

Adult Social Care COVID-19 Taskforce - Self Directed Support (SDS) Advisory Group Report

August 2020

Introduction

The group was convened in order to look specifically at what was needed to ensure that people who self direct their care and/or support (for themselves or a family member) are able to maintain their wellbeing, safety and independence during the COVID-19 pandemic. A broad definition of SDS was agreed to include not just those in receipt of Direct Payments (DPs), but anyone, whether in touch with services or not, managing their or their family members' care or support needs in the community, importantly, from all ethnic and cultural backgrounds and in all types of living arrangements.

During the short time available to undertake this work it was decided to bring in people with a range of networks and personal experiences in order to hear a variety of voices and perspectives. Links with established national forums have also enabled their work to feed in to these recommendations. Using social media we have attempted to hear people's views and check that we haven't missed anything as part of this. (See Appendix A for list of contributors).

Summary

Fundamentally at the heart of the challenges people are experiencing there is a human rights issue and this needs to be raised as a priority as there appears to be little awareness and understanding of this area. Similarly, existing legislation still applies and many of the recommendations in this report reflect the need to implement the existing requirements under the Care Act in the spirit in which they were intended.

"The right not to be treated in an unlawful and degrading way is an absolute right; it is never lawful. This might include a lack of medication leading to pain or suffering, lack of food or fluids resulting in malnutrition or dehydration, lack of care or support to maintain a dignified life and safeguarding issues including harm from self or others. There is a time factor here – a decision might be made that restricts someone's rights, but isn't degrading or inhumane treatment but over a period of time it can become so."

Sanchita Hosali, Director British Institute of Human Rights

We recognise some of the recommendations have funding implications for government but the majority require an attitudinal shift and are the result of proactive joint working at a local level and collaboration across agencies, third sector organisations and user led groups. Working together, pooling knowledge and resources to ensure that people are not left at risk is key. It is not solely the job of the state but requires concerted action to reach out to people intentionally and not assume that because people don't make contact, all is well. This reactive approach is never good but especially not in the context of Covid-19 and represents a need for a fundamental shift in approach that is essential to avoid the worst effects of the pandemic for a great many people.

Seven 'I Statements' that underpin the recommendations:

- 1. Rights:** I have basic human rights that should be respected and upheld
- 2. Trust:** I am trusted to use my PB flexibility to respond to circumstances
- 3. Information:** I have clear and accessible guidance and information in one place
- 4. Practical Support:** I am offered assistance with the admin tasks of being an employer
- 5. Connection:** I have opportunities to network and connect with others
- 6. Balance:** I have autonomy but I know someone will contact me to make sure I'm OK
- 7. Choice:** I can find, or am offered, alternative support if the service I use is not available

Recommendations:

1. Rights:

There needs to be specific guidance/ training on Human Rights in relation to Covid19 with proactive safeguarding in place where needed

2. Trust:

Implementation of existing Government guidance needs to be robustly monitored with statutory organisations being held to account if this doesn't translate into people's experiences

3. Information:

Information needs to be available at a local level that is joined up across different agencies and developed with people who self-direct their support

4. Practical Support:

The offer of practical support should result from a coordinated effort and not be left to chance

5. Connection:

There needs to be coordinated and concerted activity to ensure people have opportunities for connection

6. Balance:

There needs to be coordinated and concerted activity to ensure people are contacted in a supportive way, on a regular basis should they wish, to check how they are doing.

7. Choice:

Where services are closed there should be alternatives offered or the ability to choose to use that element of PB/PHB in a different way

1. Rights

The group heard worrying accounts of people living in supported housing schemes being denied the ability to go out, having their homes effectively turned into locked down accommodation and being prevented from leaving at all. Whilst no doubt well intentioned, this was done against the wishes of the people who lived there with no safeguarding and in direct contravention of their human rights. There were accounts of some people “escaping” this confinement and roaming the streets.

People living with disabilities need to be recognised as a priority for such things as online shopping deliveries and for PPE and regular testing for themselves and for asymptomatic PAs. There is a need for wider recognition of those disabled people living alone who may be highly vulnerable through inability to access basic supplies.

“I am self-isolating not leaving my flat for over 2 weeks now. It’s almost impossible to get a food delivery slot, I registered as an extremely vulnerable person on the government site but heard nothing. My GP claims not to have heard of it”
‘Abandoned, forgotten and ignored: the impact of Coronavirus on disabled people’
June 20
Inclusion London

“I live alone with multiple disabilities and health conditions yet did not meet the criteria for being on the shielded list and had to argue with my GP to accept that I should be included”

Recommendation:

- **There needs to be specific guidance/ training on Human Rights in relation to Covid-19 with proactive safeguarding¹ in place where needed**

2. Trust

There is a fundamental need to change the culture of how people in receipt of PB/PHBs are treated by local authorities/CCGs from one of suspicion to one of trust. In times of such unpredictability the last thing people need is to be asking permission for flexibility in how their budget is used. There needs to be a culture based on trust that assumes people will know what is needed in their individual circumstances to keep safe and well and for them to have the freedom to make extra-ordinary decisions when required.

Needing to seek permission, experiencing fear about the repercussions when their PB/PHB is monitored, and waiting weeks to receive decisions has a detrimental impact on people’s wellbeing and only adds to the stress and anxiety. Statutory organisations need to tell people explicitly that they have this flexibility as a default and apply proportionate restrictions only when there is good reason to do so.

“Local authorities should not design systems that place a disproportionate reporting burden upon the individual. The reporting system should not clash with the policy intention of direct payments to encourage greater autonomy, flexibility and innovation...”
(Care and Support Act Guidance 12.24, DHSC, updated 20 June 2020)

¹ In accordance with the Deprivation of Liberty Safeguards (DOLS) amendment to Mental Capacity Act (MCA) 2005
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"I employ 3 PA's so that I have cover and 7 day a week support. I now only have one PA... Recruiting is impossible and I received an email from DP accounts last week asking me to account for a £16 overspend in December 2019. That was the first contact since March. I feel that I have been cast out from society."

For those who receive public money to meet their needs there must be a new model of accountability that has trust and its heart, rather than a disproportionate assumption of the likelihood of fraud, coupled with light touch monitoring. The prescriptive way that DPs are allocated with a defined and often insufficient hourly rate does not allow the flexibility that is needed.

The DHSC guidance published on 31st July provides welcome explicit endorsement of the principle of flexibility and needs to be fully communicated (with examples of what this looks like in practice) in order for people to experience this directly.

"I was told I needed to contact my social worker to make any changes to my support plan. She had moved on but when I eventually spoke to someone I felt their suspicion but they did agree. Now I need to change it again and am just going to go ahead but I worry about the repercussions of this."

"Monitoring should be proportionate to the needs to be met and the care package. Thus local authorities should have regard to lowering monitoring requirements for people that have been managing direct payments without issues for a long period". (Care and Support Act Guidance, 12.24, DHSC, updated 20 June 2020)

"..the government expects LA's and CCG's to continue to give you as much flexibility as possible in how you use your direct payment. What matters most is that you are able to use your direct payment in a way that allows you to stay well and continue to get the care and support you need." (Using direct payments during the Coronavirus outbreak: Full guidance for people receiving direct payments and personal assistants, DHSC, 31st July 2020)

Good practice example: A demonstration of trust in action is the recognition by some councils (Tower Hamlets being one example) that people will likely incur additional costs and therefore have increased all Direct Payments by 10%.

Recommendation:

- **Implementation of existing Government guidance needs to be robustly monitored with statutory organisations being held to account if this doesn't translate into people's experiences**

3. Information

There needs to be clear and timely information and guidance, accessible in different formats and languages made available to people locally. This needs to include access to PPE, testing and when it is safe for someone to provide direct care or support. In particular, there needs to be specific guidance for people who are employing Personal Assistants on the associated employment responsibilities and government support for employers.

"I rang my LA and asked 'if my PA is self-isolating and can't come into work what do I do?' The Local Authority response, three weeks later, was 'have you got any friends?'"

The Coronavirus (COVID-19): guidance for people receiving direct payments (updated 31st July) on the Gov.uk website is an excellent resource for people who are employing personal assistants. This needs to be shared more widely at a local level and circulated through local networks and supplemented with the relevant local information that people will need to be aware of.

Information needs to be shared in a timely and consistent way and this raises questions about the postcode lottery of having each local authority doing different things. The gov.uk website provides a central resource that can be drawn upon to allow local areas to create their own guidance based on consistent standards across the country. Importantly, such local information should be coproduced with people who self direct their support. Evidence received from the London Borough of Brent demonstrates that this is particularly pertinent to newer communities whose first language is not English and consequently have poorer access to good quality information. Information is power and in some communities it is particularly difficult for women and girls to make informed decisions.

Such information needs to be joined up between various agencies (e.g. health, social care, education, voluntary sector, housing and DP brokerage agencies) with better communication between those agencies. This is particularly true for families of young adults with care and support needs where there is a need for 'family centred' support and for people living in overcrowded housing where social distancing is almost impossible.

Organisations led by people who receive support need to have a higher profile and funding to take a leading role. In their absence voluntary sector organisations could play a role in being a central point for communication.

Recommendation:

- **Information needs to be available at a local level that is joined up across different agencies and developed with people who self-direct their support**

4. Practical Support

Many people, including those caring for family members, reported feeling exhausted and that the offer of practical help with all the administrative tasks of employing PA's would make a big difference (gathering timesheets, sorting out annual leave, giving out payslips and organising payments etc.). External support through a 'link person' being available to call on, as and when needed and for a variety of practical tasks, would have a big impact on people feeling able to cope. Similarly many people have needed help to recruit PA's during the pandemic. Such practical assistance needs to be coordinated and proactive, not assuming that people will ask for help when they need it; many may be reluctant to request help for fear their PB/PHB may be withdrawn.

Some people need practical support to use the IT and virtual technology and this could come from a range of places but needs to be explicitly offered.

There are many examples of working creatively to find practical solutions to problems such as councils paying for food that volunteers are delivering for people who don't have payment cards and being reimbursed by cheque from the person. Such arrangements, based on common sense and trust can make a significant difference to many people.

"Not knowing what is happening or what to do with zero contact from social services is not good enough. Home schooling is a nightmare and with no support I am a broken woman."

Good practice example: Medway Council DP team have provided proactive support to all DP recipients, identified those least likely to have support networks and have coordinated access to PPE and the deployment of Personal Assistants.

Recommendation:

- **The offer of practical support should result from a coordinated effort and not be left to chance**

5. Connection

Many people, with access to a smart phone and Wi-Fi have embraced virtual technology and for many it has improved the amount and quality of the connection with others. However, this is not the case for everyone and virtual networking does not always happen naturally particularly if those groups didn't exist previously. Often it requires a third party to initiate and get the platform off the ground; this could be a voluntary sector organisation but this should not be left to chance. Such peer support can be an invaluable way of sharing experiences, information and support for many people, particularly if based around a particular geographical community.

There needs to be more opportunities to connect with others in similar situations for the sharing of ideas and experiences. This could include such things as practical support to share information about PA's who have time available and where there is a need for support.

Having access to community spaces during the pandemic where families who are shielding can connect, share activities and gain mutual support would make a big difference for many people.

61% of respondents to a survey carried out by Wiltshire CIL reported feeling isolated. 'People described their situations and feelings of loneliness - 'Yes very much, I cry most days, I feel depressed, I feel down, 'mental health crashed hugely' and 'I feel an emotional wreck'.

'Experiences during Covid-19' Wiltshire CIL, Analysis of online survey April/ May 2020

Recommendation:

- **There needs to be coordinated and concerted activity to ensure people have opportunities for connection**

6. Balance

Trust and freedom don't mean that the state should abandon people. For many, lockdown has been experienced as "solitary confinement" and the external support from families, friends or neighbours has had to cease with serious impact on many people who aim to live an independent life in the community.

Many people, including those living in supported housing schemes are experiencing high levels of isolation. This should be the duty of every support provider to ensure that individuals living in such provision receive support and contact through whatever means possible as well as access to vital health checks. Consideration of Technology Enabled Care (TEC) should be an imperative for those people with health conditions confined to home.

"I lost the support that I have personally arranged from outside specialists, which had previously enabled me to achieve person-centred care and a reasonable quality of life at the age of 95. On me, the effect has been damaging in the areas of physical, mental and spiritual wellbeing. I was not able to achieve my monthly health and medication checks for various long-term conditions. I have missed human interaction, meaningful dialogue and discussion, meeting human beings in the flesh, and endured spending many hours without any human contact by any means."

Resident of extra care housing scheme

Local Authorities need to conduct a cross-agency mapping exercise of all people receiving care and support living in the community (including supported living and supported housing schemes) to ascertain those most at risk of isolation and break down in their care or support arrangements. There needs to be collaboration across a range of partners and third sector organisations to ensure that someone is making contact with those individuals and families simply to check how they are and connect them with sources of support.

"It would be nice to have supportive communication from the LA, health and education to say 'how are you doing?' rather than 'you can't spend money on that'

"My PA is looking after her mother and has not been able to work so the only contact I have is the district nurse once a week. I had a phone call from social services in the first month but nothing since. I have started to drink my late husband's whisky to help me cope with uncertainty and isolation. I feel so useless and confused... I am afraid."

Good practice example: In Somerset the partnerships between statutory organisations, micro providers and the village and neighbourhood agents have meant that a joined up response has helped in efforts to ensure people have support and contact.

Recommendation:

- **There needs to be coordinated and concerted activity to ensure people are contacted in a supportive way, on a regular basis should they wish, to check how they are doing.**

7. Choice

People recognise the immense financial pressure service providers, including councils, are experiencing but there is an entitlement issue relating to a personal budget and where services have to close, people should have the ability to find, or be offered, alternatives. There are many great examples of day services reaching out to people in different ways and offering activities online or providing 'blended' support but this isn't happening everywhere.

Good practice example: Croydon Active Lives service have connected people and have supported them to use the Microsoft Teams app to keep in touch. They have gone on to use that platform for a range of activities such as art, drama (with Brit School), Tai Chi, quizzes, exercise classes, etc.

Many people understandably want to stop paying for services they are not receiving or for which they have found preferred alternatives; releasing this income is rarely possible yet this flies in the face of the spirit of choice and control. It is one illustration of the gross underfunding of the social care sector that people are not able to exercise choice where their personal budget is tied up in funding for congregate buildings based services that have had to close. People withdrawing their payment will likely cause the collapse of many small community providers but this should be their right to do so as a recipient of a personal budget.

Recommendation:

- **Where services are closed there should be alternatives offered or the ability to choose to use that element of PB in a different way**

Conclusion

Many of the contributors to this report have wanted to stress the value of self directed support in remaining in control of their lives and for there to be recognition of the resourcefulness and resilience that so many people have found during such challenging times. But many equally have been struggling to cope and have found themselves at breaking point, a situation which is entirely avoidable if the recommendations in this report are followed. People want to remain in their own homes, in their communities and in control of their lives and these recommendations need to be given the appropriate attention as a matter of urgency to enable them to continue to do so safely.

Appendix One

Contributors to this report:

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Members of the Advisory Group reached out to others through their networks to gain information from many people self directing their support who shared their thoughts and experiences both individually and collectively through email, telephone and social media. The group also relied on the work of other individuals and groups with particular thanks to:

Martin Walker, Policy Advisor for Personalised Commissioning and SDS, TLAP
Jon Abrams, Inclusion London
Wiltshire Centre for Independent Living
Mencap Brent
Sanchita Hosali, British Institute of Human Rights