Direct Payments in Sheffield: Key issues and ideas for change

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Summary:

This report presents a summary of responses and contributions made to Disability Sheffield as part of Sheffield City Council's Direct Payments Review and Strategy Development work undertaken in October 2020 – January 2021.

As part of the work a survey was developed with a group of direct payment recipients and distributed within Sheffield. A series of interviews and discussion groups were also held. There was a total of 87 people who responded to the survey, and 25 people participating in one to one interviews and discussion groups. From this a number of issues were noted as key concerns for direct payment recipients in Sheffield. These are:

- 'The rules are not clear' Information about direct payments is not often accessible and is hard to navigate.
- 'You can't get an answer' Resolving problems can be lengthy or sometimes just left incomplete or unanswered.
- 'It gives me more choice, freedom and better quality support'
 Direct payments offers person centred, flexible, high quality support.
- 'It's a risky staffing situation' Rates of pay, the lack of development opportunities and precarious conditions can put staff and employers at significant risk.
- 'We are exposed' Uncertainty in support and an inflexibility in what an allocation can be used for causes pressure and distress.

Additionally, people were asked about what changes they felt they would like to see made in the future. From this a number of the suggestions were noted and are summarised as follows. These are to:

- Create a clear information map of the rules and processes. To enable clarity and accuracy in understanding direct payments.
- Establish an ongoing user led review. To ensure quality and satisfaction in direct payment use.
- Facilitate a problem-solving supportive hub. Create a safe space to quickly resolve issues.
- Prioritise development and infrastructure for Personal Assistance. Build and support a strong workforce.
- **Profile direct payment success** Showcase how direct payments facilitate inclusion and high quality support options.

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Introduction

This document presents a summary of responses and contributions made to Disability Sheffield as part of Sheffield City Council's Direct Payments Review and Strategy Development work undertaken in October 2020 – January 2021.

This includes a report back on the survey and interviews and discussion groups held with a range of people with lived experience of using direct payments and social care to gather feedback, opinions and views about the future of direct payments.

Sheffield City Council commissioned Disability Sheffield to engage with a range of people with lived experience of using social care to gather feedback, opinions and views about the future of direct payments. The purpose was to identify key issues and make suggestions as to where changes should be made concerning direct payments policy and practise in Sheffield.

Approach and Activity

Disability Sheffield is a disabled persons organisation run and controlled by disabled people that aims to promote inclusive living, campaign for equality and complete control and to co-produce innovative solutions to the barriers disabled people face. Disability Sheffield facilitates the Sheffield Individual Employer and Personal Assistant Development Group that is focused on direct payment issues. Stephen Lee Hodgkins is a disabled person with research and facilitation experience of coproduction and participatory methods. This all brings a particular set of skills and insight to the work that are rooted in the principles of individual living. This is focused on ensuring that disabled people and their experiences is rooted in work that seeks to change policy and practice that impacts on their daily lives.

Disability Sheffield adopted a coproduced and participatory approach to this work to develop and circulate a 'direct payment' survey, plus undertook a number of one to one interviews, plus four discussion groups. An initial group of direct payment recipients were engaged with to shape the design of the survey to ensure its relevance and enhance responses to it.

Towards the end of this work, a further group of respondents to the survey, plus some of those who had participated in interviews were presented with a summary of the feedback, plus several themes and ideas for change', as detailed below, to develop and test these further. Feedback at this latter session has been incorporated into this report

Publicity information was distributed through Disability Sheffield's individual employer's network and other contacts, as well as through Sheffield City Councils 'direct payment' recipient mailing list. Specific information about the survey and a link to be able to complete it was distributed through Disability Sheffield's contact and networks. Additionally, effort was made to connect with the BAME community in Sheffield. Details of the survey and the opportunity to participate in the work were promoted via the BAME Covid Public Health Group. Details of the work were also shared and promoted via the organisation SACMHA, who provide support to people who feel marginalised and struggle to access services.

All of the activity undertaken to capture information for this work happened online. An online survey, enhanced for smartphone and tablets interface, interviews and discussion groups carried out by video call or phone. We recognise that the impact of lockdown has had on capturing a wider range of diverse voices from those that do not have access to online technology. We note this is a significant issue for the BAME communities, as well as other groups in Sheffield, and assert that this requires exploring further to ensure those voices are captured.

Initially a 'direct payment diary' method had been proposed for this project, though there was very little interest in and take up of this. However, through the survey a number of people expressed their willingness to engage in further work about direct payments and so a diary capture method, or other ways to engage with them is possible in the future.

People who responded

There was a total of 113 people who responded to this work. This is made up of 87 people responding to the survey, 14 people participating in one to one interviews, plus two discussion groups, with 2 people in the first and 10 in the second. The first was with 2 representatives from

Sheffield's Somali community with an interest in disability, and the second with 10 representatives from Sheffield Voices, a self-advocacy group of people with learning disabilities.

Monitoring information of personal characteristics was collated from people responding to the survey. Forty-four people gave responses. From the disability / impairment category, there was a spread across a range of groupings, with 'physical impairment' (17), 'long term health condition' (17) 'learning disability' (16), and 'autism' were most recorded. For ethnicity 'White British' (34) was most recorded. For age '55-64' (15) was recorded most, but with ages 16-84 included. For gender identity 'female (including trans female)' (25) recorded most responses, and 'unpaid/informal carer' was recorded for 22 respondents. Full details of the monitoring information recorded can be seen in appendix 1. This worksheet contains a 'summary' sheet that lists the questions, and numbers and percentages of responses to each, plus a 'results' sheet that contains all of the responses and data received.

The report includes several quotes received from people who responded to the work. These are presented to highlight key issues and suggestions made to us.

These key issues about direct payments that people told us about and the ideas for the changes that they would like to see in the future are presented next. Following this some of the further detail about relevant responses to the survey are given. This includes specific responses to experiences of direct payments in relation to, ease of set up and use, information, employment, money management, solving problems, positive aspects of direct payments and future changes.

Ideas for change

This section presents five suggestions and ideas for change to direct payments in Sheffield. These are based on feedback captured through both the survey, interviews and discussion groups. They draw together a range of experiences and suggestions people have made about where they feel change should be. These ideas were first developed in and then tested with a group of direct payment recipients, who gave feedback, which has been incorporated below to illuminate the point. These are presented below along with relevant quotes from respondents to the survey. These are not presented in priority order, though it is noted that staffing is overwhelmingly seen as a fundamental issue that impacts throughout the whole direct payment experience.

1. Create a clear information map of the rules and processes

'...Make it more open. [We should] be able see social worker submissions. Decisions being [made] clear, accurate and more timely. [And] be there 24/7...'

Create a range of accessible information, on a variety of platforms with the diverse communities of Sheffield that empower and informs recipients factually, impartially, and in a way that is culturally relevant. It should be produced in a range of formats and utilise human stories to promote potential of direct payments. Information should be presented accurately across the many contexts that it is delivered. That is, during formal interactions like assessments or reviews, official correspondence or other information material, both online and off. Information for direct payment recipients, current or potential, should be broken down into clear sections and map out the journey, expectation, entitlement and responsibilities in a transparent and accountable way. It was also noted that a 2012 guide for individual employees previously produced was useful, but now is felt to require an update.

2. An ongoing user led review

'...To universally embrace the clear rationale of D.P by those who support, work and deliver. A equal relationship between the L.A and the I E to ensure a full and rich life..'

Commit to an ongoing partnership and involvement with an expert group of direct payment stakeholders to review and assess policy and practice periodically. The group should ideally have a formal role within the statutory structure, be made up of people with lived experiences, direct payment recipients and council staff and others with formal responsibility. The purpose being to work in partnership to ensure inclusion through quality. This group could undertake reviews of performance, quality, troubleshoot barriers and develop solutions. This group should be informed by robust data about direct payment take up, usage and outcomes.

3. A problem solving supportive hub

"...What I wanted was more advice & support about recognised providers who could help us, instead of money thrown at us and being left to muddle though it by ourselves..."

Develop a peer support, but multi agency hub that offers practical guidance and advice in a human and sensitive way to support recipients resolve issues and develop strong direct payment support functions. Such a space should be able to connect people looking for advice or solutions with those that can offer help, or provide information and examples of such. It should be able to offer guidance and support and facilitate sharing problems and solutions and be supported by 'champions' within the community and local authority who actively promote direct payments.

4. Prioritise staff development and infrastructure

"... higher rates of pay for the Personal Assistants who without them I couldn't do my job..."

Increase PA pay rates and enhance direct payment recipient's opportunities to reward, retain and develop their staff doing PA roles. Develop a PA peer support network to offer support, such as through a peer support and non-managerial supervision. Enable direct payment budgets to include staff development headings specific to the individual employer. Further develop a 'back up' PA register so that people have support if emergencies arise. Coordinate opportunities for training and development so that recipients are able to access training that is relevant to their roles easily and promptly.

5. Profile direct payment success

"...Direct payments were developed to give people with a defined budget the ability to have control and choice in their lives - in order to give them equality with their able bodied peers- but in practice they have anything but these. There are still many discriminatory aspects of the whole personal budget process and operation which deny disabled people those basic rights..."

Explore ways to promote everyday direct payment success stories that will encourage new or potential recipients to make informed decisions. This could be linked to training materials that support people with setting up a direct payment or making decisions to take one on. Also, this should be targeted at professional roles. As well as this, human stories of positive direct payment usage can be profiled to ensure they showcase how inclusion can be done across a range of backgrounds, cultures, lifestyles and impairment effects.

Key Issues

Each of the following five issues are presented and explored in terms of the impact it is reported to have on individuals. This reflects experiences, frustrations, some positive aspects as well as issues of risk and staffing. These each also include a relevant quote captured through the survey responses that provides some further insight about the experience captured through this work.

'The rules are not clear' - Information about direct payments is not often accessible and is hard to navigate.

While there is a range of general information available about direct payments, such as what it is, how to access it and the support available this is not always easily accessible and can be difficult to navigate.

"...It feels like a part-time job all of its own. There is a lot to remember and a great deal of paperwork to sort out. Whilst I appreciate there has to be auditing and processes around this, it would be really helpful to have a web resource which really sets out all steps, templates and expectations. The information from the Council is okay but the financial confirmation letter is nonsense. It doesn't relate to the support in an understandable way and then that impacts on overspend..."

Members from BAME communities in Sheffield talk about disabled people find social care information to be confusing and unintuitive; especially that about care charges and report of situations where individuals avoid seeking help as they feel it to be problematic, rather than supportive.

Additionally, more detailed information about specific aspects of information, including entitlement, processes, expectations, and responsibilities are not well mapped out. The presentation of this information is also not transparent, and people report experiences of assessors withholding information about direct payment options. This was articulated as being about an imbalance of power in the relationship; That is that direct payment recipients feel as though they are treated as competitive service contractors rather than independent partner facilitating citizenship and inclusion.

'You can't get an answer' – Resolving problems can be lengthy or sometimes just left incomplete or unanswered.

When things go wrong or there are disputes about say, contributions, inflationary uplifts, reviews or expenditure queries people report a frustration at the long lengths of time it might take to resolve issues.

"...Getting the correct figures from the assessment - there were numerous errors in the calculations made by the Council. At one point, the monthly sum was being paid in weekly. Arranging uplifts for providers is a nightmare. It would be great if the money could be used very flexibly between providers..."

Additionally, when matters are resolved there appears to be a lack of ownership or responsibility taken as why the error may have occurred, such as a disability related expenditure readjustment or overcharging.

'It gives me more choice, freedom and better quality support' – Direct payments offers person centred, flexible, high quality support.

People report that direct payments enable a greater level of choice and control. Support can be styled in a person centred way to suit the individual.

'...My children get the support they need. They are able to be kept safe by dedicated PA's who are committed to their role. As a family, we are able to have a better quality of life, instead of just coping from one day to the next, and being terrified for our children's safety. We are able to put all the therapies in place (speech and language, OT, behavioural support) that we couldn't do before as we were constantly doing crisis management...'

Local management of support and assistance offer a way to wider participation as well as being able to avoid institutional values of the 'care' setting that focus on reducing tasks to body parts, not inclusion.

'it's a risky staffing situation' – Rates of pay, the lack of development opportunities and precarious conditions can put staff and employers at significant risk.

Rates of pay, development opportunities and support infrastructure are reported as fundamental workforce and management issues. For individual employers with PAs recruiting skilled staff can be difficult, and for those using staff via agencies there is a key issue about consistency.

"...[it's a problem] finding quality PAs, especially at such low pay e.g. £10 [and] training them especially as funding is hard to get at the time needed. Coping with Covid, the risks of PA passing on Covid if they are in property. It takes a lot of time recruiting PAs, induction & training then twice I've found they're unreliable or not suitable and it's very hard to terminate them as legal advisors are fearful of litigation, regarding unfair dismissal due to alleged discrimination. Which is very distressing for [us as] the employer..."

Overwhelmingly respondents raised issue with the low wages for staff and the difficulties this causes. An individual employer noted from a BAME community in Sheffield reported PAs persistently asking for wage increases, and the relationship breaking down. People report challenges of staff retention and will try and use creative ways to reward staff, such as encouraging training opportunities or flexible working arrangements etc. Back up cover can be problematic and can put additional pressure on families who will take on support responsibilities.

'We are exposed' - Uncertainty in support and an inflexibility in what an allocation can be used for causes pressure and distress.

People report feeling isolated and having to sort out things for themselves from the off. While some initial guidance maybe given, set up and development of the support arrangement can become a significant responsibility.

"...I found the whole process extremely slow. We no longer have a social worker assigned to us so cannot approach anyone for further support or advice. It's not monitored even though I keep getting hints that [the council] will start this, you [the council] haven't actually asked for any paperwork yet. I didn't want to be an employer but was left with little choice and found this aspect extremely daunting. ... I think it has been more to do with the mental health team not knowing how it works properly and not supporting the whole thing appropriately. It is much better now I have different people involved but it put me in a lot of dangerous positions..."

While some are keen and capable to take on the direct payment, they also can feel unsupported, with some managing and some not, which can lead to difficulties and a breakdown in the support arrangement. There is also a frustration concerning the lack of flexibility in what a direct payment can be used for, the length of time it can take to get authorisation for minor changes and an excessive focus on budget lines, rather than broader headings that relate to independent living.

Survey

The content for the survey was developed with a group of direct payment recipients. A series of questions were developed around respondents' relationship to direct payments and refined in collaboration with this group. The intention was for the survey to capture specific data from people responding to this work about their experience of direct payments in relation to, ease of set up and use, information, employment, money management, solving problems, positive aspects of direct payments and future changes.

The survey was developed to be completed by direct payment recipients as well as others using social care. The intention to capture information about the experience of using direct payments, as well that about challenges and opportunities for those who might be able and choose to make use of them.

The survey was developed and made available using the RIX EasySurvey software tool, a web based survey interface with a range of accessibility features built in. These include, large text, text to speech and image options. The final survey contained 39 questions, including single and multiple select responses, scales and free text responses. A copy of the survey can be seen here - https://www.rixeasysurvey.org/kiosk/PK42

As was mentioned above there were a total of 87 responses to the survey. Of these 9 respondents 'did not receive a direct payment', 17 'had a direct payment managed for them, 26 'received a direct payment for themselves' and 34 'received and managed a direct payment for someone else'.

Table 1. Responses to Q#1 - 'Which of these applies to you?'

Question option	Count	%
I receive and manage a direct payment for my	26	30.20%
own care and support.	20	30.2070
I receive and manage a direct payment for	34	39.50%
someone else.	34	39.30 /6
Someone else receives and manages a direct	17	19.80%
payment on my behalf.	• •	1010070
I don't receive a direct payment.	9	10.50%

The following sub sections provide a summary of responses to the survey in terms of experience of direct payments relation to, ease of set up and use, information, employment, money management, solving problems, positive aspects of direct payments and future changes. Where responses to questions are shown these are presented as numbers of responses, rather than %. Where relevant additional feedback and reflections captured through the interviews and survey from 'free text' responses these are presented alongside summary of survey responses.

Because of the low response by those not receiving a direct payment, these responses have not been include in the following section that provides an summary of the survey. Though they can be viewed in appendix 1, along with a full summary of responses to each question included in the survey.

Ease of use

A response of 'very easy' was recorded as highest for question #11 'how easy was it to set up your direct payment'. For question #12 'how easy do you find it to organise and manage your direct payment' there were '20' responses as 'very easy' and '18' as 'difficult'.

Table 2. Responses to Q#11 – 'How easy was it to set up your direct payment?'

Question option	Count	%
Very easy	26	37.1%
Easy	10	14.3%
Neither Easy or Difficult	16	22.9%
Difficult	14	20%
Very Difficult	4	5.7%

Table 3. Responses to Q#12 – 'How easy do you find it to organise and manage your direct payment?'

Question option	Count	%
Very easy	22	31.9%
Easy	13	18.8%
Neither Easy or Difficult	13	18.8%
Difficult	18	26.1%
Very Difficult	3	4.3%

While it should be noted there may be some bias in responses here, people not want to reveal their 'difficulties', feedback from the interviews noted that for some difficulties setting up or managing a direct payment were not necessarily related to an individual's personal capacity. Rather that it can be associated with complications with processing an application. Or, in the case of setting up a direct payment, difficulties arising from the adjustment of having the need for social care following the experience of acquiring an impairment.

Information

Being able to 'access clear information' (16) and 'communicating with the council' (16) were recorded has the highest response to problems experienced about 'information and advice'.

Table 4. Responses to Q#15 – "What problems have you had with your direct payment that are about information and advice?"

Question option	Count	%
Accessing clear information.	16	29.6%
Getting advice.	11	20.4%
Communication with the council.	16	29.6%
Understanding documents: like contracts and	4	7.4%
terms and conditions.		

In addition, the following quotes were recorded in 'free text' responses that requested further details about problems experienced with information.

- '...[There is] conflicting information between Social Care and the CCG...'
- "...We had trouble recently because our older daughter has to pay towards her care. It wasn't clear if we should be paying the council or [provider]. It has taken ages to sort out in fact I not sure it is sorted. COVID hasn't helped as many people are working from home...'
- '...[Council] staff kept making mistakes in all sorts of different ways, and it often took months to resolve problems, because THEY didn't have access to the information that I had, and I found that it was usually down to me to tactfully give them the information and advice that THEY needed. I think I probably knew more about Direct Payments than many of the social care staff did because of my involvement in the 2009 Pilot scheme, and my involvement (as a service user) in the training that all staff received...'

Employment

Problems relating to 'staff training and development' (8) were recorded as the highest response to the question 'have you had problems that are about being an employer', though this question invoked a lower response rate than the similar question for information. Though feedback captured through the interviews noted the issue of pay being highly significant for all aspects of staffing.

Table 4. Responses to Q#17 – 'What problems have you had with your direct payment that are about being an employer?'

Question option	Count	%
Managing redundancies.	6	17.1%
Maternity cover.	4	11.4%
Sick leave.	6	17.1%
Staff training and	8	22.9%
development.		

In addition, the following quotes were recorded in 'free text' responses that requested further details about problems experienced with employment.

- '...[There are problems with] being an 'employer' on paper, but Social Care [department] dictating the hours and rates of pay...'
- "...On one care package, despite being just the person named as the employer and funds being managed by [provider] we are still responsible for nest pension letters and updates and tax documents. I asked for an agency to cover so I would not have these issues. Also [provider] do not tell staff how much holiday they have remaining when asked..."
- "...[Knowing when to apply for] wage increases for staff, as I get no notification of any increases. This is despite recently being told that the council increases regularly the wages of staff..."
- '...There could have been problems when I needed to make someone redundant, but I worked it all out (the redundancy payment) and then asked social care staff to check it. I couldn't find anyone who would check my calculations. I kept getting 'signposted' to other departments. So I gave up, and got advice from ACAS instead, and my calculations were correct...'

Money

Responses to the question about problems relating to managing the money recorded highest responses to 'inaccuracy in financial assessments' (11) and 'calculations of disability related expenditure' (12). Feedback capture during the interviews echoes this, with some describing considerable time periods taking to resolve financial issues, and sometimes being left with matters being left unresolved.

Table 5. Responses to Q#19 - 'What problems have you had with your direct payment that are about managing the money?'

Question option	Count	%
Inaccuracy in financial assessments.	11	25.6%
Opening a bank account.	4	9.3%
Calculation of disability-related expenditure.	12	27.9%
Making payments.	6	14%

In addition, the following quotes were recorded in 'free text' responses that requested further details about problems experienced with managing the money.

- '...Had an annual review last year and the payments have been a) inconsistent, causing anxiety over late payments to support provider and b) playing "catch up" with monies paid into account...'
- "...Time to do the payments. I struggle to have enough hours in day..."
- '...[The] Mental health team not allowing me to use my direct payments to help me live safely especially during the pandemic...'

Monitoring

Problems relating to monitoring were highest relating to 'understanding what information I should keep' (5) though overall this question generated a low response rate.

Table 6. Responses to Q#21 - 'What problems have you had with your direct payment that are about monitoring?'

Question option	Count	%
Keeping receipts.	1	4%
Completing financial monitoring forms.	4	16%
Returning unused money.	4	16%
Understanding what information I	5	20%
should keep.		

In addition, the following quotes were recorded in 'free text' responses that requested further details about problems experienced with monitoring.

- '...[There is an] uncertainty about the frequency, this has ranged from a couple of months to over a year..'
- "...A monthly invoice used to be sent to the employer, but this doesn't happen now..."
- '...[There is] no feedback whatsoever after submitting monitoring forms (no acknowledgement of receipt of forms, no additional information requested for any discrepancies)...'

Solving problems

Responses to issues of solving problems were given as 'dealing with changes' (14) as highest. Though responses to other options here were somewhat evenly spread, with 'resolving disputes over acceptable costs' (11), and 'correcting errors' (10).

Figure 7. Responses to Q#23 'What problems have you had with your direct payment that are about 'solving problems?'

Question option	Count	%
Resolving disputes over 'acceptable costs'.	11	26.8%
Correcting errors.	10	24.4%
Dealing with changes.	14	34.1%

Feedback captured through the interviews presented a range of experiences relevant here. While some note experiences of not being able to resolve issues, and being constantly referred on to other departments, others note the 'direct payment team' responding well when presented with clear questions and a paper trail of evidence.

In addition, the following quote was recorded in 'free text' responses that requested further details about problems experienced with monitoring.

- "...General unwillingness to confirm any aspects of the package, until it all goes wrong and then it's my fault..."
- '...No respect for PA's as valued employees PA's are very much seen to be 'lesser' in the hierarchy of professionals involved in

families lives, yet play a vital role in supporting children and young people with disabilities...'

Additionally, a full list of feedback given to the question 'please tell us about any other problems you have had with your direct payment here' is given in Appendix 4.

Positive aspects of direct payments.

There was a high response to the question 'what is good about having a direct payment?', a total of 53 responses, with 'better quality support' (15) and 'I can be more independent' (15) with most replies.

Table 8. Responses to Q#25 - 'What's good about having a direct payment?'

Question option	Count	%
It gives me more choice.	10	17.2%
It puts me in control.	13	22.4%
I can be more independent.	15	25.9%
It gives me better quality support.	15	25.9%

Feedback captured during the interviews also highlight the value people place on being able to achieve more person centred, and a higher quality of support. A full list of feedback given about positive aspects of direct payment is give in Appendix 3.

This is also reflected the following quotes were recorded in 'free text' responses that requested further details about positive aspects of having a direct payment.

- '...It has enabled me to provide myself with care which is personal to my needs. I have been able to employ carers on a permanent basis...'
- "...I can settle invoices with organisations quicker than the council, so organisations have minimum or no cashflow problems. Any mistakes can be sorter quicker..."
- '... [I'm] feeling more secure and confident about my health and social life and privacy ...'

Future changes

Responses to the question 'in the future, where do you think changes should be made to direct payments' recorded 'employing and managing staff' (36) and 'information and advice' (33) as highest, though responses were relatively evenly spread.

Figure 9. Responses to Q#27 - 'In the future, where do you think changes should be made to direct payments?'

Question option	Count	%
Information and advice	33	21.9%
Setting up a direct payment	23	15.2%
Administration and record keeping	25	16.6%
Employing and managing staff	36	23.8%
Support to manage a direct payment	28	18.5%

In addition 36 'free text' responses were given in response to the question 'Are there other changes would you like to see made to direct payments in the future?'. Theses have been incorporated into the themes developed for the section 'ideas for change towards the end of this document and are presented in full in appendix 2. A small range of these are given here to reflect these responses.

- "... A more speedier process, especially in decision making, a quicker payment process when changes are agreed..."
- "...Flexibility for families to use Direct Payments how they see fit. Allocate a budgeted amount of money, and it is up to the family how they use that amount in terms of hours per week/rate of pay/times of day to use it. It would be much a more realistic reflection of families busy (and often chaotic) lives which undoubtedly needs lots of flexibility that PA's can provide..."
- "...The whole process for me was slightly shrouded in mystery, if I asked questions people said they would find out and come back to me but never did. I have never been in constant touch with a social worker or any other person from the council. The only person who contacted me regularly is an assessor to check if I am still eligible..."

Interviews, discussion groups and additional material

In addition to the survey, several interviews were carried out. This included 8 direct payment recipients and 4 informal carer/PAs. These were held via zoom video call. Participants were given the questions in advance, 'what is your experience of direct payments, what is good, what is bad and what needs to change in the future?'. The interviews last approximately one hour each.

Two discussion groups, the first with 2 representatives from Sheffield's Somali community with an interest in disability, and the second with 10 representatives from Sheffield Voices, a self-advocacy group of people with learning disabilities were held. The questions used for the interviews were asked again in these groups.

In additional, an email submission from a direct payment recipient was received. This gives a detailed account and personal experience of a range of aspects, including support, administration of payments, negotiation of changes and problem solving. This is included in full in appendix 5.

Both the interviews, discussion groups and additional material captured a range of insights and experiences, as well as some considered thoughts about future change. Several themes were noted, through similarity in responses and have been presented above in the previous sections as key issues and ideas for change.

Conclusion

This report presents a range of information that was captured by Disability Sheffield as part of the Direct Payments Review and Strategy Development work led by Sheffield City Council. Disability Sheffield's brief was to facilitate the involvement and coproduction of direct payment stakeholders.

By way of a survey, a series of interviews, discussion groups and some additional material received as part of the process, Disability Sheffield engaged with a range of people with lived experience of using social care to gather feedback, opinions and views about the future of direct payments. The purpose was to identify key issues and make suggestions as to where changes should be made concerning direct payments policy and practice in Sheffield.

A range of key issues were captured from people responding to this work and are presented here, along with quotes given to us. While people report that direct payments can offer a higher quality of support, there are also many concerns and frustrations. These include issues about the lack of clarity of information, inflexibility in what people are allowed to use their budget for, that complications are more often difficult to resolve, rates of pay and staffing issues are overwhelmingly risky and that the uncertainty in support arrangements can cause a great deal of pressure.

Through this work we have noted and reflected upon a number of issues about the direct payment experience. While many people asserted to us that direct payments are positive in enabling a better, higher quality of support, there is also a sense that many are extremely frustrated with many aspects of it. This relates to what is made available and administrative inefficiencies. A fundamental concern relates to the low rates of pay for personal assistants and the impact this has on staff turnover, retention and skills.

Through this work people also expressed to us extreme frustration at the long lengths of time it can take to set up a direct payment, as well delays when requests for changes are made. People told us that delays can be so lengthy that by the time a decision is made the original need has changed. People also reported that they feel there is both a lack of clarity about, and inflexibility regarding what a direct payments can be

used for, with a focus on rigid budget lines, rather than broader headings focused on personal independence goals. While people are sympathetic to the need for accountability and check they also told us they feel this to be often excessive and inefficient. With that said, we also note that there is a significant willingness among direct payment recipients in Sheffield to contribute to making positive changes to local policy and practise. This is not only about giving feedback, but also taking a proactive role in supporting recipients and those involved in administrative roles to shape future outcomes for people. This is a significant community asset that could be engaged with to ensure a broader person centred vision.

From the responses made to us we have presented five ideas where we feel changes should be made.

These include:

- Creating a clear information map of the rules and processes that will enable clarity and accuracy in understanding direct payments for recipients and those involved in the administration alike.
- Establishing an ongoing user led review to ensure quality and satisfaction in direct payment use. This should be informed by robust data and regular feedback and involvement activities.
- Facilitating a problem-solving supportive hub, so that when people encounter difficulties, they can connect with a range of experienced others to develop personal and enabling solutions.
- Prioritising the development and infrastructure of the Personal Assistant workforce, including increasing pay rates, ensuring development opportunities, offering peer support and supervision.
- Profiling direct payment successes and how it can be flexibly used in person centred way so as to showcase inclusion and high quality support options.

We are extremely grateful to the many people who shared with us their lived experiences of direct payments as part of this work. While we note that we have been able to capture and engage a range of disabled people in this work, we note that due to lockdown related restrictions, not

being able to hold face-to-face meetings is a challenge for engaging with some groups who may be digitally excluded. We also recognise in particular the need to explore further the experience for people who have very specific support needs where direct payments has been reported to us to work well, such as with people who are DeafBlind.

We also note that while we did engage with representatives from BAME communities in Sheffield, we also note the impact of lockdown and note that further work may be needed to explore specific issues, with this and other community groups. We also Additionally, while the survey had been intended to be completed by those receiving direct payments and other using other forms of social care, we note that the majority of people who responded were recipients of direct payments.

In addition to the contributions made to this work that enabled us to present the key issues and ideas for change, we have been able to connect to a wider group of direct payment stakeholders who have indicated a willingness to engage in further work. This will be positive for future work look at improving the direct payment experience and Disability Sheffield will maintain and facilitate connections to this group.

Appendices

Appendix 1. Disability Sheffield Direct Payments Survey Summary and Results Jan 2021. Full results and summary of responses to each question included in the survey.

Appendix 2. Survey 'free text' responses to question #28. Full list of quotes and feedback received to question 'in the future, where do you think changes should be made to direct payments'.

Appendix 3. Survey 'free text' responses to question #26. Full list of quotes and feedback received to question 'Please tell us more about what is good about having a direct payment'.

Appendix 4. Survey 'free text' responses to question #24. Full list of quotes and feedback received to question 'Please tell us about any other problems you have had with your direct payment here'.

Appendix 5. Email submission of a personal experience of using direct payments.