

Self Directed Support – Post Legislative Scrutiny

Health Social Care and Sport Committee – January 2024

Scottish Parliament

This response is submitted on behalf of Age Scotland and About Dementia, Age Scotland's Dementia Policy and Practice Forum. We ensure the voice of those living with dementia, and unpaid carers, is heard at a policy level. We build our policy responses with the voice of lived experience at the core. We believe that the people who face the challenges are also best placed to discuss the solutions.

We welcome the opportunity to contribute to this exercise by scrutinising Self Directed Support, ten years after its introduction. The passing of Self Directed Support (SDS) legislation in the Scottish Parliament in 2013 should have been a watershed moment for social care users in Scotland.

When offered and applied properly, the Options introduced via this legislation empower social care users to access care however it works best for them. We know that when SDS works, the impact can be transformational - even life changing - allowing people to live with the choice, dignity and control that is their right. However, through our extensive engagement with older people including people living with dementia and unpaid carers, we know that far too often, SDS is poorly applied or not offered. The consequences can be profoundly damaging.

It is worth noting that Age Scotland's 2023 Big Survey found that 46% of respondents 'strongly agreed' that they were concerned about the current costs of social care and 28% 'agreed' with this statement. Respondents were even more likely to 'strongly agree' with the statement 'I am concerned about paying for social care in the future' - 53% 'strongly agreed' that this was a concern and 28% 'agreed'. At a time when people, especially older people, have lost faith in their social care system, ensuring a transparent and accessible model of SDS is of the utmost importance.

Offering the Full Range of Options

Due to issues including resourcing, and capacity within local authorities, many people all over Scotland are unaware of the full range of Self Directed Support Options available. For those living with dementia and unpaid carers, we see all too often the gaps between policy aspirations and the reality of implementation. Figures for 2016/2017 showed that less than 10% of people with a 'primary diagnosis of dementia'[sic] were using Option 1 or Option 2 (Scottish Government, 2018). Many are placed on Option 3 as a standard. We also believe that people lack awareness of SDS Options and often don't understand how SDS applies to them. Many carers are unfamiliar with SDS and are not informed about its potential

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relevance in their caregiving journey or their right to a needs assessment and Adult Carer Support Plan through the Carers Act 2017. Additionally, there's a prevailing sense that individuals must 'fight' for their rights, which prompts a lack of confidence that SDS will be accessible when needed. Having spoken to people directly affected by dementia, we have heard that the SDS Option they were assigned was not an active choice but all that was on offer. In 2021, Alzheimer's Scotland and Age Scotland networks participated in Scottish Government research on SDS finding that 37% of participants felt the four SDS Options were not explained to them clearly, and a further 21% did not have the Options explained to them at all.

While some people are prevented access to Options 1, 2 and 4, we have also heard of scenarios where people are unwillingly being placed into Option 1 because the local authority does not have the specialist care staff available to provide the necessary care. Shifting the onus onto the person who requires care, without the support to manage or direct their care (as would be the case perhaps through Option 2) is a definite misuse of SDS. Option 1 also places great responsibility on the budget holder, often an unpaid carer, to correctly report on and manage any staff they employ. Effectively, a budget holder will become an employer. While this may be manageable for some people, it is not manageable for all. Option 2 was developed to remove those responsibilities from the person requiring care, but it is continually underutilised and therefore ineffective.

We believe that access to appropriate person-centred and personalised social care is an important solution to enabling people to access their human rights and live with dignity. In the words of one carer, "It's not about any care, it's about the right care." For many people, SDS can be difficult to obtain without being at the point of crisis, and even when given often lacks the flexibility to which people are entitled. Adding to this challenge is the stringent eligibility criteria. Many carers have expressed that they feel they have to demonstrate that they are beyond a crisis before they qualify for any support in their caring. This not only hinders flexibility but also fosters a sense of distrust and cynicism among carers. The cumulative effect of real terms cuts to local government funding over the past fifteen years, as well as a lack of clear national standards often results in the bar for eligibility being set so high that it becomes unattainable for numerous carers and people living with dementia, impeding their access to assistance. Consequently, this approach obstructs opportunities for early intervention and works against a preventative approach to health and social care, ultimately costing the state significantly more over time.

We are aware of some scattered good practice examples where flexible approaches to SDS have been able to work effectively. A person with dementia living in North Lanarkshire has used their direct payment to enable them to attend online yoga classes. This helps them to manage their breathing, also relieving stress and anxiety. Another person in Glasgow hired a personal assistant to support him in going out on day trips and participating in hobbies. We have similarly heard of carers who have successfully employed a personal assistant through Option 1, which enabled them to access respite breaks more readily and enjoy time away

from their caring role to visit friends or family. Option 1 can also empower people from within their homes.

These are positive examples of the aspiration for an ‘outcome focused’ approach enabling SDS to be used to meet other needs outside of personal care. Other examples we are aware of have included buying dementia friendly concert tickets, dementia friendly telephones and much more. SDS is not narrowly designed to meet basic ‘life and limb’ personal care needs, but to enable people who have cause to draw on social care and their informal carers to lead a fulfilling life.

These examples take a creative and holistic approach to identifying and meeting people’s desired outcomes through social care. While having significant benefits to individuals, we contend that they also represent a preventative approach to social care that could have significant cost saving benefits to the public purse, if implemented early enough. Sadly, these examples are very much in the minority of experiences. By ensuring that older people, and people living with dementia in Scotland are made better aware of the choices they have, and by providing creative and holistic good practice examples, SDS could become much more than a means to meeting basic care needs. Without increased flexibility or awareness, however, this is not possible.

Lack of Information and Misinterpreted Options

In general, information provided by local authorities about social care entitlement, availability and processes is perceived to be very poor. The inconsistent interpretation and implementation of Self Directed Support (SDS) in Scotland highlights a concerning trend within the health and social care system. The landscape of SDS across the country is inconsistent due to a lack of standardised information and processes for informing individuals about their entitlement to SDS.

This lack of knowledge and understanding on both sides has serious consequences, with individuals often being directed towards SDS options that are ill-suited to their needs, and being denied the opportunity to consider options that are better suited. As noted above, people living with dementia are frequently guided towards Option 3 without adequate information about the alternative options or a comprehensive understanding of the available support services. This not only limits the individual's autonomy but also raises questions about the transparency and effectiveness of the decision-making process used in social care assessments.

We believe the information provided by local authorities regarding social care entitlement, availability, and processes is lacking. This contributes to a system where individuals are left uninformed and vulnerable. It would be worthwhile for the Committee to review relevant process literature and implementation reports to understand the reality of SDS at a ground level. A streamlined approach to information and processes may close the gap between the policy and practice of SDS.

Accountability

The absence of a robust mechanism for ensuring accountability means that when things go wrong or when individuals are offered ill-fitting support, there is a lack of recourse to justice or avenues for creating meaningful change.

Individuals who find themselves directed towards inappropriate SDS Options or encounter problems in the support provided face a significant barrier in seeking resolution. The absence of a clear accountability framework leaves them without a structured process to address grievances, rectify mistakes, or advocate for the appropriate support that aligns with their needs. Without effective accountability mechanisms, there is limited incentive for local authorities to rectify systemic issues or learn from past shortcomings, perpetuating a cycle of inadequate support.

We welcomed the recommendations in the Feeley Review to enhance accountability within social care. However, the ongoing delays related to the National Care Service have frustrated these aspirations. The establishment of a robust accountability framework within the SDS system would be beneficial, not only to streamline the service being provided but also to reduce the postcode lottery of process, information and care offered to those applying for SDS. The framework should encompass transparent channels for lodging complaints, a fair and impartial review process, and measures to hold local authorities accountable for their decisions and actions. Additionally, mechanisms for both continuous improvement and learning from feedback should be integrated into the system to make it more responsive and effective.

Clear Point of Contact

To complement increased accountability, people who have cause to draw on social care support should be provided with independent advice and advocacy to enable them to make informed decisions about what option is best for them. A common barrier and gap in the current system are the challenges individuals face when seeking support due to the absence of a single, accessible point of contact and a lack of clear independent advocacy services. There has been advocacy funding granted to local authorities, however, each local authority has funded the area to different degrees and with differing approaches. As a result, the read-across of support available to people seeking information on SDS becomes difficult to navigate. Which once again creates a postcode lottery and prevents people from accessing independent advice about their rights.

An example of this inconsistent approach to advocacy is evident in the NHS Forth Valley health board area. There are two health and social care partnerships operating in this area, but one advocacy organisation operating across the region. Individuals in the area covered by the Falkirk Health and Social Care Partnership receive advocacy support from the moment they apply for a social care assessment. Those in Clackmannanshire and Stirling, a different Health and Social Care Partnership, however, are only able to access independent advocacy support

(from the same organisation operating in Falkirk) after they have been assessed and approved a budget under Option 1. This is because of the lack of standardisation of the advocacy offered at a national level, meaning that HSCPs can put in place vastly different service level agreements.

The landscape of SDS advocacy is complex and unclear. Frequent accounts of individuals receiving disparate information at various stages of the process contribute to a sense of confusion and frustration. The lack of consistency, coupled with the experience of never speaking to the same person twice, amplifies the complexity of navigating the SDS framework. This disjointed communication structure leaves individuals feeling as though they are repeatedly starting over, perpetuating a cycle of uncertainty and hindering their ability to make informed decisions about their care. Establishing a clear point of contact or a dedicated independent "point person" and ideally a consistent relationship with social work services within the SDS process is instrumental in mitigating these challenges. This individual would serve as a reliable source of information, offering consistent guidance and support throughout the entire journey. Incorporating this point of contact aligns with the broader theme of accountability, as having a designated point person fosters a more transparent and accountable process.

Want to find out more?

As Scotland's national charity supporting people over the age of 50, Age Scotland works to improve older people's lives and promote their rights and interests. We aim to help people love later life, whatever their circumstances. We want Scotland to be the best place in the world to grow older.

Our Policy, Communications and Campaigns team research, analyse and comment on a wide range of public policy issues affecting older people in Scotland.

Our work is guided by the views and needs of older people themselves.

About Dementia: Shaping Our Worlds Together, launched in April 2019 and is Scotland's forum for improving lives. It is hosted by Age Scotland and funded by the Life Changes Trust.

We bring together people affected by dementia, and organisations who are interested in working for change, to look at how we can improve policy and practice across many different areas of life.

About Dementia believes that people affected by dementia, including people living with dementia, and unpaid carers, are in the best position to say what is and isn't working and how to do it better.

Further information

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