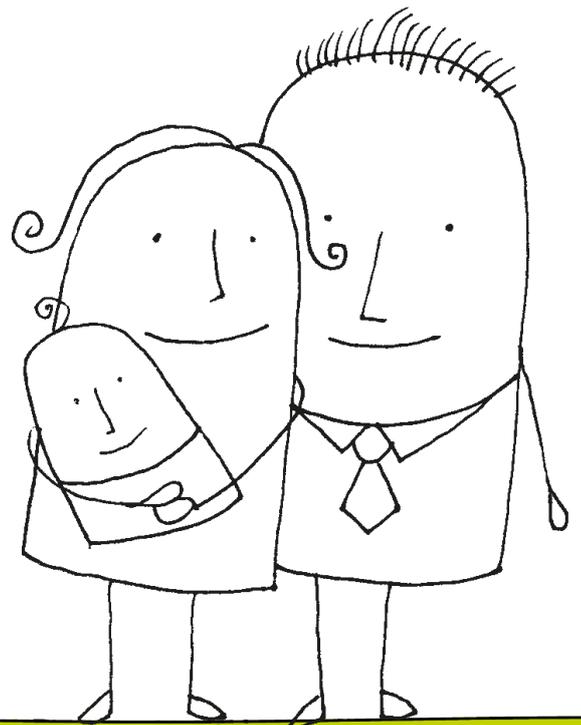
Three participants specifically mentioned the support they receive from the Centre for Independent Living NI in administering payroll and tax, saying they wouldn’t continue taking direct payments if that support was not there.

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***“Only for the Centre for Independent Living doing the tax I don’t think I would have carried on with the self-directed payment because, well, I was afraid of getting into trouble with the tax people...”***

*Female Carer*

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## 2.2 Information

By far the biggest issue reported by service users and carers was around information, or the lack thereof, given to them about self-directed support and how it works. Ten participants told us that they didn't really understand all of the options available to them under self-directed support, with six saying their social worker didn't explain SDS very well. Awareness of other methods of arranging social care beyond direct payments varied between respondents with a small number indicating they hadn't heard of the other options available. One participant in particular reported that they felt forced into taking direct payments and weren't given any other options.

***"I feel that social workers on the ground need to have more training so that they can provide an understanding when they're making their assessments on self-directed support."***

*Female Carer*

Three recipients of self-directed support did not feel confident they were following the correct process for administering and handling the paperwork for direct payments, with five participants saying they felt that their social worker and the Trust did not provide enough information or support when they first started receiving direct payments.

***"I still have that fear that I'm just not doing everything right."***

*Female Carer*

***"Whatever job you go for anywhere in life you get training for it... You don't just fire money at people and say 'here, do what you like' and then a year later 'oh no, you're doing that wrong' you know and they take it back off you."***

*Female Carer*

People also told us they would like greater clarity on the funding panels that assess how much social care support someone needs. They felt that this process was not transparent and questioned if there was a defined criteria for determining how many hours of care someone is entitled to.

Recipients of SDS were keen to point out their reliance on their peers for finding out information about self-directed support and direct payments. Three participants told us they were part of peer-support groups, either online or face-to-face and these would often be their first point of call when seeking information or advice. It was suggested that those who were contemplating using direct payments should be given the option to speak to someone already using them to enable them to understand their experience as a service user. Others felt a training course provided by the Trust might help better equip people to administer direct payments confidently.

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***“What [people] don’t need is leaflets thrown at them. What these people need is to talk to somebody who is in receipt of direct payments.”***

*Male Service User*

***“Obviously as parents of children with complex needs we all speak, we all communicate and it’s not nice, you know, whenever different trusts are being more supportive and more understanding.”***

*Female Carer*

***“It became very obvious that the social workers do not know the process, we had more guidance from our peers and the Centre for Independent Living.”***

*Female Carer*

***“I did the Go for It programme years after I took on [my son’s] direct payments. The Trust should have a tailored course and empower anyone who wishes to take it on their choices in life...”***

*Female Carer*

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Six participants told us there seemed to be confusion around what they could spend their direct payments on and who they were allowed to employ, with particular focus on the eligibility of close family members and friends. Conflicting advice and an awareness of peers being able to employ people that they were told they were not allowed to employ have added to the confusion.

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***If I could change one thing about self-directed support [it would be] clear guidance on what you can spend the money on. You find yourself in the scenario where you’re kind of going ‘oh well if I spend this will I get in trouble?’”***

*Male Service User*

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Two people were unaware of the support that the Centre for Independent Living NI were able to provide, particularly with respect to payroll administration. Five participants felt that there should be better support for people becoming an employer and it was suggested that Trusts should provide a bespoke training course, or possibly an e-learning package for recipients of direct payments.

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***“It’s a bit complicated at the beginning, you know? Because of the jargon and the tax and having to pay your employee and things...”***

*Female Carer*

***“What I’d say to change is to have a standard training programme within the Trust to take on direct payments.”***

*Female Carer*

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## 2.3 Recruitment / Retention of Staff

Eleven participants expressed varying degrees of difficulty in recruiting staff and keeping them. Nine of them felt that the initial process of posting advertisements, shortlisting and interviews was very time consuming and onerous. This was then compounded by having to liaise with their local HSC Trust to conduct background checks on potential employees. Ten participants expressed frustration in organising the Access NI checks through their HSC Trust, which they felt was a very bureaucratic process. In addition, people felt that the length of time it took for these checks to be carried out meant that good quality candidates were dropping out because they managed to secure employment elsewhere.

*“Typically I get students, but when they finish their course and get a full-time job it can be hard to find people that have the right skills and that you think you can trust...”*

*Female Carer*

*“There’s got to be a streamlined system where we identify a prime candidate, give the names to the Trust, the Trust clears them within a maximum of a fortnight. Anytime after a fortnight, you go back to them there’s a good chance they’ll have got another job.”*

*Male Service User*

*“It can be very hard to find suitable carers, the delay can cause arrears on direct payments which mean they can be cancelled and looks like there isn’t a need when there very much is.”*

*Female Carer*

People with a smaller assessed need for social care expressed great difficulty in recruiting personal assistants. They said that it was hard to attract someone to apply for the job when they can only offer a few hours per week.

*“Unless you’re offering somebody like sixteen hours or a full-time job, nobody is really interested in doing two hours here and two hours there you know?”*

*Female Carer*

*“[We get] eight hours a week, so it’s extremely hard to find people because it’s not viable for them to get a full-time wage out of it.”*

*Female Carer*

Six participants expressed an interest in having a central database of people that could be used to help identify suitable personal assistants or care workers. People were keen that such an information source would show people’s training and experience, their location and possibly include reviews from other people. This, they explained, would help to relieve some of the burden of trying to identify suitable candidates.

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***“If the Trust could get their head around like a database of available workers that tells them apart that would be really good... I met a girl yesterday and she was looking to do direct payments and stuff, it would have been great to be able to say to her there is a database, try that.”***

*Female Carer*

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Three of the people we spoke to told us that carers with particular skills usually command a higher wage with a care agency. This has meant that the ‘flat rate’ that is offered through direct payments is often lower than what someone may get working for a care agency, making it very difficult to attract staff. Often this leaves people with no option but to ‘top up’ a carer’s wage with their own money. Additionally, people often ended up employing staff without the necessary skills and arranging training. However, there was a feeling that staff who were then trained in these more specialist skills were then moving elsewhere where they could get a higher wage.

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***“I don’t feel that there’s a lot of flexibility mainly because of the difficulty in employing and maintaining appropriately trained carers, especially whenever it is a child that has significant complex needs.”***

*Female Carer*

***“The recruiting and retention of carers and personal assistants is a major issue. We have to pay a supplement to retain carers who have to have specific skills whether gained academically or via life experiences.”***

*Male Carer*

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A big issue for participants was their inability to employ close family members, such as a sibling, to provide care and assistance to them or their loved one. They explained that these family members already have a close relationship with the person and understand their care needs well, so would be best placed to provide it. This was thought to be even more important when the person needing care has complex needs or a learning disability and where they may have difficulties or reluctance to have a stranger care for them.

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***“My son has a big brother and I’m not allowed to pay him out of the direct payment money, which I think is a bit of a negative. He is probably the best support worker that my son could have but I’m not allowed to pay him.”***

*Female Carer*

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## 2.4 Financial issues

Three people reported that their social worker explained how their direct payments could be used to pay for gym memberships, clubs, or other similar activities. Whilst some of the people we spoke to were able to use their direct payments for these activities, two participants told us that any money spent on this type of thing 'took away' money that could be spent on direct care and therefore was not a viable option for them.

***"Every penny goes on care... So if I take travel or gym membership that cuts into me back doing unpaid care for [my son]."***

*Female Carer*

One participant highlighted that the hourly rate of direct payments hasn't risen in line with inflation, further adding difficulty to recruiting and retaining good quality staff.

Two carers of children who have complex needs expressed difficulty around childcare arrangements. They explained that most people would use working tax credits to pay for childcare services whilst they are working, however many childcare facilities are unable to accommodate children with complex or specific needs. This left parents feeling like they were losing out on money because they were unable to use their tax credits and they weren't allowed to use direct payments to pay for childcare services. This issue was made more difficult for parents during school holidays, with the participants explaining they had requested additional direct payments to cover the holidays but were refused.

Another issue mentioned by participants was that direct payments don't cover the costs associated with the administration of being an employer, such as the fee charged by the Centre for Independent Living NI for payroll services. They also stated that direct payments cannot cover the provision of an alternative member of staff when a carer or personal assistant is off sick or on maternity leave, leaving them reliant on Trust provided services, which aren't always as flexible.

***"When somebody lets you down you don't have the backup of the Trust, that's the negative."***

*Female Carer*

Four participants said they strongly believed that self-directed support should enable carers to stay in paid employment, but often felt that they weren't allowed to pay for services that would support them staying in full-time employment.

***“The ‘vision’ we’ve all seen at SDS events about family carers being able to return to work and really happy disabled people enjoying themselves is a facade.”***

*Female Carer*

***“[Self-directed support] can’t be used to enable parents to work which is a huge issue for parents and carers who want to work but can’t find appropriate childcare for their child with disabilities.”***

*Female Carer*

## **2.5 Disparity of service**

People who live with long-term conditions, or who care for a loved one often connect with their peers in similar circumstances for advice, support and companionship. As mentioned previously, many of the people we engaged with said they were involved in peer support groups and were therefore aware of a disparity of services between Trust areas and sometimes even within their own area.

Five participants felt that they were part of a ‘postcode lottery’ in terms of what services they are able to arrange or purchase through direct payments. Four participants said their local HSC Trust was very prescriptive on what could be purchased, with direct care services only being allowed. Others felt that their local HSC Trust was very flexible in what they were allowed to spend their direct payments on, which included things like gym memberships, or going swimming, etc. People felt that there was no clear explanation as to why some people could avail of more services than others.

***“We need a safe, hassle free way to recruit personal assistants. We need honesty, there’s so much variation throughout trusts regarding who gets what and what it’s used for.”***

*Female Carer*

***“It really does vary between trusts regarding what [direct payments] can be used for. In ours it’s respite only, can’t be used for anything else that would really benefit the child and carer.”***

*Female Carer*

Two participants said they were aware that different HSC Trusts pay different hourly rates for direct payments and felt that this was unfair. They felt that a standard homogenised rate should be paid across Northern Ireland.

***“Some parents are getting less than us and some parents are getting more than us, depending on their circumstances, but we should all be getting the same rate of pay. I do think overall it should be standardised, I don’t think one trust should differ from the other.”***

*Female Carer*

## 2.6 Administration / Bureaucracy

Nine of the people we spoke to said they found the volume of paperwork and administration involved in being an employer of carers / personal assistants was a burden. They felt this could be very off-putting to people and may discourage people from availing of direct payments.

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***“You’re trying to manage the money, you’re trying to manage people and you’re trying to manage your health and that can be a challenge, especially if you’re feeling particularly bad.”***

*Male Service User*

***“At the back of my mind there’s a possibility that they don’t really want all these people on direct payments and I reckon the system was made complicated so people give up.”***

*Male Service User*

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Five participants felt that the process of applying for, and receiving direct payments was very bureaucratic and greater support should be provided. Some indicated that there should be a person employed by the HSC Trust to provide advice and support with some of the administrative tasks.

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***“It is time consuming, hugely time consuming... The time that I have taken to chase up after people, to find out what to do with HMRC, to find an employee, to do all those things has taken me away from my mummy and that I really hugely resent. I do believe that there should be so much more support for people who are trying to set this up.”***

*Female Carer*

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One participant believed there was too much unnecessary administration, particularly around Access NI checks. They reported that they had tried to recruit a personal assistant who had already had a successful Access NI check within the last 12 months, but their HSC Trust insisted a new one was carried out.

## 2.7 Other

There were a number of other issues raised by participants which did not fall into the main categories in this report. One issue that seven participants raised was the feeling that they had to 'fight' to get the correct level of support they believed they were entitled to. For some, this meant getting a higher number of assessed hours for social care. For others, it was to get approval to spend their direct payments on a specific service.

*"I had to go through seven directors to get [my son's] care package. I actually ended up phoning seven different numbers for the Chief Executive... The lengths I have went to try and get this care package off the ground was just beyond belief."*

*Female Carer*

One person felt that the expectation of self-directed support supporting people to "get out into the community" was very prescriptive and didn't suit everybody. They felt that whilst SDS should absolutely support people to get out of the house, it shouldn't be the only option. People shouldn't feel forced into activities they do not want to do.

*I think self-directed support is a bit prescriptive because they're saying "We'll look up these classes, we'll look up these courses and we'll get you out to that and you'll be in the community." Now I find that's quite patronising to be honest.*

*Female Carer*

Another participant told us that looking after a loved one with complex needs affects the whole family unit, so self-directed support should focus on supporting the family as a whole, not solely the individual that receives it.

*"In my experience, from a direct payments point of view, the hours can only be used for [my son's] care, whereas the guidance for self-directed support says it's meant to be the whole family, it's meant to be flexible, it's meant to give choice and it can be used for things other than care."*

*Female Carer*

## 3.0 Conclusion and key points

It is clear from speaking to recipients of self-directed support that it can make a big difference to their lives. People value the flexibility that it affords them, with many being able to live active, independent lives and avoiding institutional care. People have told us they feel in control of their own agenda and day-to-day lives by being given the tools to direct their care how and when it suits them. For carers it has enabled them to have a life beyond their caring duties and allows them to feel comfortable knowing that the person providing care to their loved one is consistent and trusted. This is very encouraging to hear, however, it appears there is substantial work that needs to be carried out to improve people's overall experience of the service.

Many of the issues people face with self-directed support involve poor communication and a lack of clear, concise information. These are issues that should be relatively easy to address, and involve little cost. Confusion around what self-directed support can and cannot be used for, and what services can be purchased through direct payments has led to frustration with many users. Indeed, many participants told us that this lack of clarity made the option of using self-direct support and direct payments very off-putting to them.

People are very aware of the differences in the implementation of self-directed support between Trust areas in Northern Ireland, and in some cases even within their own Trust area. This disparity of service, particularly at a local level, has engendered a feeling of unfairness and has led to a great deal of frustration with some users. A perceived lack of transparency around how people are assessed for self-directed support has added to this frustration. We believe by making the assessment process clearer, service users and carers will be better empowered to challenge decisions they feel are incorrect.

As envisaged within the 'Power to People' report, with self-directed support being further rolled out across the province and a larger market being created for care providers, it is hoped that some of the issues around recruitment and retention of staff will reduce. In this interim period, however, we believe it is important that Health and Social Care services do what they can to support people to employ high-quality, qualified care workers and personal assistants. Efforts to reduce the levels of bureaucracy involved in administering the scheme, reduce delays in background checks and better support in identifying suitable candidates for hire would go a long way to alleviating the burden that many people feel when receiving direct payments.

The key points arising from this report are summarised as follows:

1. Service users and carers need greater support in identifying and recruiting high-quality, reliable and qualified personal assistants and carers. A scoping exercise should be carried out to determine the feasibility of commissioning a website, or other resource that can aid recruitment.
2. Users of self-directed support, particularly those that opt for direct payments, often feel unsure of the options of support available to them and their obligations as an employer. It would seem prudent that Health and Social Care Trusts alongside the Health and Social Care Board should 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 consideration should be given to those who do not have access to a computer / the internet.

3. Recipients of self-directed support often feel there is a disparity of service between the different Health and Social Care Trust areas. Work should be done to ensure that there is parity across the five Health and Social Care Trusts with respect to what services are available through self-directed support and direct payments.
4. Service users and carers commonly feel that their social worker did not provide them with adequate information about self-directed support when they first availed of it. It would seem necessary that the five Health and Social Care Trusts should ensure that social workers are fully aware of all of the options available to recipients of self-directed support. Social workers should also be given sufficient time to explain the detail to their clients and answer any questions they may have.
5. The Health and Social Care Trusts should consider running a 'self-directed support champions' scheme, where new users and people thinking about taking self-directed support can speak to someone who already uses it and learn from their experiences.
6. Issues with administration and bureaucracy were highlighted as a negative factor of self-directed support. One action that would help to improve this would be for the Health and Social Care Trusts to look at ways in which they can reduce the length of time it takes to organise and process background checks for potential care staff.
7. Participants raised concerns that the hourly rate for paid care through direct payments differed across the five Trust areas. The people we spoke to felt that this rate should be homogenised across Northern Ireland and reviewed to ensure it remains competitive within the market.



## 3.1 Acknowledgements

A special thank you to the staff at the Centre for Independent Living NI for assisting us in advertising our engagement sessions.

Thanks also go to the administrators and members of the Direct Payment User Group NI on Facebook who supported the Patient and Client Council with this project.

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