Self Directed Support Scotland
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Building Better Pathways

Exploring Barriers to Self-Directed Support for People Living with Dementia

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1. Foreword from Self Directed Support Scotland

This report originates in the numerous enquiries that Self-Directed Support Scotland has received in recent years which relate to the barriers to accessing social care faced by people with dementia or their carers. To place this report in a policy context, The Self-Directed Support Improvement Plan (2023) refers to the "universality of SDS" and identifies "golden threads" as follows in an attempt to ensure that communities marginalised by eligibility criteria are given added consideration:

"Golden threads include a number cross-cutting issues which are fundamental to the full delivery of SDS as intended by the SDS Act and other relevant legislation. The golden threads are areas that all activity related to SDS improvement should consider in implementation."

We hope that the insights offered by this report will generate further discussion in relation to the social care needs of those with dementia and their carers, resulting in improved implementation.

Donald Macleod

CEO

Self Directed Support Scotland

2. Executive Summary

Self-Directed Support (SDS) represents one of Scotland's most ambitious social care reforms, offering people genuine choice and control over their support. Yet ten years on, its transformative potential remains unrealised for many, particularly those living with dementia as what was designed as a flexible, person-centred system continues to be hampered by inconsistent implementation, structural barriers, and a lack of dementia-informed practice, creating what many describe as a postcode lottery in both access and quality[1, 2, 3]. This report examines the barriers that may prevent people living with dementia from accessing SDS and proposes concrete solutions to realign SDS with its original vision of empowerment and inclusion.

For people living with dementia, barriers to SDS may begin at the most fundamental level: information. Just 49% of SDS users first hear about the system through health or social care professionals[4], leaving many reliant on weakening social networks for crucial guidance - a particular challenge given the isolation that often follows diagnosis[5]. Those who do engage with SDS encounter a system still structured around traditional, service-led approaches[6], with processes ill-adapted to the unpredictable reality of dementia and how it can impact the person in the short, medium, or long term. Financial pressures compound these issues, creating an environment where support is costed at the equivalent of residential care, effectively imposing an age-based cap on independent living for those over 65[7, 8].

These systemic challenges are exacerbated by fundamental misunderstandings about dementia itself. Public understanding remains dominated by stereotypes of memory loss, with little awareness of how different dementia types can affect emotional regulation, sensory processing, executive function and behaviour[9, 10]. This limited understanding of dementia conditions can be particularly damaging when combined with persistent stereotypes about dementia as an "older person's condition" to create challenges for those with rarer types or early onset dementias, while a lack of awareness about how dementia manifests differently across individuals—or how factors like ethnicity, gender or sexuality shape experiences of care—can leave many struggling to access a process that fails to see them[11].

Critical gaps in monitoring and accountability disguise the true impact of these barriers. Current data systems, including Public Health Scotland's dashboards, offer little in depth insight SDS provision, relying on vague categorisations that obscure more than they reveal[12]. Without disaggregated data on ethnicity, gender or younger-onset cases, local authorities lack the evidence to identify—let alone address—these inequities[13, 14]. The consequence is a cycle of exclusion that particularly impacts already marginalised groups.

Despite these complex challenges, opportunities exist to take meaningful action to address barriers to SDS access and realign SDS with its founding principles. This report proposes comprehensive reforms to data collection and reporting to make visible the experiences of people living with dementia. It calls for the elimination of age-based funding caps that contradict SDS's human rights foundations, alongside investment in dementia-competent advocacy and accessible information formats. Most fundamentally, it advocates for professional training and supported decision-making tools to enable genuine co-production with people living with dementia - ensuring the system finally delivers on its promise of choice and control for all.

3. Introduction

Self-Directed Support (SDS) represents one of the most ambitious reforms to UK social care in recent decades. The policy framework, established through the Social Care (Self-Directed Support) (Scotland) Act 2013 and subsequent strategies[15, 16, 17] had a clear vision at its core: promising to move away from a system that *does for* people, to one that *works with* them, granting service users genuine choice and control over their support, with services adapting to their needs rather than the reverse.

Yet, a decade later, evaluations consistently detail a policy struggling to achieve its potential, trapped by a combination of structural and cultural processes that transform the revolutionary concept of SDS into the proverbial 'square peg in a round hole'; an inconsistently embedded framework that is often poorly understood by both the organisations seeking to work within it and those wishing to use it[2, 3, 18, 19, 20, 21]

Issues include:

- Inconsistent, limited, and unclear implementation across Scotland's 32 local authorities[1, 3, 20, 21, 22, 23, 24, 25]

- A system of care that is resistant to change attempting to 'bolt on' SDS services to existing structures[21], creating a lop-sided landscape where Option 3 (provision of care through local authorities) remains the most consistently supported[2, 6, 26] while Options 2 and 4 are often unavailable[7, 20].

- Formal IT systems, contract agreements, and Social Work teams that have been optimised for service-led provision, rather than person-centred or person-led models of social care[6, 20, 27].

- Evidence that SDS users are rarely engaged as true co-productive partners with the ability make meaningful contributions in the shaping and delivery of their care, but merely consulted after decisions have been made[4, 27]

- An economic environment where spending on services and social care has been placed under increasing pressure, creating issues with both SDS infrastructure[2] and application[3, 8, 28].

This grinding pressure of both long-term issues and acute crises, like the COVID-19 pandemic, has created a 'wicked problem' where social workers and local authorities must seek to limit spending and risk while simultaneously attempting to provide the proactive and enabling SDS presented in the legislation[2, 7, 17, 23, 29, 30].

And yet, despite these challenges, evidence strongly suggests that this remains a fight worth having. The majority of SDS users who took part in the My Support, My Choice study indicated that they received better support under SDS than their previous arrangements[4], sharing:

> *"Previously the local authority provided this care, you had no choice. […] But now with SDS I have control. I can choose what option I want (within the rules, of course!). […] Basically, it has been the passport to independence. Whereas before, oftentimes, especially if you're disabled you have to take what you get, you haven't really any choice. But to have the ability to decide for yourself is liberating. So, it makes a big difference."*
>
> *"Self-directed support is a fantastic idea; it has improved my life no end. I would recommend it to anyone […]. Once you get through the initial paperwork, setup etc. it gets easier.*
>
> *Keep your eyes on the outcome that you are hoping to achieve. The assessment is time consuming and a bit overwhelming but tell the social worker everything relevant […] Self-directed Support is the perfect solution."*
>
> [p29]

Between the positive outcomes described by users of SDS, and the striking vision set out by SDS as a system that places "human rights principles at the very heart of a fundamental framework of delivering and accessing social care support"[7], it is easy to argue that SDS has a vital part to play not only in the future of Scotland, but in the future of her ageing population. This is further outlined by initiatives like the Reshaping Care for Older People programme

(2011-2021), the Fairer Scotland for Older People framework (2021) and, critically, the Scottish Government's 10-year Dementia Strategy (2023).

This enthusiasm demonstrates how vital it is to consider not only how well-evidenced barriers and challenges around SDS access and implementation might create barriers for people living with dementia, but how ongoing issues around recording and reporting might disguise profound barriers for those with dementia who wish to access Self Directed Support.

4. Informing the Report: Literature, Enquiries, and Workshop Insights

This report draws upon three distinct but complementary sources of insight to examine the barriers faced by people living with dementia in accessing and utilising Self-Directed Support (SDS) in Scotland. First, a rapid literature review established the policy and practice context by analysing peer-reviewed studies as well contemporary grey literature including reports by third sector organisations, government publications, and submissions to the Feeley Review[8]; second, a thematic analysis of 68 anonymised enquiries to Self Directed Support Scotland; and, finally, the integration of feedback and insights gained through two participatory workshops at the SDS National Voice Conference in March 2025.

Rapid Literature Review

Between January and March 2025, a rapid review of academic and grey literature was conducted to synthesise existing evidence on SDS implementation, with particular attention to barriers affecting people living with dementia. Search terms combined SDS-related concepts (i.e. "Self-Directed Support" OR "personal budgets") with dementia-related terms (i.e. "dementia" OR “Alzheimer*” OR “Lewy Bodies”) and barrier-related terms (i.e. "access" OR "challenges"). Additional steps to ensure the review captured key grey literature including key government publications, reports by third sector organisations, and evidence submissions to the Independent Review of Adult Social Care in Scotland[8].

The review focused primarily on UK-based evidence published since 2010 to align with the implementation period of Scotland's SDS legislation. Key themes emerging from the literature included: inconsistent application of SDS across local authorities[1, 2, 4; 6, 20, 21]; structural and organisational barriers to SDS implementation[3, 6, 7,10, 17, 21, 23, 27, 29, 30, 31], the impact of wider economic and global events on SDS provision[2, 3, 8, 28]; and additional barriers for marginalised communities[4, 13, 14, 32, 33, 34, 35]. Additional in-depth insights were drawn from the extensive doctoral work of Velzke[31], Morrow[36] and Njoki[30].

An additional review was conducted of the Evidence Submissions to the Independent Review of Adult Social Care in Scotland[8]. These submissions from third sector organisations and individuals were screened for content specifically relating to SDS, older people, and people living with dementia, and analysed for relevant insights.

Thematic Analysis of Enquiries Data

To complement the literature review with grounded, real-world examples, a thematic analysis was conducted on a record of enquiries provided by Self Directed Support Scotland. These enquiries were collected by SDSS staff between January 2020 and March 2025, and varied in length between 24 and 649 words.

Thematic analysis was used to identify key patterns and similarities in the data, which were gradually refined into five key themes. These were sense checked against both the original enquiries data, the wider literature, and the evidence submissions for the Feeley report[8]. The five themes were:

- **Structure**: Practical challenges in SDS delivery including issues around provision, and the significant regional variations in how criteria are applied and implemented across local authorities.
- **Access:** A need for fundamental information about who can apply for SDS and how, encompassing eligibility confusion, requests for basic process clarification, and need for support to navigate systems.
- **Changing Needs:** Cases where the enquirer highlighted difficulties relating to the changing needs of the person living with dementia.
- **COVID-19:** Pandemic-specific disruptions including suspended services and breakdowns in traditional support networks.
- **Advocacy:** Instances where individuals and families sought out or were referred to advocacy organisations for support around rights, provision, or other issues with SDS.

Insights from Participatory Workshops

The initial findings from the literature review and enquiry analysis were put to the test during two hybrid workshops held at the SDS National Voice Conference in March 2025. These sessions created a space where older people, academics, and third-sector representatives—all with direct experience of SDS system—could examine our emerging conclusions and share their own recommendations for improvement.

Designed to reflect the real challenges identified in the report, the workshops focused on three critical areas: the attitudinal barriers surrounding dementia that shape SDS experiences, the practical difficulties people face when trying to access and navigate the SDS system, and the structural issues that influence how SDS is delivered across different regions. At each stage of the discussion, participants were asked two key questions: "Does this match what you've seen in practice?", and "What advice would you give to someone encountering these problems?"

The workshops then moved from general discussion to a specific case study. Participants were introduced to Rose, a 72-year-old artist recently diagnosed with dementia who was considering SDS as a way to maintain her independence while getting the support she needed. This fictional vignette, informed by evidence in the wider data, prompted rich discussion as those attending—both in the room, and joining online—shared practical strategies, personal insights, and potential solutions to help someone in Rose's situation navigate the SDS system. These contributions, ranging from specific advice about explaining needs to SDS assessors to broader observations about systemic barriers and resources, have been carefully integrated throughout the report.

5. How Data Gaps Mask the Challenges of People Living with Dementia Seeking SDS

SDS in Scotland is built upon two key sets of principles: firstly, its statutory principles of involvement, participation, informed choice, and dignity; secondly, the human-rights based PANEL Principles of Participation, Accountability, Non-discrimination, Empowerment, and Legality[7,37]. Together these principles outline a framework of legal and moral values that should endure at the heart of all SDS provision – yet it remains difficult to establish with any degree of confidence how well or frequently SDS meets these goals[1,7]. The Care Inspectorate[20] review goes so far as to state that "It is impossible to determine the extent to which choice and control was being offered and delivered through SDS" (p.9).

While efforts have since been made to improve visibility of and access to data around social care in Scotland, the current system fails to provide meaningful insight into key aspects of SDS provision. At the time of publication, Public Health Scotland hosts two data dashboards relating to social care: the outdated SDS dashboard and the current People Supported by Social Care dashboard each of which manages to provide partial insights while leaving critical gaps in understanding[12, 38].

The SDS dashboard[38] is built upon a five-year dataset spanning between April 2017 and March 2022 and allows users a valuable, albeit limited insight into key indicators associated with SDS. Drawing on demographic data around SDS users' location, age, needs, client group, the dashboard allows a summary overview of how frequently the different SDS options were chosen by age group and location, the types of needs SDS was used to address by age and location, and SDS users by client group. While this information gives some insight into the pattern of SDS use over Scotland, it has significant limitations, including in its choice of categories for client groups (learning disability, physical/sensory disability, dementia, mental health, and the particularly vague 'elderly/frail' classification), it's wide age bands (0-17, 18-64, 65-74, 75-84), and critically, its lack of data around gender, ethnicity, or the presence of multiple healthcare conditions.

It's presumptive replacement, the People Supported by Social Care dashboard[12] is built on a dataset spanning between January 2018 and March 2024, and collects data about a range of social care services, including SDS. This majority of this data is, however, inaccessible to the lay user. Where the SDS dashboard permitted basic exploration of SDS option by age and location, the new system obscures even these rudimentary insights behind aggregated service-type statistics – care at home, meals, day care – removing insights into both the type of package being delivered and the extent to which packages are expected to support critical social, educational, or recreational needs, as well as access to equipment and adaptations. In doing so, the new dashboard simultaneously makes improvements by allowing for insights into the impact of gender and ethnicity, while removing any opportunity for insight around the implementation of SDS despite its own data documents marking SDS data as mandatory for reporting.

The data is further undermined by the way it processes and categorises data, noting that client cases should be marked with either a 1 or 0 to their affiliation with a set of client groups, including: Physical or Sensory Disability, Learning Disability, Mental Health Problems, Neurological Condition, Dementia, Autism, Drugs, Alcohol, Palliative care, Elderly/Frail and Other Vulnerable Group. Such aggregated groupings allow for limited detailed analysis, with the reliability of the data being further undermined by the statement accompanying the dashboard's output around client groups which reads:

> *"The Client Group (or Service User Group) is determined by a Social Worker or Social Care Professional and is used as a means of grouping individuals with similar care needs. An individual can be assigned to more than one Client Group."*
>
> [12]

Such an approach to data collection, sharing, and analysis raises profound questions about how well the information collected can be used to better understand the provision of SDS and its barriers. Not only do such categorisations disguise the differing support and access needs that those within the category may have (considering, for example, the significant differences between the experiences of d/Deaf people, those with a visual impairment, and someone living with paralysis, all of whom would fall within the 'Physical or Sensory Disability' category), but they place the responsibility of correctly identifying and noting complex and varied conditions like dementia in the hands of social workers and social care professionals, rather than clinicians.

The impact of these gaps in data should not be underestimated; without age-disaggregated data, we cannot detect whether younger people with dementia are accessing SDS. Without ethnicity reporting, we cannot identify the impact of established cultural or linguistic barriers on minority communities. Without a common format for recording discussions and processes we cannot systematically evidence how (or if) people are being supported co-produce their care[20], or what supports might be put in place to ensure people who experience additional barriers to communication, or degenerative cognitive conditions like dementia can remain active participants in their own care over time. Without such crucial data, we cannot authoritatively identify either systemic issues with SDS, or examples of best practice. This leaves policy makers, practitioners, and users all to rely on small scale, tightly focused, predominantly qualitative studies for their information without access to the broader view best provided by robust statistical analysis.

This report represents an important step in outlining and identifying some of the key barriers that may prevent people living with dementia from accessing Self Directed Support. By drawing together existing research evidence, real-world enquiries data, and insights from two participatory workshops it seeks to outline not only potential challenges for those seeking SDS, but a series of practical, actionable recommendations to allow greater insight into, and mitigation of those barriers.

6. On the Outside, Looking In: Barriers for Applicants, Users, and Carers

The Impact of Social Networks, Understanding, and Marginalisation

> *“The chances are that the average man, woman and child in the country has neither yet heard of SDS nor is aware of the opportunities that it presents for themselves, their friends and their families. This means that many people will only learn about SDS when they first encounter the social care system, often at a time of personal or family crisis when they are least equipped to integrate new information.”*
>
> [7]

For people living with dementia and their families, accessing Self-Directed Support (SDS) often begins with a fundamental problem: knowing that it exists. This is not surprising, given the growing body of evidence that suggests that even front-line healthcare workers and professionals have a limited understanding of SDS or who could benefit from it[2, 20]. This lack of insight has real world implications, as only 49% of the SDS users taking part in the My Support My Choice study reported learning about SDS from health and social care professionals, meaning 51% of those taking part had to learn about SDS by other means[4].

This reliance on social capital, on having access to friends, family, colleagues, or organisations that can highlight SDS as an option, is particularly problematic for people living with dementia who often experience shrinking social networks as their condition progresses[5, 39, 40]. The challenge goes beyond simply finding someone who knows about SDS; individuals need contacts who understand both the system and their unique experience of dementia in the present and how that may change in the future. This can be acutely difficult when the public understanding of dementia remains dominated by depictions of memory loss and forgetfulness, with limited awareness of how different dementia types can affect emotional regulation, sensory processing, executive function, and behaviour[9, 10].

This creates a situation where people may receive a dementia diagnosis and ongoing support from health and social care professionals who never mention SDS, while attending dementia-specific peer support groups where the option remains either unknown or misunderstood. Even the minority who find out about SDS independently, whether through their previous roles (3%), social media (3%), or searching internet (2.7%)[4], face further obstacles as the information most easily available to them may fail to reflect local variations or post-COVID changes in practice.

Further barriers are then introduced for those with rarer types of dementia, who fall outwith the stereotyped view of 'who gets dementia', or who do not feel they are welcome or belong in traditional dementia support services including queer individuals, people from BME communities, and those with young-onset dementia[10, 11, 41]. Improving SDS access, therefore, requires more than simply raising awareness within traditional dementia services or educating SDS professionals about dementia. Efforts must instead be made to meet the person with dementia where they are, in all of their complexity, at the intersection of their marginalised identities, where ageism and ableism meet with those aspects of their marginalised identity that predates their diagnosis[11, 42]. This involves challenging entrenched assumptions about what support people with dementia need and how they should access it. Crucially, it means acknowledging and actively addressing the barriers that have historically prevented marginalised groups from engaging with traditional health and social care systems including fear of discrimination[43, 44], stigma[45], and cultural narratives prioritising informal family care over formal support[13, 14]. Active steps must be taken to address these barriers while also establishing new relationships and avenues of support.

The Role of Independent Support Organisations

Independent Support Organisations (ISOs) stand at the heart of Scotland's current social care landscape, serving as vital interpreters between the policy of Self-Directed Support and the people it aims to empower. Emerging from the very barriers outlined above, ISOs often step in to fill roles that statutory services cannot such as raising awareness of SDS options, providing guidance through complex systems, and delivering targeted advice to the groups they serve.

The evidence consistently shows ISOs operating across three critical levels: individual, community, and national[4, 8, 20]. At the individual level, they represent the frontline of SDS practice, providing a consistent source of support throughout both the application process and ongoing provision. Over 71% of the My Support My Choice participants, as well as several respondents in the By My Side project, indicated that access to independent support made it easier to access SDS, with interviewees stating:

> *"I think my biggest advice would be to get professional advice. So something like [local independent advice and support organisation], or an advocate, or something; get somebody who that's their speciality, to support and advise you. Because I've found that going it alone you tend to get pushed back – and it shouldn't be like this, but the system is a case of who shouts loudest gets the most."*
>
> *"I'd like you to put in the report that sometimes we get better care from the voluntary sector than from the government. I am more likely to phone charities than social work if I need even an answer or an explanation. There's so much rhetoric about equality, about diversity – but the gap between the aspiration and delivery is huge."*
>
> [4, p.98-99]

Secondly, at a community level, ISOs represent both opportunities for connection and visible repositories of knowledge. The enquiries data from Self Directed Support Scotland provides numerous examples of this vital work from the organisational perspective, documenting cases that range from straightforward requests for information to more complex situations where:

- relationships between users and service providers had broken down,
- individuals experienced financial hardship, or were missed out on benefits they were entitled to,
- dementia symptoms created unique barriers to accessing appropriate support,
- people were seeking information about SDS, their eligibility, and advice for navigating the system.

These complex enquiries often required staff to occupy dual roles, serving simultaneously as advisors providing available information and as navigators directing people to more localised or specialised support when their needs exceeded the staff's expertise, for example:

> *"[Contact] rang from the [region] and was looking for some information about her mum being able to access support through SDS. She explained that her mum was in her 80s now and had been diagnosed with Alzheimer's. She wasn't sure if someone with Alzheimer's would be eligible for SDS. [...] However, her mum was finding it difficult manage everyday tasks and be aware of danger. [Staff] discussed how access to SDS depended on her mum having an assessment of her needs by the Social Work Department. If she meets local eligibility criteria she would then be eligible for funding to pay for her needs. At that point, choices about the 4 SDS Options come in. [Staff] also mentioned about the support being provided by [organisation] in the [local] area and passed on their contact details."*

-Self Direct Support Scotland Enquiry Data

Finally, at the national level, ISOs amplify these grassroots experiences into policy advocacy. The evidence submitted to the Feeley Review[8] contains powerful examples of ISOs championing both individual needs and systemic change, including this case study submitted as part of the joint Deafblind Scotland and Deafscotland response which highlights both the impact of process failure at the individual level and the need for a system wide review:

> *"Deafened man transferred from acute mental health service to care establishment. He has no communication support provided during his telephone based, dementia assessment – the result was borderline [...] He has had no access to communication support when dealing with advocacy and legal services. SDS could have been used to support him and he might have been able to return to his home, self-managing for longer had his communication needs been taken into account. [...] Legal intervention has called for a review, however, it is an expensive lesson for the state and duty*

> *bearers have a requirement to understand the rights based approach better and differently.”*
>
> [46, p.19]

Yet, for all their recognised value, ISOs face persistent structural challenges that limit their impact. The Care Inspectorate's 2019 review[20] found troubling gaps in awareness of advocacy services among both service users and professionals, while ongoing financial pressures create a situation where demand far outstrips capacity. This risks leaving many without the impartial guidance necessary when navigating complex systems[4, 8, 20].

These insights are particularly concerning when one considers the potential impact of underfunding and stretched resources on people living with dementia navigating SDS. For example, the 2024 Impact Report for the Scottish-Government funded Support in the Right Direction Programme revealed that over 2,000 people had reached out to participating organisations specifically regarding dementia, whether for their own diagnosis or that of someone they supported. This is, perhaps, unsurprising as several of the supported ISOs are carers organisations, with others providing services around Housing and Living. It is of note, however, that while many supported ISOs specialise in carers’ services or housing support, none focus specifically on dementia. This means relying on access to resources to secure additional training to gain dementia competency, an undertaking made more challenging by the need to understand not just dementia in the abstract, but the profound variations in symptoms and support needs across different dementias such as Alzheimer's disease, vascular dementia, and posterior cortical atrophy, and at different stages of progression. Acquiring this level of nuanced understanding requires dedicated time and high-quality resources, both of which can be challenging to access in the current funding climate. This risks creating and sustaining ISO networks which inadvertently replicate existing access inequalities for marginalised groups, rather than resolving them.

This disconnect between an ISO’s potential and the current reality raises fundamental questions about how well SDS can meet its emancipatory and human rights-based goals in the current climate. The Feeley Review's recommendation to expand ISO services alongside reopening the Independent Living Fund[8], and the Scottish Government’s £9.3 million investment in the Support in the Right Direction programme can be seen as meaningful recognition that, without properly resourced independent support, the promise of SDS remains out of reach for many. The question becomes how, and where, increased awareness and understanding of dementia can be meaningfully integrated into the wider ISO network to ensure that people living with dementia, and those that support them, have access to the information, support, and advocacy they need to enjoy the benefits of Self-Directed Support.

7. Rigid Systems, Flexible Needs: Structural Challenges in SDS Delivery

While it is important to acknowledge the impact of barriers around dementia and SDS awareness on the provision of support, these weaknesses can only be understood in the context of the wider structural issues that continue to undermine SDS provision across Scotland. A growing body of literature details the impact of the inconsistent implementation of SDS across Scotland's 32 local authorities, creating a postcode lottery for those attempting to access support[22, 24, 47] where SDS is 'bolted on' to existing service-led structures[21] and a lopsided system where Option 3 (council-managed care) dominates while Options 2 and 4 remain inconsistently available[20, 26].

There are a number of structural issues that are particularly, though not exclusively, detrimental to people living with dementia. Though each barrier represents it’s own challenge, they are underpinned by the particular impacts of dementia on the individual, which frustrates their ability to interact with an already inaccessible system, namely communication challenges, cognitive changes, and the progressive nature of their condition. This section examines three fundamental structural barriers that perpetuate this exclusion: inconsistent eligibility frameworks that determine who can access support, financial processes that prioritise cost containment over individual need, and systemic failures in coproduction that leave people feeling like decisions are made without them.

The Impact of Economic Pressure on Eligibility

Structural barriers are present from the first moment an SDS application is considered, as each individual application is assessed on the basis of need and risk, both of which are interpreted and applied inconsistently across Scotland’s local authorities, with many authorities setting thresholds so high that only those in crisis qualify for support[23, 47] while others are referred to services provided by third-sector and community organisations[31].

These challenges are further exacerbated by SDS’s long waiting lists and overly bureaucratic decision-making processes, which can leave individuals in crisis without access to timely support[4, 8, 20, 21]. The My Support My Choice research found 54% of respondents (176 people) reported waiting times made the process more difficult, with many waiting over six months for assessments and some over a year[4]. For people living with dementia, whose needs may change unexpectedly, such delays can render initial assessments obsolete by the time support arrives.

This systemic sluggishness, paired with local authorities' prioritisation of cost and eligibility over personalised planning[8], fuels anxiety for those navigating SDS amid dementia's changing needs. These concerns are far from theoretical: authorities have actively defended restricting SDS access for over-65s, most notably through the 2018 Mrs Q v Glasgow City Council case where the final ruling endorsed comparing community care costs to residential placements for this age group, institutionalising what Dalrymple et al.[7] term an economic rationale to "to forcibly replace 'community care' with 'residential care' when the cost of the former exceeds the average cost of the latter", becoming in effect an age-based cap on independent living.

It is important to recognise, however, that health and social care practitioners often share a distinct sense of unease when encountering such policies, as both Njoki[30] and Morrow[36] detail:

> *"Basically, when someone turns 65 the budget available to them to capped at the cost of a residential care home placement. So…the local authority is basically saying, we'll only fund you in the community if it is cheaper than a residential placement. […] As soon as the cost of community care goes over that, either the person can top it up to stay at home, or the local authority basically says it isn't safe to keep them at home and the recommendation is made for a care home. [...] I think it is horrendous. Totally ageist. […] I get we can't just fund people indefinitely in the community, but what gets me is the difference between younger people and older people. […] How can that be right?"*
>
> (36, p89-90)

> *"If you are a younger person and your [direct payment] is in lieu of day centre, and you want to use that to go to the gym, fine we can sort that for you, but if you are an older person with dementia, and your package is personal care, there is a limit to how you can be creative and flexible with that."*

[30, p108]

Such uneven and discriminatory implementation is, therefore, directly contrary to not only the statutory principles of SDS and the PANEL principles of human rights it echoes, but the desires of both SDS users before the system and professionals charged with its upkeep. Nevertheless, people living with dementia are likely to face significant barriers attempting to access the system as a result of both inconsistent interpretation of policy and informal cap placed on their right to independent living.

Implementing Co-Production

Another barrier for those wishing to access SDS becomes evident when examining the extent to which SDS users are truly supported to become co-productive partners with the power to design their own care, and how ongoing limitations might additionally disempower people living with dementia.

At the heart of this barrier lies the requirement for what might be termed a ‘professional bilingualism’ - where professionals are required to communicate simultaneously in two languages, one the outcome-focused language of empowerment to be adopted with service users, and the other a more traditional deficit-based terminology to used when completing assessments and justifying budgets[20]. This linguistic divide reflects deeper systemic failures, as processes remain wedded to time-and-task models, forcing practitioners to speak the bureaucratic language of "commissioning and procurement" rather than the creativity and choice envisioned by SDS legislation[48].

The disconnection between these two languages undermines the extent to which social workers and other professionals can engage in true co-production, trapped as they are in a system that consistently seeks to enforce the opposite[25]. The gap between aspiration and reality is highlighted in the My Support My Choice research, where the 74% of users who felt involved in making care decisions are offset by those who report being offered incomplete information or options, and others still who reported that

> *"We didn't have any choice in the matter, [… we] were told it was happening and that was that."*

[4, p30]

Time constraints further undermine meaningful participation. Although 56% of respondents felt they had adequate time to choose options, 26% disagreed - particularly those given under a week to decide. One participant described feeling pressured to *"get it to panel"* with *"very little options available"*[4, p44]. For people living with dementia - who often require additional time to process information and make decisions - these hurried processes directly undermine their ability to meaningfully participate in co-producing their care.

The combination of rushed timelines and frequent lack of accessible, easy-read materials creates a double disadvantage: limiting both the individual's capacity to prepare for meetings and the professional's opportunity to build rapport and identify communication needs[49, 50]. These systemic failures risk causing additional harm by reinforcing restrictive assumptions about who can benefit from SDS, while simultaneously stifling opportunities for collaborative problem-solving around key challenges like budget management, staff recruitment, and the role of unpaid carers[51, 52, 53], despite a growing evidence - including multiple submissions to the Feeley report[8] demonstrating how Independent Support Organisations (ISOs) and providers have successfully delivered such support when properly empowered to do so.

> *“Where SDS is embraced we have numerous examples of how outcomes-based support planning and creative use of individual budgets (which includes tailored support, harnessing community opportunities and technology) has helped people live great lives and achieve their goals. Even where SDS has been less consistently applied, the tenacity of the person and those in their life alongside working closely with creative and committed colleagues has led to positive results in people’s lives. […] Social and health care services already share a national framework of standards, the National Health and Social Care Standards. They offer the potential for everyone involved in social care to be very clear about what to expect from the support they receive or provide but perhaps would benefit from greater awareness raising of their existence and how they can be used to ensure support is truly person-led.”*
>
> [54, p38]

8. Recommendations and Next Steps

A: Improvements to Data Systems & Reporting

For Public Health Scotland, analysts and data teams

- **Create transparency by including SDS data in the Social Care Dashboard**
  Updating the People Supported by Social Care dashboard to incorporate SDS variables - including user demographics, specific health conditions, needs addressed, and package metrics (net/gross value, wait times) that would enable richer analysis of access equity. Collaboration between data teams and frontline staff could ensure the tool remains practical for identifying service gaps while meeting transparency goals.

- **Improve data categories by conducting a collaborative review**
  Reviewing outdated classifications like "Frail/Elderly" presents an opportunity to adopt standardised, clinically meaningful terms for conditions including dementia, neurodivergence, and mental health conditions. Partnering with people with lived experience, social care staff, and clinicians during this process would maintain both data integrity and frontline relevance.

- **Promote consistent reporting by providing clear data guidance**
  Detailed manuals explaining new data categories (including required diagnostic codes), data cleaning protocols, and plain-language interpretation guides would help social workers and analysts maintain data quality. These changes could be supported by providing fully funded or low-cost training sessions to support rollout across teams as well as formal feedback mechanisms to ensure process both meets the needs of frontline teams and captures the complexity of SDS users' lived experiences.

B: Changes to Policy and Implementation

For Scottish Government, local authorities, and key partners

- **Develop a national eligibility framework for SDS**
  A nationally standardised but locally adaptable SDS eligibility framework

would improve transparency and equity in access across Scotland. Scottish Government could provide critical guidance for this initiative by working with key stakeholders across local authorities to co-create both the framework itself and clear, easy to access, publicly available guidance explaining eligibility criteria in plain language while allowing for necessary regional variations.

- **Remove systemic barriers for older adults and people living with dementia**
  Protecting Scotland's human rights-based approach to care will require meaningful and targeted action to address the disproportionate barriers to SDS faced by older people and people living with dementia. Efforts to address these challenges would align with the golden threads in the SDS Improvement Plan and could include:
    - **Revising funding benchmarks** that use residential care costs to cap SDS packages, removing the potential for residential care to be seen as the 'default' option for older people.
    - **Reforming age-specific guidelines** that restrict SDS entitlement and flexibility based on the age of the applicant.
    - **Supporting personalised support planning** by resourcing additional time for social workers and other frontline professionals to properly explore SDS options with applicants.

- **Create shared SDS information resources**
  A nationally coordinated suite of accessible SDS materials would provide consistent, high-quality information across Scotland while maximising resource efficiency. The Scottish Government could work with key stakeholders, disabled peoples' organisations and people with lived experience to develop core resources that:
    - **Present all SDS options neutrally**, from direct payments to council-managed support, using realistic case examples.
    - **Incorporate multiple accessible formats** including Easy Read, multilingual versions, BSL-interpreted videos and audio guides

    - **Include a national freephone advice service** with extended hours for immediate support.

  Local authorities could then adapt these materials by adding local contact details and service examples as needed, meeting Standard 13's pre-decision requirements while maintaining consistency and reducing duplication of effort across regions.

- **Increase signposting to Independent Support**
  Independent Support Organisations play a critical role in helping people navigate SDS options and overcome access barriers. Ensuring frontline professionals including social workers, GPs and hospital discharge teams are equipped to make these connections requires dedicated support through training on local ISO services, up-to-date accessible referral materials, and clear organisational expectations about proactive signposting. A 'better safe than sorry' approach to signposting may prove particularly valuable when supporting individuals likely to face additional barriers, helping prevent missed opportunities for crucial support through the SDS process in line with Standard 13.

C: Support for Dementia-Aware Frontline Practice

For social workers, training providers, and third sector organisations

- **Transform professional understanding through linked training**
  Limited awareness of both SDS options and dementia leaves many people without reliable access to appropriate support. Addressing this gap could involve reviewing existing training and co-developing two interconnected programmes with people who have lived experience:
    - **Enhanced SDS training covering complex cases** that builds practitioner confidence and supports them to think creatively about how SDS could meet diverse needs. This would involve presenting people living with dementia alongside other SDS users who experience similar cognitive, sensory or communication challenges for other reasons to demonstrate how adapted solutions like visual supports or environmental modifications can transcend diagnostic categories.

  - **Evidence based dementia awareness training** that moves beyond basic memory loss education to explore the different ways dementia symptoms can impact a person's life by impacting other areas of their cognition to create executive functioning challenges, sensory processing differences, communication changes and emotional regulation. This training should be closely aligned with SDS' human-rights focus, and explore how different options for adaptation, support, and care, including SDS, can support people to live well with dementia. The programme could prove particularly valuable where it draws upon examples of people with different types of dementia, at different points in their journey, and from diverse backgrounds, to show how person-centred care provision, like SDS, can maintain independence and quality of life while challenging assumptions about what people with cognitive changes can or should access.

- **Empower frontline professionals to deliver dementia-informed SDS support**
  Ongoing professional relationships play a critical role in helping people living with dementia navigate SDS options and adapt support as needs change. Ensuring frontline practitioners including social workers, care coordinators and third sector staff can develop this continuity requires protected time for meaningful engagement, dementia-specific training on progressive needs, and organisational systems that prioritise relationship-building over transactional assessments. A proactive approach to regular check-ins may prove particularly valuable for monitoring subtle changes in needs and circumstances, helping prevent crises and missed support opportunities and maintain the 'golden thread' of SDS throughout the dementia journey.

- **Create spaces where Dementia and SDS exist together**
  For people living with dementia, accessing SDS often depends on encountering peers and professionals who understand both the potential impact of their condition and the options available to them. Independent Support Organisations and third sector groups are therefore uniquely placed to address critical knowledge barriers between people living with

dementia and SDS. These organisations should therefore be supported to:

- Develop and maintain accessible services where SDS guidance and dementia awareness go hand in hand.
- Deliver regular, accessible learning opportunities for staff, volunteers, and service users that improves dementia awareness and knowledge of SDS.
- Build networks, share resources and signpost between groups and services, ensuring people living with dementia and their families encounter relevant information whether accessing traditional SDS services or dementia support.

Such efforts would need dedicated resources to withstand staff turnover, including accessible, evidence-based training materials, collaborative partnerships between those working in SDS and dementia spaces, and protected time for knowledge-sharing between communities. While not replacing systemic reform, such targeted capacity-building offers a practical interim solution for existing barriers by improving access to SDS support while efforts are made elsewhere to address wider systematic barriers for people living with dementia.

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Dr Catherine M Pemble is a social scientist and Research Fellow at the University of Stirling. Her work focuses on understanding how social structures, physical spaces, and interpersonal relationships can create barriers for disabled people and people living with dementia, and uncovering opportunities for people to work together to create more vibrant and inclusive communities.

About Self Directed Support Scotland

Self Directed Support Scotland (SDSS) is a membership organisation that links national policy and local experience to improve the implementation of Self-directed Support in Scotland. They champion the values of choice, control, and flexibility in social care support, working collaboratively with the Scottish Government, Local Authorities, third sector organisations, and their members to drive meaningful change and improve access to SDS for disabled people across Scotland.

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