



People-led Policy Panel Submission to the Independent Review of Adult Social Care

4 December 2020

Inclusion Scotland

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1. Introduction

The People-Led Policy Panel (PLPP, or the Panel) is made up of people from across Scotland who need adult Social Care Support, as a supported person or an unpaid carer. The Panel is balanced to reflect the range of people who need adult Social Care Support, their locations and circumstances. There is a mixture of experienced activists and first-time participants, although with capacity building and peer support, they have all now become experts by experience. The PLPP is now in its third year of working with the Scottish Government and other stakeholders on the Reforms.

At their October 2020 meeting PLPP members reflected on whether their ideas and priorities for adult Social Care Support have changed from those identified when the panel was first launched. In 2018, these priorities were:

- Adult Social Care Support that **means you can have a life, not just survive**;
- Adult Social Care Support should offer **flexibility, choice and control**;
- Adult Social Care Support should **recognise the supported person's potential not just their needs** ;
- People who are employing Personal Assistants should receive **training and support to help them in their role as an employer**;
- Adult Social Care Support **should provide freedom** – support to be independent **without having to rely on family members and friends**. For panel members' freedom was also about being supported by **the same staff and having time to build a relationship with them** and a **'portable' support package** to enable them to move to another part of the country should they wish;
- Adult Social Care Support should provide **respect and dignity**. For panel members this means **respect for their agency, views, hopes and dreams**;
- The Adult Social Care Support **system should be simple**; easy to understand, easy to find your way around, **accountable and transparent about how decisions are made**;

- Adult social care support should be **connected to other local services** such as housing and transport¹;
- Adult social care should provide **attractive, well-paid careers**.

Panel members confirmed that these priorities were all still important and relevant to them now. They also identified a range of other factors which have an important role to play in the design and delivery of high-quality Social Care Support and a National Care Support System that has the needs and wishes of disabled people and their unpaid carers/supporters at its centre. These views form the basis of the PLPP submission, which should be read together with Inclusion Scotland's submission.

2. PLPP views on a National Social Care Support System

The panel broadly agree with the idea of a National Social Care Support System. However, they do have some concerns about what this could mean in practice. In particular, the need for a system that promotes geographical consistency of eligibility criteria but is also able to adapt to reflect local conditions. For example, recognising that the cost to deliver social care support is likely to be higher in remote or rural areas. They would also want any national system to provide portability of care that would allow disabled people to easily move to another part of the country without the need for reassessment. Panel members are concerned about the 'postcode lottery' around what social care support options people are offered and the eligibility criteria local authorities are using when assessing people for social care support. In particular that support is often limited to providing 'life and limb' personal care at home, for example, showering, dressing, eating and drinking, getting up and going to bed, or even ten minute appointments providing even more basic support. Social care support, above and beyond 'life and limb' personal (or medical) care provides essential support to daily living

¹ The right to Independent Living cannot be fully realised without access to other rights and resources such as income, legal rights, social civic and judicial participation, personal assistance (Self-directed Support), independent advocacy, access to the environment and communication support. Independent Living is also dependent on accessible housing, healthcare, education, transport and employment. (Please see the "Independent Living Jigsaw").

without which many disabled people are unable to exercise their basic human rights.

Panel members also have concerns that a National Care Support System could focus too heavily on the medical model of disability. It will therefore be important that a national system is separate from and delivered differently to the NHS. It will be vital that any national system places the human rights and equal citizenship at its centre, as well as the principles and values of Independent Living. It is also vital that a national system is designed and co-produced by disabled people and unpaid carers/supporters. The Panel wants to see a national rights based system that keeps the person at the centre. They want everyone to work together using meaningful co-production to achieve this. They also believe that there will be an important role for capacity building and experience led training for professionals and disabled people.

Underfunded social care support prevents people from going to work, getting an education and even from leaving their own home and participating in their community. It can lead to illness and the indignity of having to be taken from your own home, family, and community and cared for elsewhere (which usually costs more). This is in direct contradiction of one of the aims of integration, i.e. prevention.

Unmet need is not recorded so currently we have no way of knowing how many people are not getting services or support they are entitled to and how many people are getting all they need.

There are different models of funding a national care service, we ask that disabled people and their organisations (including the PPLP) continue to be at the heart of decision making. Panel members have concerns about Place Based funding (an idea suggested by providers) and how it would fit with a national system. They are very clear that budgets for social care support should be ring fenced. They are therefore broadly supportive of what is called “hypothecated” (ring-fenced) taxation as a potential funding model for a national system as described by the Social Justice and Fairness Commission². It will be crucial to make sure that disabled people are part of discussions and decisions about the funding model of a national system.

² Social Justice and Fairness Commission (2020) Discussion Paper 2
<https://www.socialjustice.scot/wp-content/uploads/2020/09/reform-of-social-care-discussion-paper-september-2020.pdf>

Our recommendations

- Develop a national social care support system with disabled people at the centre of its design, oversight, delivery, monitoring and evaluation;
- Ensure disabled people are at the centre of discussion and decision making about the different options and models for funding a national care system;
- Commit to ring-fenced spending on social care support;
- Eligibility criteria in a national care system must also be able to be flexible and responsive to local conditions;
- Needs identified must be recorded robustly, and on deciding funding, any unmet needs must be clearly recorded;
- Require local authorities to publish easily accessible information about how they have used funding allocated for social care support;
- Decisions about Social Care Support should always be based on need and not by budget restrictions at local authority level.

2.1 The social care workforce

Scotland is facing a recruitment crisis in social care, with the Care Inspectorate watchdog last year pointing out that more than one in three services had unfilled vacancies.³ If one of the goals of health and social care integration was to reduce reliance on acute services/ address bed-blocking by moving/ keeping more people into/ in the community - is to be achieved – then there are already implications for social care workforce, which needs to increase.

Some disabled people who manage their direct payment are concerned that they have not been able to afford to pay their Personal Assistants the real living wage and are concerned that they may not be complying with Scottish Government Regulations. They were particularly concerned that if their direct payments are not increased they may need to reduce the number of hours of support they have already been assessed by the local authority as requiring, or risk losing skilled staff to higher paid posts. Disabled people on options 1 or 2 of SDS also express concerns

³ Care Inspectorate (2016) Staff Vacancies in Care Services
<https://www.careinspectorate.com/index.php/news/4096-staff-vacancies-in-care-services-2016>

that their funding does not allow them to provide training for PAs on an equal basis as support workers contracted to local authorities or other providers.

“My personal assistants need to be incredibly skilled and capable - this is not reflected in the level of pay the council expect me to give them. I have tried to increase their pay slightly, at detriment to me because it means I have less hours, but it's still way off what my staff should be earning.”

July 2020 Social Care short survey respondent

Some disabled people reported that their direct payment budgets have not changed in years even though costs such as salaries, pension schemes, employer insurance etc. have gone up. Some Panel members are concerned they are unable to increase payments or pay their staff the Living Wage. Any differential between the hourly rate set by the local authority and the rate a disabled person pays their PA has to be met by the disabled person themselves, effectively amounting to a surcharge for being disabled.

There is also concern about the potential impact of the withdrawal of the United Kingdom from the European Union on their ability to recruit and retain personal assistants. The potential impact of a no deal Brexit on the Scottish workforce within Health and Social Care is a key issue for disabled people in Scotland. Disabled people have a higher than average need to access healthcare in Scotland, and social care support is fundamental to independent living for disabled people.⁴ As the UK leaves the EU disabled people's right to independent living must be considered and protected.⁵

Decision makers and professionals, at all levels, responsible for the design and delivery of health and social care support need a better understanding of the needs and wishes of disabled people. They must be willing to listen more and work in equal partnership with disabled people,

⁴ See, Principle 4, in Inclusion Scotland (2018) 'Plotting A Course: Brexit and Disabled People's Rights In Scotland: A Statement Of Principles'

<https://www.brexitcivilsocietyalliance.org/resources-indexpage/plotting-a-course-brexit-and-disabled-peoples-rights-in-scotland-a-statement-of-principles>

⁵ Inclusion Scotland (2018) Plotting a course: Brexit and Disabled Peoples Rights <https://www.brexitcivilsocietyalliance.org/resources-indexpage/plotting-a-course-brexit-and-disabled-peoples-rights-in-scotland-a-statement-of-principles>

using for example the coproduction model of the PLPP. People who use or need social care support should occupy more leadership roles in the design and delivery of their support. Professionals still need more training, which should be designed and delivered by disabled people with lived experience of social care support. Training is also needed to develop the skills and confidence of people with lived experience to be able to deliver training themselves.

Our Recommendations

- Make sure that the additional funding to pay care workers at the Real Living Wage,⁶ more if necessary, is passed on to those who employ personal assistants using Self-Directed Support;
- Make sure that when individual budgets are decided on and reviewed that they can reasonably be expected to deliver the agreed outcomes;
- UK Government and Scottish Government must consider the equality impact implications for disabled people and their right to independent living as well as the right to personal and family life (Article 8 of the European Convention of Human Rights⁷) as the UK exits the EU.
- Include a commitment to ongoing capacity building and training led by disabled people and unpaid carers/supporters in the development and rolling out of a national system.

2.2 Lack of Accountability and Transparency within the Social Care Support System

It's important that all stakeholders have confidence that the social care support system operates in a way that; is fair to all, safeguards people's human rights and stands up under scrutiny of; their decision making processes, the quality of support provided and the management of public funds.

Panel members are keen that there is an element of national oversight to monitor quality of care or assistance. The current Care Inspectorate offers appropriate inspection of independent and private care providers,

⁶ Scottish Government (2020) Letter from Cabinet Secretary and COSLA <https://www.gov.scot/publications/coronavirus-covid-19-fair-work-and-the-living-wage-in-adult-social-care---letter-from-cabinet-secretary-and-cosla/>

⁷ ECHR (2010) https://www.echr.coe.int/documents/convention_eng.pdf

but is not appropriate for Personal Assistance. Panel members strongly reject the idea of “inspection” of the relationship between them and their PA. But they do think there is a role for national standards or a national charter to ensure issues of geographical consistency and also to tackle issues such as consistency of payment of staff, staff training and development. Also, the panel believes strongly that there is a continued central role for Centres for Inclusive Living in maintaining national and local standards and that any monitoring of standards should be led by disabled people and our organisations.

Our recommendations

- Any new National Care Support system should include an element of national oversight to promote national parity and the mechanism for doing so should be led and governed by disabled/supported people and our organisations;
- People should start to get some clarity about what services will be offered differently and what compensation they might expect for services that have permanently been suspended;
- An audit of how money is spent;
- A programme of investment in disabled people’s organisations, such as Centres for Inclusive Living.

2.3 An independent complaints process

Panel members feel strongly that the Adult Social Care Support system should include an independent complaints system and an independent appeal system. The current system where your complaint is heard by the manager who made the decision in the first place is flawed and leaves disabled people feeling that there’s nowhere for them to turn when things go wrong.

There should be a right of access to independent advocacy for anyone being assessed for or receiving social care support. There needs to be independent peer advocacy, where disabled people help each other navigate and manage the system. “You can’t empower the individual without empowering the collective” (Panel member). Another panel member spoke about the difficulty they had when their complaint was suffocated internally. They had to push for legal action and ended up going to court; however, at that point and at great stress to this person, the Council settled the case. Most third sector organisations do not have the legal backgrounds or the money to fight these cases. There is no case law in Scotland associated with social care support decision. Local

authorities prefer to pay off individuals rather than risk that a legal precedence is created through case law that could be used by everyone. Local authorities have huge legal teams and it can be difficult to access legal aid to take a case to tribunal. We therefore call, along with the Scottish Human Rights Commission for the incorporation of the United Nations Convention on the Rights of People with Disabilities (CRPD) into Scots Law. Incorporation should include duties on the Scottish Government and local authorities to embed Convention rights into decision making, including taking a rights based approach to budgeting, so at every turn they are compelled to consider the impact of all decisions on the rights of disabled people.

Our Recommendations

- The new Social Care Support system should include an independent complaint process and appeals system, with powers for redress;
- Embedded within the new Social Care Support system should be the right to Independent Advocacy, including peer, Collective Advocacy as outlined in the Scottish Independent Advocacy Alliance's Principles and Standards and code of guidance;⁸
- That the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) be incorporated into Scots Law and therefore decision making (including taking a human rights approach to budgeting), policy making and delivery, as argued by the Scottish Human Rights Commission.

3. Conclusion

COVID-19 has exposed existing inequalities and created new ones. The impact on disabled people has been devastating. There has never been a more important time to invest and build a social care support system that protects the human rights and equal citizenship of disabled people and their unpaid carers/supporters. Equally important is that the People Led Policy Panel want to have a voice in this process. We want the voices of disabled people to be at the heart of planning and delivering a

⁸ SIAA (2019) Independent Advocacy: Principles Standards and Best Practice <https://www.siaa.org.uk/publications/principles-standards-code-of-best-practice/>

human rights based Social Care Support System. We believe Social Care Support is a fundamental human right.

We, along with many others, are calling for the incorporation of the CRPD into Scots law. Incorporation would mean that the CRPD Articles are justiciable, which means they can be used in courts to challenge decisions that discriminate against or threaten the human rights of disabled people. This would include the ability to challenge more effectively, and crucially get redress any Social Care Support decisions that compromise disabled people's rights. In general making justiciable Article 3 (Guiding Principles) and in particular Article 19, "Living Independently and being included in the community" will have a transformative impact on the ability of disabled people to uphold our human rights. Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights are fulfilled⁹.

Even when the principles of dignity, respect and control are built into the fabric of national social care policies, as with Self Directed Support (SDS), we find that local authority budget constraints, inflexibility, lack of adequate infrastructures, and poor information and advice provision concerning options available to people have frequently led to poor experiences for disabled people. It therefore makes sense to consider how we might scale up models of social care support that have actually worked for disabled people. Self-Directed Support as a nationally funded system in the style of the Independent Living Fund could be one course of action for the Independent Review to consider.

The People-led Policy Panel warmly welcome continued dialogue with the Independent Review and the future Government, to ensure that we can together create a human rights based Social Care System Scotland can be proud of.

⁹ Inclusion Scotland (2017) General Comment No 5 on living independently and being included in the community
<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh>

