

Regulations and Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

SCVO response 10 July 2013

Summary

The Self-Directed Support legislation provides an opportunity to create a shift in power to ensure disabled people and unpaid carers are able to live independently, to achieve their ambitions and goals, and to direct how these ambitions are achieved.

In our response SCVO calls for:

- **Real and different choice** – we need to think outside the box when we seek to implement self-directed support – achieving dignity, resilience and the ability to live independently can be achieved through a wide range of interventions, which can sit outside “traditional” social care activity e.g. social and sport activities, dance, lunch clubs, help to access food, development of digital skills and so on. Less risk aversion within local authorities could truly help to make self-directed support a reality whilst in-depth consultation and direct involvement of service users and carers is essential.
- **SDS must not mask cuts in social care** – existing approaches and a focus on resources rather than outcomes serve to reduce choice and resilience, and can create more dependency and crisis situations.
- **Be radical, pool resources and ensure SDS connects with other policy changes** – we have an opportunity to think strategically and collectively. Combining different spending pots linked to independent living could help achieve greater impact and cut through bureaucracy for individuals, families and professionals. We have the opportunity to rethink social care and all the elements linked to achieving the vision and principles within the SDS legislation. Tinkering at the edges will not work.

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Our response

SCVO welcomes the opportunity to respond to the consultation on the above regulations which will drive implementation of the Self Directed Support (SDS) legislation.

Our response covers some specific points in relation to the tone and emphasis of the guidance and specific issues arising from the current experience of older people, people with disabilities and unpaid carers. Lastly we highlight the opportunities arising from the current legislative and policy context to take forward public service reform.

SCVO recognises the intention and spirit of the Self Directed Support legislation and the desire to seek a sea change in how social care is delivered. The feedback from carers' and other organisations suggests that achieving this presents significant challenges, with bureaucratic procedures and tightening eligibility leading to families often having to "fight" for sometimes very small amounts of support. The guidance has a lot of work to do as a result of this.

As implementation of the Self Directed Support strategy continues, with a range of third sector organisations operating in this context, it's vital that the funding allied to this and implementation of the legislation is fully evaluated and we learn important, practical lessons about what works well and what doesn't. The Scottish Government's commitment to include case studies within the guidance is an important step in showing how SDS can work – not just for professionals but to ensure that service users and carers are better informed about what the SDS options are, what they could mean in reality and how to prepare for assessment processes. Effort in this area would be worth further investment and work.

Regulation-specific comments

Setting the right tone

The need to drive change in how social care operates has never been greater and there is a real desire amongst disabled people's organisations and carers' organisations as well as across the third sector, to see power, choice and control shifted towards individuals and families. More widely, the vision within Christie is one where public services are empowering and building up resilience and autonomy. Self-directed support can contribute in this regard.

To that end, the regulations must encourage new ways and approaches – they need to be ambitious and inspirational. However, opening statements and some of the language used throughout the guidance seem almost to discourage the kind of innovation needed to shift power and control to service users and carers.

As Age Scotland has pointed out, SDS can and should be empowering for individuals and families if properly presented. We would argue that the tone and emphasis within the guidance does not always contribute to this sense of empowerment.

For example, in the first few sections of the guidance, and in the section on the Person's Pathway, there is a very evident focus on needs, resources and risk – rather than a focus on clear outcomes, assets and achieving goals. There is a tone set which seems at times to emphasise and perhaps 'endorse' the current bureaucracy that surrounds social care assessment for families who struggle consistently to navigate complex, resource led systems.

Awareness of risks is important in term of protecting people, but as the Coalition of Care and Support Providers in Scotland (CCPS) points out in its response, it is much more positive and effective to focus on risk enablement, and the realisation of key human rights, as indicated by the principles of the legislation. More could be made of this in the regulations.

Examples of good outcome-based plans and how discussions between professionals and families have achieved those outcomes (as well as innovative approaches and interventions) must feature strongly in the guidance to ensure that professionals are encouraged to think widely about the range of ways in which people can get to where they want to be. The assessment process must not limit the options and opportunities for outcomes to be achieved. The case study on page 41/42 (Lisa) is a good example of this.

Such examples can also demonstrate to disabled people and carers what can be possible, and that much more can be done within the context of self-directed support than 'traditional' social care interventions. We explore this in more detail later in the response.

Resource Allocation and Accountability

A significant concern surrounds the myriad of **resource allocation processes** developing which can include Resource Allocation Panels (RAPs). The guidance avoids this issue and, worryingly, it does not touch on the fact that decisions can be made about personal budgets/packages of support by people who perhaps have not even met the individuals being assessed. In some cases, RAPs can meet and agree support packages without any direct input from individuals whose lives are being discussed. Although this is not something which specifically relates to Self Directed Support (as these processes precede the legislation) the guidance provides an opportunity to tackle this and to ensure there is **accountability** to service users and carers. It also provides an opportunity to tackle the postcode lottery in care and, as the National Carer Organisations group outlines in their response, the emergence of arbitrary decisions to reduce allocations to a disabled person based on an unpaid carer being present. Again, this works against the spirit and intention of the legislation and leave us with existing systems which can work directly to reduce choice and control.

Monitoring and Review

The guidance is very light on **monitoring and review**. Whilst this should not be cumbersome or create additional stresses for individuals and families, monitoring and review can be positive, as it means that fluctuating conditions are taken into account. People may change their mind and wish to move between any of the options outlined within the legislation and people's abilities and goals may change. From the perspective of organisations (including those within the third sector) involved in providing support, this is vital to ensure that they are truly helping an individual achieve the goals they have identified. It also makes sense to ensure that families providing informal care have their needs and wellbeing taken into account e.g. if an unpaid carer's health is an issue or he/she no longer wishes to provide the same amount of care.

This section needs to be much more detailed and include examples of good practice.

Unpaid Carers

SCVO supports the concerns and issues raised by the National Carers Organisations (NCO), specifically:

The benefits of accessing a Carers' Assessment – and the fact that accessing an assessment should not be based solely on an unpaid carer having to prove they are providing regular and substantial care. Also, the NCO group highlights the increasing use of Carer Self Assessments which should not replace a co-produced assessment involving professionals (social work and voluntary sector). Emphasising terminology such as “regular and substantial” implies eligibility and a resource-led process and can lead to carers being managed out of the social care system, even where they may need significant support. There is no economic or moral basis for this, especially given the increasing need for unpaid care due to demographic change.ⁱ

The importance of access to information and advice as well as other ‘universal’ free services which help an individual to make informed choices about how they access support are as valid for unpaid carers as they are for people with disabilities. Disability, carer and advocacy organisations offer vital, free services which empower and help people to make their journey towards accessing self-directed support. They are crucial to achieving the intention and will behind the legislation.

Lastly it is important to point out again that there is, potentially, a **legislative “inequity”** between carers and people with disabilities. The access to self-directed support and the carers' assessment is driven through a discretionary power to support carers, not a statutory duty. This benefits no one and will lead, in turn, to more (and not less) demand on statutory services.

The principles underpinning this legislation – dignity, independent living and so on – apply equally to unpaid carers. This must be made clearer in the guidance. The goals of independent living and ensuring that carers have a life of their own outside of caring are not separate or mutually exclusive.

Wider issues for regulations and implementation

Early Intervention

There is a need to give much more prominence to early intervention, preventative approaches and support throughout the guidance documents. This should be up front and much more visible throughout the guidance. This point is emphasised strongly by the response from the National Carer Organisations group.

Real - and different - choice

The essential principles underpinning the Self Directed Support legislation are choice and control. A number of factors can work against this vision and include:

Risk aversion in local authorities e.g. prescriptive lists which determine what people can purchase with direct payments or personal budget – whether or not these are ‘held’ by an individual. CCPS mention in their response the need to avoid practices such as “approved provider lists”.

The need for better recognition of the benefits of “one off” purchases or investment in equipment which can help an individual achieve specific goals or help reduce pressure on unpaid carers e.g. driving lessons, purchasing IT equipment, reworking a garden or bedroom space (e.g. for a child with autism) or purchasing relatively inexpensive items e.g. black out blinds.

An unwillingness to recognise the wide range of support which can be accessed via self-directed support. Whilst these interventions or activities might sit outside of “traditional” social care interventions they can, nevertheless, help achieve goals around wellbeing, reducing isolation, supporting independent travel, maintaining an individual’s health and connections to their community. This can include accessing sports activities and clubs (often run on a voluntary basis), social events, dance and other activities, lunch clubs, shopping services and so on.

We would raise the possibility of people being able to allocate a specific amount (or indeed all) of a personal budget to these kinds of activities, where this is the choice of the individual/family. There must be a greater emphasis and strong examples of the wide range of ways in which self-directed support can truly help people participate in their communities, in work and in day to day life.

Another element which can be encouraged are “cooperatives” where people with similar ideas, interests and goals can work together to pool personal budgets which enables them to purchase more, or specific supports which might meet, for example, religious or cultural needs.

Choice must mean choice – people should not be ‘forced’ to take a personal budget or be left to manage this of their own accord. However, retaining the status quo – where the local authority provides services directly - should also offer choice for people. This means an increasing facilitation role for local authorities in arranging support, including more “non-traditional” services and activities.

Choice and Control - Hidden costs

The importance of informed choice is a key element of the SDS legislation and is highlighted throughout the guidance. This is essential if people are to understand what options are available and what taking a more personalised package might actually mean for them (e.g. implications around employment law, accountability for spend etc.). It’s also vital to ensure that people can understand what provision exists, including services which can meet outcomes in a range of ways. (See above.)

Research commissioned by the Scottish Governmentⁱⁱ indicated that some of the costs of the increased flexibility arising from SDS packages can fall on individuals and family carers e.g. people are awarded a personal budget and then left to find out what is available on their own. There are examples of service users and unpaid carers working together through social networking to share good practice, experiences and “provider” contacts because they have not been supported to do so – either by the local authority, or where they have not been made aware of organisations which can broker or provide advice and support. The research suggests that this cost (including emotional strain and time) may be offset *“if Local Authorities invest in independent advocacy and support organisations, to give users and family carers support in managing SDS.”*ⁱⁱⁱ

Professionals involved in providing support to access SDS must also have a stronger knowledge of the local ‘market’ especially where a person may be deemed ineligible for self-directed support but could still access other services which could help them achieve their outcomes, e.g. carers’ centres, disability user groups, local community organisations etc. This applies equally to third sector organisations operating in “social care” whether they are

providers of support or are providing information and advice to disabled people and/or their carers.

Lastly, the issue of **charging for social care** is not really tackled within this guidance – nor is the postcode lottery which continues for people across the country and indeed within local authorities. This remains a challenge in implementing the SDS legislation and regulations. What is vital is transparency and equality in how charges are determined – although as the Health and Social Care Alliance points out in its response, achieving the right to independent living is not something which should be charged for.

SDS should not mask cuts

There is increasing evidence being picked up across the third sector which shows that the implementation of Self Directed Support is ‘masking’ cuts to social care budgets. This is leading to cuts in existing personal budgets/allocations (in some cases 40% or more) or reduced hourly rates being offered to individuals. It can mean that personal budgets or Direct Payments awarded are not enough to purchase the supports which will best enable people to achieve their goals.

There is also increasing evidence of a move towards ‘life and limb’ provision through social care as a result of cuts at local level, highlighted by the CCPS response. This disempowers and works against the underpinning principles and provisions within the SDS legislation.

Care and support services, particularly those offered through the voluntary sector, were already experiencing downward pressure as a result of local procurement practices which focus on ‘price’. Another challenge facing services users is that the cost of statutory run services may be more expensive per hour than outsourced services. This means an element of choice has been taken away for families who may wish to remain with e.g. a local authority run day care service, but who may not be able to afford this from their allocated budget.

SCVO’s response to the consultation on the Procurement Bill highlights the challenges surrounding current processes. The key points within this response fit well with the intentions of the SDS legislation particularly the need for “person-centred” procurement and a focus on social outcomes and impact (not just social ‘benefit’ and ‘best value’)^{iv}.

Rural implementation

The specific challenges of implementing self-directed support in rural areas must be considered within the guidance. As procurement continues to place downward pressure on care providers, it becomes challenging to deliver choice and control compounded by issues such as lack of access to transport, no (or poor) digital access (broadband infrastructure) and the physical distance between people. This means that the voice of people in rural communities is vital, and models such as Community Care Assynt^v are worth investigating further. One alternative solution developed in the Scottish Borders was to pay a local pub in a rural village to provide lunch for a group of older people who did not want to be transported to a day centre miles away from their homes. Other examples include Westhill Men’s Shed^{vi}, which can provide activities for older men to reduce isolation whilst giving something concrete back to communities both here and abroad. These approaches can still achieve social care goals but see the wellbeing of an individual in wider terms.

Older people

Feedback from members including Age Scotland and Foodtrain highlights that there is still relatively low take up of SDS amongst older people, especially those who are frail. Foodtrain suggests that many of their 1,100 members have little or no knowledge of self-directed support. An Age Scotland poll of 1,000 people aged 50 years and over from across Scotland and local authority revealed that over four-fifths had never heard of SDS, with lack of knowledge increasing across older age groups.

Ironically, Foodtrain also highlight the reality of the current social care system where older people often have very little say or choice in how care and support is provided. Cutbacks in provision for older people, and more generally, are leading to restrictive care e.g. early tuck-ins (6pm) and short visits which only meet the most basic of needs. As pointed out in recent research by the Royal Voluntary Service^{vii}, the notion of “personal deficit” can drive services affecting older people. How can we use both the legislation and the regulations to create a shift which recognises their capabilities and experience? The notion of services being ‘done to’ people is also picked up by this research^{viii}.

Portability of Outcomes Plans/SDS packages

Portability of social care remains a challenge both within local authorities (e.g. where a social worker/named professional changes or where a child reaches transition to adult services) and when people move *between* local authorities. Whilst a reassessment could lead to a positive outcome for an individual or family, the reality can be quite different – yet more assessments and bureaucracy to face in order to maintain or reinstate existing support packages where the individuals concerned are content with this.

As people move towards having more control over the care they receive, we must ensure that where a package and budget has been agreed by one council, and where a service user/carer is satisfied with this, this is not reduced or compromised when they move to another area. The guidance can be used to tackle this issue positively.

Digital agenda

We have yet to fully harness the power of technology to connect and support people who require support within health and social care and more widely in other public services. The guidance should include examples of how technology has enabled people to move towards independent living and to feel better connected to their communities and to their families. Lessons from the use of tele-care must be emphasised and updates from the DALLAS project in Scotland (Living it Up)^{ix} could also be useful.

This need not always be expensive. Peer support amongst disabled people and carers who use social networking to share good practice in self-directed support, review providers, share prices and experiences about what worked for them - and what didn't – can be positive and empowering. Taking this a step further, people could use digital to develop digital cooperatives perhaps to jointly purchase services using their personal budgets.

Technology can be used positively in the context of self-directed support especially in relation to advice and information provision to support choice. This is not a solution for all and must not replace one to one advice and support from a range of organisations who can help individuals and families navigate assessment, outcome development and allocation processes.

Investigating ideas to improve digital access, particularly in the context of the current welfare reform agenda, is important. Ideas such as Lead Scotland's (people with disability and their carers) [Thinking Digitally Learners Module](#) supports disabled young people and adults and carers to develop digital participation skills, find their online voice and identity and become digitally responsible.

Connections with other legislation

We would like to emphasise the point made by the Health and Social Care Alliance in its response to this consultation about connections between the self-directed support legislation, the new Public Bodies (Health and Social Care integration) and Children and Young People's bills.

In relation to plans to bring health and social care services together, there may be occasions where a health board takes the lead for planning and delivering services that are 'covered' by the SDS legislation. Here, we have the potential of two very different models 'clashing' – medical models versus a focus on the wider context in which people live their day to day lives. It will also mean that health staff will require much greater awareness of the variety and options which the legislation seeks to drive.

Sadly, the need to involve the sector directly in planning for integrated health and social care services is not recognised in the Public Bodies Bill, potentially moving us backwards from any achievements gained through the Reshaping Care Change Fund processes. The SDS legislation will transform the context in which third sector organisations – both providers and advice organisations – operate so they should be supported through that transition. The BRIA must take account of this.

Self-directed support and welfare reform

The current substantial and poverty inducing changes to benefits drive through the intentions behind the SDS legislation. Already, people may have lost amounts of significant income, without even considering the potential loss of mobility components/support in the transfer to PIP. These could undermine existing SDS packages and more generally the independence and resilience of individuals – disabled people and unpaid carers.

How will guidance/implementation of the SDS legislation take account of this and how are risks to implementation being analysed? We must also consider whether or not the commitment by the Scottish Government to maintain existing pass-ported benefits under Universal Credit/in the event of losing disability benefits will be enough to mitigate against any identified risks.

Independent Living Fund

We must be cognisant of plans by the Westminster Government to wind up the Independent Living Fund (ILF), and how this could potentially impact on implementation of the SDS legislation. If the funding attached to ILF is to be devolved to Scotland, like the Scottish Welfare Fund, there must be a thorough analysis of options to administer this. This presents some opportunities linked to the Public Service Reform agenda.

Public service reform – theory to reality

The danger with the SDS legislation and guidance and more widely with health and social care integration and newer developments like the Scottish Welfare Fund is that we tinker at the edges and reinforce existing processes, approaches and models. We have an opportunity here to consider a range of elements and funding linked to social care more strategically and collectively to drive through radical change.

Could we combine any monies devolved through ILF, Community Care Grants (which currently sit within the Scottish Welfare Fund) and any investment relating to SDS implementation to get more back and to drive some real change in how people access social care? More widely, organisations and local authority/third sector and other professionals – and importantly, individuals and families – would not have to navigate different application systems for funding which all essentially support quality of life and independent living. Here we have a potential opportunity to bring the Christie principles to life.

The language used by the Christie Commission to describe transformed public services could feature more strongly in this guidance – four key elements of better and more effective public services were highlighted and these seem to capture the essence of the SDS legislation. These are:

- **Services built around people and communities**, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience;
- Organisations working **together effectively to achieve outcomes** - specifically, by delivering integrated services which help to secure improvements in the quality of life of people and their communities
- **Prioritising prevention, and reducing inequality**
- Services which are **open, transparent and accountable**

We need to tackle compartmentalisation of policies, legislation and funding as outlined above. By doing so, we provide space to consider how we can truly shift power towards people and communities and how we plan and fund the kinds of public services needed to tackle continued and deep inequalities and poverty experienced by the very people most affected by the SDS legislation. The third sector has a critical role to play in this context.

The recent intervention of the Local Government Committee in the Scottish Parliament is timely – highlighting as it does:

- Ingrained risk aversion to change and innovation^x (we need to challenge this if the SDS legislation is to transform social care)
- That public service reform is not happening at the scale and pace needed to drive the change envisaged by the Christie Commission
- The need for a *safe space* to take stock of what is in place just now, particularly in times of austerity
- That the public sector must change its approach to those to whom it supplies services

A safe space is needed now more than ever as a whole raft of changes and legislation are being driven through, sometimes without any overarching, strategic connection to the outcomes sought through Christie.

Conclusion

In emphasising the findings of the Local Government Committee, we must not lose sight of the crucial nature of the services and supports which the SDS legislation and guidance cover. In all of the debate which will follow this consultation, the plea we would make to MSPs, political parties, to local authorities and others with an interest, is not to lose sight of the people whose lives could be transformed – both positively and negatively – in the light of this legislation.

We pose some questions below and would ask those scrutinising the regulation to consider it from their own perspective:

How would you want to be treated if you were in the social care system and facing up to the implementation of self-directed support?

If your life changed overnight and you suddenly needed support to do the things which we normally take for granted – e.g. dressing, toileting, getting out and about, staying in employment – would these regulations help you to achieve your wishes?

Would you know where to start if you suddenly had a personal budget or were told to 'choose' how you wanted to receive social care support?

When we focus on resources and not outcomes, we lose sight of the fact that everyone has the right to participate in life and that it is the job of any civilised society to ensure that we do all we can to achieve this goal. This legislation and the supporting guidance have a vital role to play in this regard.

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About us

The Scottish Council for Voluntary Organisations (SCVO) is the national body representing the third sector. There are over 45,000 voluntary organisations in Scotland involving around 137,000 paid staff and approximately 1.2 million volunteers. The sector manages an income of £4.4 billion.

SCVO works in partnership with the third sector in Scotland to advance our shared values and interests. We have over 1300 members who range from individuals and grassroots groups, to Scotland-wide organisations and intermediary bodies.

As the only inclusive representative umbrella organisation for the sector SCVO:

- has the largest Scotland-wide membership from the sector – our 1300 members include charities, community groups, social enterprises and voluntary organisations of all shapes and sizes
- our governance and membership structures are democratic and accountable - with an elected board and policy committee from the sector, we are managed by the sector, for the sector
- brings together organisations and networks connecting across the whole of Scotland

SCVO works to support people to take voluntary action to help themselves and others, and to bring about social change. Our policy is determined by a policy committee elected by our members.¹

Further details about SCVO can be found at www.scvo.org.uk.

References

Scottish Voluntary Sector Statistics 2010, SCVO
www.scvo.org.uk/evidencelibrary/Home/ReadResearchItem.aspx?f=asc&rid=1078

ⁱ <http://www.scotland.gov.uk/Publications/2010/07/23153304/7>, esp 2.30 onwards

¹ SCVO's Policy Committee has 24 members elected by SCVO's member organisations who then co-opt up to eight more members primarily to reflect fields of interest which are not otherwise represented. It also includes two ex officio members, the SCVO Convener and Vice Convener.

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- ii <http://www.scotland.gov.uk/Resource/0038/00388624.pdf>
- iii As above
- iv <http://www.scvo.org.uk/policy/briefings-and-consultation-responses/response-procurement-reform-bill/>
- v <http://www.communitycareassynt.org.uk/assyntcentre2.html>
- vi <http://www.westhillmensshed.co.uk/index.php/how-we-got-here>
- vii <http://www.royalvoluntaryservice.org.uk/our-impact/reports-and-reviews/involving-older-age-the-route-to-twenty-first-century-well-being>
- viii As above
- ix <http://livingitup.org.uk/hidden-talents/>
- x http://www.scottish.parliament.uk/S4_LocalGovernmentandRegenerationCommittee/Reports/Igr-13-09w.pdf
e.g. page 3