What works in social care?

Preliminary research report

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Research conducted as part of the Glasgow Disability Alliance Future Visions for Social Care programme.



'I can BE just like everyone else ... I can be more spontaneous.'

"... when the assessment was done, [the social worker] really did look at every aspect of my life, and not just what was going on at the present, but goals I had for the future, things I wanted to work towards, and how my care package could support me to do those things."

'As soon as you get the right [Personal Assistant] it transforms your life – this is what life should be like.'

'... overall, you know, I'm happy where I'm at with social work, having the two PAs. I'm in control of who I invite into my home, which is really important to me, that private space for me.'

The above quotes, from participants in this study, demonstrate why the concept of independent living is fundamental to understanding adult social care in Scotland. The goal of Scotland's principal social care legislation, the Social Care (Self-directed Support) (Scotland) Act 2013 (Scottish Government, 2014, p.4), is that:

Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.

The Independent Review of Adult Social Care (IRASC) (Scottish Government, 2021, p.9) defines independent living as follows:

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

IRASC notes that this definition has been adopted and agreed over many years by the Scottish Government, COSLA, the NHS and the disabled people's independent living movement. The definition has also been agreed in Scotland's largest city, including with Glasgow's strategic Independent Living Programme Board (2012-2017).

Glasgow Disability Alliance's (GDA) 'Future Visions for Social Care' project supports disabled people needing or using social care with improving their

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independent living options and outcomes, with the ultimate goal of accessing social care including through Self-directed support. Future Visions also enables the participants to collectively influence social care-related policy and practice in Glasgow and Scotland. This work has identified multiple barriers experienced by disabled people who need good social care.

To complement this evidence, Future Visions has initiated this 'what works in social care' research project. The purpose has been to find examples of how social care should work for all disabled adults in Scotland, enabling independent living, but all too often does not. The study has interviewed a range of disabled adults in Scotland who have had good experiences of social care.

The research sought to identify:

- what factors make people's social care work well for them;
- the work that people had to do to achieve and maintain good social care; and
- any support needs, wishes and ambitions that may still not be met by the social care package.

To maximise credibility, the research has been conducted independently of GDA, through the Centre for Disability Research at University of Glasgow. The findings will contribute to GDA's Future Visions work to influence social care, National Care Service and related policy and practice locally and nationally. The findings will also be able to inform the Scottish Government, Health and Social Care Partnerships, Integration Joint Boards (IJB), and third sector and community projects and organisations seeking to transform social care into independent living for disabled people.

The fieldwork for the study has just been completed. This is a preliminary report that describes how the research was done and describes some prospective themes. Full, thematised findings will be published in June 2023.

Method

This is an in-depth qualitative study. This type of study is good at understanding the mechanisms behind how events occur, and for testing 'established' knowledge and assumptions. As such, it is strong at identifying new insights for policy makers, practitioners, and communities, and for drawing out themes for future research. An in-depth qualitative study does not seek population representativeness; it seeks to get 'a lot from a little' (Silverman, 2001, p.5). The credibility and fitness for purpose of insights from qualitative research come from the rigour of analysis and transparency of reporting (Spencer et al, 2003).

Participants in the study self-identify as having had a good experience of social care. Individual semi-structured interviews were conducted to allow participants to articulate and reflect on their good social care experience. Individual interviews enable clear personal narratives unmediated by group norms. They also allow participant anonymity and confidentiality. All interviews were conducted by telephone or on Zoom and were audio-recorded with consent. The study proposal was ethically reviewed by University of Glasgow and the fieldwork was conducted between January and March 2023.

Participants

Because the study involves a small sample, the ethics of anonymity and confidentiality demand that limited information about participants is disclosed. Participants were recruited through Disabled People's Organisations and allied third sector bodies. Prospective participants were asked to contact the researcher directly and in confidence.

Ten individual interviews were conducted, including two with parents describing the good social care received by their late-teenage and early-20saged children. There were six female participants, three male, and one trans male. Two participants were BAME disabled people. Ages ranged from one late-teenager to one person in their '70s. All participants had several impairments. These included lifelong and chronic conditions, visual impairments, psychosis, other mental health issues, learning difficulties, and mobility impairments. Several were wheelchair users.

Participants described good experiences in eight different IJB areas in Scotland. They lived in rural, town, suburban, and urban neighbourhoods, including in three different Scottish cities. Good experiences had lasted between 14 years and 4 months. All experiences were within the past 14 years. Most were recent and ongoing.

Participants had a variety of social care support packages: one SDS option 3, three SDS option 2, four SDS option 1, one ILF, and one informal care/DPO support only. Hours of support per week ranged from informal and DPO support only to 30+ hours of paid care per week. People described good experiences from a range of providers: four had self-employed P.As, two used private companies, one local authority support, two third sector organisations, and one informal/DPO support. Some participants had additional informal support from their family, some had paid support only.

This data already indicates several points. It shows that people can interpret 'good' social care as being about informal care and DPO support, with no formal package. It suggests that good social care can be experienced at any age. It indicates that good social care can be provided by local authority, private providers, the third sector, self-employed P.As, and under different

SDS options. And good social care can be provided in rural, suburban, and urban areas.

Therefore, this data already indicates that it is not possible to generalise in a simple way about 'good' versus 'not good' in terms of, for example, SDS option, age, or location. However, once fully analysed, patterns may emerge. This will be seen in the full analysis to be published in June 2023. At this stage, prospective dominant themes can be cautiously outlined, as below.

Prospective themes

The semi-structured interviews were typically discursive, lasting 45 minutes to one hour. Participants frequently discussed the following themes:

What good social care feels like:

 Prospective themes include: feeling in control, flexibility of care package, security of care package, dignity in care, subjectivity.

What helps disabled people to have good experiences of social care:

 Prospective themes include: the role of the social worker, the need for assertiveness, knowing the system, the qualities of carers and P.As.

• Intersectional experiences:

 Prospective themes include: the importance of confidentiality, feeling respected.

• What barriers to independent living are still experienced:

 Prospective themes include: delays to getting good social care, the work needed to get good social care, barriers in the world outside the home, being 'trapped' by a good social care package, funding limitations, P.A pay limitations.

The full analysis of the interview transcripts with substantive themes, plus implications for policy and practice and future research priorities, will be reported in June 2023.

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Centre for Disability Research, University of Glasgow 23 March 2023.

References

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