



# Self-Directed Support: Your Choice, Your Right

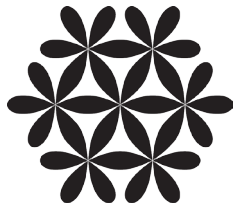
A DISCUSSION PAPER FROM THE CENTRE FOR WELFARE REFORM

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## Foreword

Good social policy is not enough. Good implementation is essential, and when power is at stake, new policy tends to be interpreted through the lens of the old power relations. As this important paper makes clear, the ongoing power imbalance in social care undermines human rights, not just for disabled and older people, but also for their supporters. Real change is possible, but it will require more determined and clear-headed action.

The paper helpfully outlines how human rights, if taken seriously can create a useful framework for testing and amending current practice. The PANEL model could create real accountability for the quality of implementation for SDS by rooting practices in a legal and administrative framework that would be helpfully challenging.

But it is not just the old that is standing in the way of the new. Austerity and Scotland's decision to integrate health and social care both seem to have taken away some of the necessary energy to make Scotland's commitment to Self-Directed Support (SDS) real. In terms of SDS legislation Scotland is a world leader. But to turn that legislation into meaningful options - encouraging innovation and starting to trust front-line workers - will require much more work.

However it is encouraging that the authors, representing key constituencies of the civil society in Scotland, are showing the leadership necessary to engage in a public discussion of these issues. I hope this paper acts as another useful stepping stone towards greater dialogue between government and citizens and that it helps promote the creative collaboration necessary to give life to human rights.

Simon Duffy

Director of the Centre for Welfare Reform



# I. Introduction

In 2012 we published a discussion paper: *Personalisation and Human Rights*. It highlighted that Self-Directed Support (SDS) is the Scottish Government's chosen method to ensure (within the broader movement of 'personalisation') that each individual's right to choice, power, control and, ultimately, citizenship, is delivered and enhanced through a substantive shift in power within our social care system. The paper also outlined how this shift will further help to reshape this system and improve the combined benefits of state support and the person's natural resources.

This paper will explore in more detail why SDS is our best option for providing a person-centred, long-term, human-rights based approach to social care. We will also examine to what extent SDS – and that vital shift in choice, power and control – has been implemented following the legislation of 2013.

Achieving this shift in approach and power requires innovation, substitution, creativity and (for many people) supportive and engaging relationships. It does not require the typical practices which have become evident during this implementation phase. These practices permit the person requiring support to make a choice from one of four SDS options, only then to have other individuals or agencies allocate a number of hours of support (priced at an arbitrary 'hourly rate') which then becomes a crude quantification of the level of support the person is entitled to which in turn forms the basis of the support package either provided by a social care agency, or managed by the person in the role of employer. This not only misses the point, it undermines the very purpose of co-produced, innovative, flexible support; instead replicating the outmoded and deeply problematic 'hourly rate', timetabled approach which is neither efficient nor sustainable. It also does little, if anything, to empower or give control to the person relying on the social care system in the way that the legislation intends. Despite the powerful opportunities offered through SDS, it is clear that even its most basic principles are being lost in the method of implementation.

It is also clear that SDS cannot deliver a meaningful platform of human rights for individuals being supported at a cost to the rights and dignity of the worker. This paper sets out to explain and describe how we should be able to deliver both.

If we simply use SDS to sustain the old process of commissioning by creating slightly more bespoke versions of it, we merely sidestep serious systemic problems that must be addressed as a matter of urgency. These emanate from the emergence of spot-purchasing and commissioning

practices, which have a direct, causal influence upon the number of people in social care employed through part-time and sessional contracts. Most social care provision is now commissioned on a spot-purchased, framework agreement basis, leading to a number of hours of support being assessed and agreed for each person, with the subsequent allocation of a support provider. The provider organisation has no real role in the assessment process and is often instructed exactly which times and days that support is to be provided. This leads to people receiving a significantly episodic pattern of care, with support being provided according to set routines. It also means that the workforce required to deliver this becomes very large. Furthermore, due to a lack of longer-term certainty over commissioned hours, a very high number of workers are held on low volume contracts so that they can respond to increases or decreases in requests for service provision. Neither the worker nor the provider has the autonomy to decide when to support a person, how long to support that person for and what type of change in support might deliver better outcomes. These are the new, strictly monitored, ‘timetabled workers’; not trusted to manage even their own diaries, unlike their counterparts in social work and health visiting. The contribution of this vital workforce is systematically devalued as we continue to diminish and underestimate the value of social care in general.

It is clear that, for individuals attempting to direct their own support, the system does not deliver; it is instead characterised by wasted time, unmet need, poor outcomes and continued imbalances of power and control. For the workforce, the implications of these practices are limited job satisfaction, low morale, high turnover and very poor terms and conditions of employment. Here rests the conundrum: Can we develop a system of social care that satisfies the need for the person to have choice, power and control, whilst simultaneously restoring greater power to the worker by enhancing the choice, power and control apportioned to this part of the workforce? Or, to put it another way, can we truly support the creative and practical design of transformational care for the individual with a workforce that, despite being heavily regulated and monitored, is barely trusted to practice with any degree of autonomy?

We believe that these changes in support and delivery are possible, but they require greater leadership and further change. We must stop the current commissioning practice of timetabling support and stop seeing SDS as more of the same. Organisations must start to innovate by clearly laying out what they, as organisations, are good at doing; explaining what they can bring to this creative dialogue with individuals. They must not be frightened to say what they are good at, what they do not (or cannot) do, the realistic costs of using their services, and when they are available to provide this support. Too many organisations are being pushed by the contracts



that emerge from commissioning. They bow to the pressure to overstretch their workforce, having reached the view that, in order to comply with these contracts, the people they employ simply must be infinitely flexible and available. This, at least partly, accounts for the cycle described above, and whilst some organisations are good at managing this fairly efficiently, others are not. They are much better suited to the provision of other forms of support. There should be no problem in acknowledging that distinction and in helping people to make choices within this context.

If organisations are to provide services in any given locality, and put their best workers into that locality, then they should be not only permitted but encouraged to let the worker and the person together determine the best time not only to provide support but also design that support to achieve the best outcomes. We must not allow the allocation of support to be driven by poorly conceived, episodic care patterns, driven by tick-box assessment processes. Instead, we should let the person choose which organisation is the best fit for them and involve local workers in designing support and engineering the right outcomes for that individual. We must stop itemising hours of support as a determination of need and start talking about the creative use of budgets and outcomes.

It is in this context that the social care system needs to empower workers and give them the ability to control some of their work patterns in line with achieving the person's aspirations and outcomes. Prior to the advent of the National Health Service and Community Care Act 1990, most commissioned services did not attempt to commoditise care on the basis of hours or minutes of support and achieved some excellent outcomes. These same projects are now measured and controlled through an approach described as 'real time monitoring'. Services that previously had a small number of well-paid, full-time, autonomous staff will likely now have an extremely fragmented group of up to thirty very part-time staff, allocated a small amount of hours to work within a timetable of support and paid, at best, at the national living wage. These same individual workers will in all likelihood be working with two or three other employers, perhaps even in other sectors of the economy, in order to bring home a sustainable wage.

There is no point empowering individuals who commission SDS support while at the same time disempowering these social care workers, and forcing them into working practices they neither choose nor control. We must accept that choice of care will lead to preferences, which in turn will impact on both the viability and long-term stability of some organisations. Yet this risk should not be borne by the workforce, which should not be required to demonstrate infinite flexibility in order to sustain either a struggling organisation or a failing system. We must become much more sophisticated in the articulation of the contrasting needs of people, workers

and organisations, and in the design of a flexible system that addresses these differing requirements without diminishing either the human rights of people directing their own support, or the fair-work rights and expectations of the people providing support.

## 2. Human rights at the heart of SDS

In this section we will explore the extent to which a human-rights based approach can be used to challenge current practices, address operational concerns (especially within an integrated environment) and potentially renew Self-Directed Support (SDS) in Scotland. Alongside this, we will explore the opportunity to use the recently developed Fair Work Framework as a means of balancing the reciprocal rights of the workforce, many of whom face additional challenges as a result of low pay and lack of job security and are at risk of experiencing in-work poverty, inequality and potential poorer health outcomes themselves.

*Personalisation and Human Rights* (2012) already articulated both the human rights underpinning and the operational, human-rights potential of personalisation and SDS. The legislation itself is part of a perhaps accidental but nevertheless consistent human-rights articulation of social care legislation and policy in Scotland. Taken together, these show significant progress over the last decade towards (at least in theory) embedding a human-rights based approach at the heart of care and support services. These are evident both in (some) practice and within primary legislation, such as the Mental Health (Care and Treatment) (Scotland) Act 2003, the Adult Support and Protection Act Adult Support and Protection (Scotland) Act 2007 and more recently the Social Care (Self-directed Support) (Scotland) Act 2013. All three have had a core set of human rights principles central to their emphasis. Most recently the articulation and development of the new Health and Social Care Standards, based as they are on clear human rights principles, offers the further potential of embedding a rights-based approach to social care delivery in Scotland

The SDS Act describes the mechanisms by which all adults should receive social care support in Scotland and has at its core a set of principles and values which should be at the centre of all social care support and provision. These Principles include: **Involvement, Collaboration, Informed Choice, Participation and Dignity**. These are in turn supported by a set of values which underpin the Act: **Respect, Fairness, Independence, Freedom and Safety**.

**Statements in the Statutory Guidance underline the centrality of both the Principles and Values for the Supported Person's Pathway:**

*'The statutory principles are important because they carry legal weight. They articulate the underlying aims or "spirit" of the legislation and complement the detailed duties and powers provided elsewhere in the Act.'*

Self-Directed Support Statutory Guidance, section 4.3

In addition, there have been positive individual projects to embed human rights, but these have not had a recognisable impact within service provision or statutory practice.

**Examples include:**

- The Care About Rights project (Scottish Human Rights Commission (SHRC))
- The Charter of Rights for People with Dementia and their Carers in Scotland (the Scottish Parliament Cross Party Group on Alzheimer's disease, supported by the SHRC and Alzheimer Scotland)
- The Convention on the Rights Residents in Care Homes for Adults and Older People and the Convention on the Rights of People receiving Care at Home and Housing Support Services (both Scottish Care).

Since the SDS Act came into law in April 2013, there has been only minimum evidence of these human rights principles impacting on those who receive social care, particularly older people. Some even argue that the principles are there simply to inform and guide. This ignores their importance and potential. This legislation is unique in western Europe; placing a set of human rights principles at the very heart of a fundamental framework of delivering and accessing social care support. These principles are not just aspirational statements of the ideal, but are the legislative underpinning and barometer by which the success or otherwise of implementation is judged. From that perspective and through that particular human rights lens, the current status of SDS in Scotland leaves a great deal to be desired.

## Why a human rights approach?

As our 2012 paper articulated, there is every reason why there should be, in theory and in practice, a close connection between human rights tenets and the implementation of personalisation and SDS.

Human rights are the rights that we are all entitled to. They guarantee the dignity and worth of all human beings; the autonomy to make our own

choices; the freedom to live without discrimination and the support to participate equally in society. Human rights are universal; they belong to every individual regardless of nation, location, religion, race, age, capacity or any other status.

In its simplest terms, a human-rights based approach (HRBA) is an approach which seeks to promote and protect human rights and **is based on agreed international human rights standards and principles**. The approach seeks to work alongside groups and people whose rights are at risk of being, or have been, violated or ignored; understand why certain people are unable to enjoy their rights; and redress imbalances of power that prevent progress. It identifies **rights-holders** and their entitlements and corresponding **duty-bearers** and their obligations. It works to strengthen the capacity of duty-bearers to comply with their obligations and rights holders to claim and exercise their rights.

A human-rights based approach seeks to ensure that individual rights are actively promoted and embedded in health and social care policy and practice. Every person has the right to be treated with dignity, respect and without discrimination; this includes both the people who are receiving care and the workforce delivering it.

Our first paper also articulated how the use of the FAIR model could be developed to ensure a human-rights underpinning for implementing SDS. Yet it is clear that the challenges and barriers towards a human-rights based implementation of SDS are so embedded in systems, culture and the popular experience that FAIR, on its own, is unlikely to promote change or improvement. In light of this, this paper recommends an alternative approach. Many human-rights based approaches have adopted the PANEL principles as a mechanism to determine the extent to which human-rights have been embedded in practice.

### **PANEL stands for:**

**Participation** – People should be involved in decisions that affect their rights.

**Accountability** – There should be monitoring of how people’s rights are being affected, as well as remedies when things go wrong.

**Non-Discrimination** – Nobody should be treated unfairly because of their age, gender, ethnicity, disability, religion or belief, sexual orientation or gender identity. People who face the biggest barriers to realising their rights should be prioritised when it comes to taking action.

**Empowerment** – Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

**Legality** – Approaches should be grounded in the legal rights that are set out in domestic and international law. (From the Scottish Human Rights Commission)

The PANEL approach goes beyond the minimum legal requirements and embeds human rights in services, policies and practice to make them run better for everyone. We contend that PANEL, alongside a human-rights based assessment framework, is now vital to deliver the systemic change promised by personalisation and SDS and to ensure that promise is not lost. It is also critical to assess the extent to which the human rights criteria of availability, accessibility, quality, affordability, acceptability and principles of non-discrimination, participation, access to information, accountability and sustainability are evidenced in practice.

In what follows we will explore the extent to which these criteria are evident in SDS together with their potential for ensuring a rights based approach is implemented.

## Participation

As mentioned in our introduction, SDS was never envisaged as ‘an option’, but as the only route into social care supports and services for anyone needing those in Scotland. In practice, however, it is clear that a patchwork of provision and availability has grown up within the 32 Scottish local authorities.

In the SDS Act, the local authority has a duty to give independent information to those seeking the provision of support. The authority must provide the supported person with any assistance that is reasonably required in order a) that the person can express their views about the options available and b) make an informed choice about those options. The authority also has a responsibility to explain the implications of those options to the individual. However, it is clear in current SDS implementation that there is no consistency in either the content or delivery of this information and that, in some cases, it is being communicated in a non-independent manner. The authority should use terms appropriate and relevant to the supported person that can be easily understood, and it should make the options clear. However, it is also evident that many local authorities and social work practitioners are not communicating this information in a way that recognises the needs of the individual involved or using other appropriate methods of communication where this could aid in participation in SDS.

Public understanding of SDS and its potential is woefully inadequate, reflecting the inadequacy of information available, where it is even present at all. The lack of any consistent and clear media and public awareness campaign, either at national or local level, is indicative of the lukewarm approach to implementation from central and local government. There are significant examples across Scotland where individuals have not been enabled to be involved in decisions that affect their rights under

the SDS Act. They have not been able to be fully engaged in assessment, support-planning and determining their access to all the four options. In addition, it appears that duty-bearers at local authority level have actively discouraged participation, either through poor understanding or lack of training in SDS or an unwillingness to accept a power shift to the individual.

SDS means that the individual being supported should have much more control of the support relationship; not just at the point of initial choice but in its delivery. For this to be achieved, assessment processes must be as person-centred as possible. This applies to the whole relationship between a professional or provider and the supported person. It seeks to place person-centred support based on an individual being able to exercise their human rights at the heart of all social care support and delivery. It is of particular importance when making decisions around risk enablement and personal safety. In order for the person receiving care or support to exercise choice and control, the worker providing that service must also have the knowledge, training and autonomy to assist in the interpretation and delivery of that service.

## Accountability

The issues raised by the problematic implementation of SDS can only be addressed by adequate and robust monitoring and evaluation. Whilst bodies such as Audit Scotland have a role in this, ultimate responsibility lies with central government. Central government also has primary responsibility for ensuring that implementation of new legislation is robust, that barriers are removed, that public awareness is raised and that action is taken where legislation is not followed. In current circumstances it is questionable if this sense of accountability at national level can be evidenced.

The lack of a rigorous central accountability in favour of local implementation and autonomy has served to create an SDS postcode lottery across Scotland. Apart from through civic society, there seems little monitoring of how people's rights are being affected, nor have there been active remedies when things have gone wrong.

## Non-Discrimination

Some social work practitioners are openly using language such as 'we are putting that person through the SDS route', 'not everyone wants to take the SDS option' or 'SDS isn't going to work for everyone.' These statements, particularly the latter one, imply that some individuals should not have access to SDS. This attitude – that SDS will not work for certain individuals



or situations – has disproportionately affected key groups such as people with mental health conditions, people living with homelessness, people with a criminal record, people over 65, people with dementia and people in residential care. Many individuals fall into all of those last three groups and, as such, are currently being prevented from accessing all four SDS options; indeed some cannot access any options. Ostensibly this is because there are two pilot test sites exploring residential care and SDS, but in reality this has acted as a convenient excuse to prevent individual authorities from tackling enabled choice within a National Care Home Contract framework.

The stated human rights assumption that nobody should be treated unfairly because of their age, gender, ethnicity, disability, religion or belief, sexual orientation or gender identity has not been achieved. There has been a clear failure to embed the stated human rights principle that the people who face the biggest barriers to realising their rights should be prioritised when it comes to taking action.

In addition, the implementation of SDS has occurred against a backcloth of austerity and financial restriction (as we will explore later in this paper). This has created a negative association between personalised models of assessment and support with the need to make savings and increase cost efficiencies. We need to address this as a matter of priority. While implementation happens at a local level, the influencing of attitudes around SDS in a time of austerity occur at a national level; it is here that the issue of affordability becomes most acute and where decisions based on affordability need to be directed by a human rights perspective. It is here that debates over equitable funding and political expediency must be at their sharpest and most articulate.

## Empowerment

The current situation requires a context where everyone – people requiring support themselves, family members seeking support on behalf of someone else and social care workers providing support – should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

Historically, whenever someone presented themselves to social care services, the assessment process concentrated on individual needs and whether those could be met within the eligibility criteria the professional was working to. The problem with this type of ‘needs as deficiencies’ based assessment is that it results in supports provided around task and time, rather than addressing what is ultimately important to the supported individual (‘needs as common human needs’) It emphasises the deficits of an individual – ‘what is not working’ – rather than highlighting (and looking



to support) the attributes, strengths and abilities that allow people to have their common human needs met – ‘what is working’. There is also a potential for individuals, whether the supported person or the practitioner, to over-emphasise the deficits because that has traditionally been the most effective route through which support and services have been achieved.

While an individual must be fed, warm and safe, people also have other fundamental needs which must be recognised and met. To keep in touch with friends, to continue to be engaged in a pursuit or activity, to continue to be involved in your community and its organisations, are as essential to any of us as food, drink, shelter or safety.

SDS Guidance and the Act itself encourage social work practitioners and other duty bearers to embed a more holistic approach to assessment. This should be driven by a person-centred conversation with the individual (and those seeking support on that individual’s behalf, where appropriate). It emphasises the importance of helping an individual discover solutions to their challenges that might not come through traditional services but from natural, community and social networks.

### **Sections 1 and 2 of the Act specify the general principles that guide practice:**

- 1.** Involvement – this requires that the supported person must have as much involvement as they wish in both the assessment and in the provision of any support agreed on completion of their assessment.
- 2.** Collaboration – practitioners and providers must collaborate with the supported person in the provision of any support identified and agreed on completion of their assessment in order for them to be supported to achieve the outcomes they have identified.
- 3.** Informed Choice – the supported person must be provided with any assistance that is reasonable to assist them to express their own view about the support that is being provided or to make any changes to that support including the specific involvement of individual staff in their lives.

Clearly, as has been stated, the lack of real information, robust communication, resourcing of delivery amongst neglected groups – all have countered against a sense of empowerment, which was such a clear driver in this legislation. In addition, the systemic disempowerment of social care support workers, constrained within an outmoded, time-allocated approach to service delivery that stubbornly refuses to shift, is creating a volatile job market marked by low morale, poor pay and condition, and high turnover.

## Legality

To date there has been little legal challenge to the current practice of SDS. It is the contention of this paper that there is no shortage of potential challenge for the failure to ground the legal rights set out in domestic law in the implementation of SDS.

It is therefore our conclusion that, against any human-rights based assessment, the current implementation of SDS is failing. Fixing this situation, we have argued, can only be achieved by the greater articulation and embedding of a human-rights based approach to the future delivery of Self-Directed Support in Scotland.

### 3. Fair Work Framework

**The Scottish Fair Work Convention, after an extensive period of consultation and engagement, developed a new Fair Work Framework in May 2016. The Convention defined ‘fair work’ as work that offers effective voice, opportunity, security, fulfilment and respect.**

Whilst the Convention recognised that it is not an easy task to define fairness given its subjective nature, the five dimensions were informed by a strong academic evidence base.

Therefore it is our view that alongside the constructs and human rights basis described above, we have an excellent platform from which to view the rights of the workforce and the duties of employers in all their various shapes and forms in the Self-Directed Support (SDS) landscape.

This does not, and should not, mean that workers’ rights conflict in any way with the rights of individual choice, power and control. However, it does mean that organisations need to ensure that fairness and the voice of the workforce is strong as they adapt to this new way of organising and providing services. As people accessing and receiving support exercise their right to choice, power and control some organisations will evolve to these opportunities, others will no doubt struggle to adapt and may disappear, and new organisations will emerge to respond to the emerging needs and choices of an empowered body of people looking for better outcomes.

The framework needs to be built into the way organisations operate at every level and in every aspect of what they do. We want to see a workforce based upon the very principles of flexibility and the ability to deliver personalised support. We also want to see a workforce that has chosen to work in this way, people who are actively engaged in the process of change and improvement, and who are not restricted to timetabled support but are treated with respect and empowered to make decisions to support the individual. A care-delivery world where workers are forced to be infinitely flexible, where all the risks are stacked towards them and where costs and inappropriately funded commissioning and contractual arrangements underpin care far more than any recognition of human rights is not a world that will implement SDS effectively or meaningfully. This is exacerbated by the focus of some local commissioners on Electronic Homecare Monitoring (EHM). EHM, whereby payment from the local authority is based on the exact times when a social care worker ‘checks in’ or ‘checks out’ of a support session via a phone call from the house of the individual receiving care, not only precludes any autonomy of engagement between the worker and the individual, it also makes the worker feel as though they are not trusted to do their job without being watched.

We are of the view that commissioning bodies, individuals and organisations should adopt the Fair Work Framework and that we must build its principles and guidance into all our cost structures and processes.

## 4. SDS – Opportunity vs Practice

The legislative foundation created by the Social Care (Self-Directed Support) (Scotland) Act, 2013 is substantial, facilitative and empowering. Combined with the associated Statutory Guidance, it creates a national framework supportive of authentic Self-Directed Support (SDS) and represents a significant transfer of choice, power and control from professionals or organisations and agencies to citizens.

For some people, the experience of being supported to think and plan how to use all the available resources to achieve the right support for them has been transformational; they have moved from being slotted into available services to truly having (and being closely involved in) support and services that make sense to them as individuals or families. There are many people with this experience, but as with other aspects of implementation, it would be difficult to describe it as the consistent experience across the board.

There is a realisation in some quarters that SDS policy thus sets the conditions for a radical change of social care at a time when the prevailing approach is widely understood to be unsustainable. Innovations which harness the power and spirit of the legislation are evident in a number of instances. Positive things are happening throughout Scotland and across all the various ‘client groups’. This sets the scene for yet further innovation and the spread of good practice, limited only by the extent that to which it is (a) apparent and (b) effectively shared.

Since key leaders at national level (including politicians, civil servants, third and independent sector CEOs and others) appreciate the potential scope for positive change inherent in the policy, there is an ongoing climate of creative possibility that is supportive of SDS innovation, albeit restricted at times to the margins of demonstration and pilot projects. Positive SDS practice has proponents and leaders in all sectors of the social care system; not only among the men, women and children who direct their own support, but also within third-sector and independent service-provider organisations, local government, advocacy and self-advocacy organisations, national bodies representing the various social care interest groups, and central government.

There is an extensive, nationwide network of people committed to making the most of the opportunity that SDS represents; affording people the chance to have better lives. The Scottish Government has done much to foster this network through its facilitative support and funding, and has used the offices of Inspiring Scotland to effectively monitor this investment. It would be good to see the network being more effectively co-ordinated, less fragmented, and moving forward.

The political climate in the UK, as it affects people who rely on the social care system, has for some time been characterised by a rhetorical determination to distinguish the ‘deserving’ from the ‘undeserving’, accompanied by overt stigmatisation. This has coincided with the ‘economic austerity’ of the period following the financial collapse of 2008, and the continuing economic uncertainty of the post-EU-referendum UK. This has not therefore been the most opportune time to attempt to implement a comprehensive strategy of SDS with its emphasis on increased autonomy, enhanced rights, and full and equal citizenship. While the level of resources made available by government remains at best static, demand for social care services continues to grow, in the context of the changing demography of the country.

This has two effects on the implementation of SDS: It creates an environment that is not conducive to the more radical (and thus impactful) changes offered, while at the same time creating a causal link in the public and professional imaginations between the implementation of SDS on one hand and the increased rationing of resources on the other. This perception is exacerbated by the current cost pressures within the system, associated with increasing minimum and living wage levels, and the increased costs of providing overnight support. In some parts of the country this has led to increased competition and reduced choice for people who use services as some providers withdraw from the market. Though merely coincidental with SDS implementation, these cost pressures add to a sense that SDS is, per se, ‘too expensive’; and are used to justify proposals (evident recently in at least one local authority) to forcibly replace ‘community care’ with ‘residential care’ when the cost of the former exceeds the average cost of the latter.

The implementation of SDS is further restricted by a lack of public awareness of the rights and options for increased choice and control which the SDS Act and its associated statutory guidance describe. 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. There is a clear need for a public information strategy to improve this situation and to ensure that knowledge about SDS is not restricted to those already within the system.

Public understanding of, and attitude to, SDS are also fundamentally influenced by the approach of the local authority. It is clear that the implementation of SDS has been hampered by a variety of negative stances adopted by a number of local authorities across Scotland. These range from

outright non-compliance outlined earlier in this paper to approaches which contradict its very essence – ‘we have put x number of people through personalisation’ (or discussions about people who are said to be ‘in receipt of’ SDS). Individual leaders have disproportionate levels of influence on the implementation of SDS, for good or ill. It is hard to see how SDS can prosper when the agencies charged with the major responsibility for its implementation are either set against it to this extent, lack an understanding of its main tenets, or resist those principles because they threaten a major shift of power from the authority to the individual. The Scottish Government has worked well with a variety of partners, including COSLA, to provide a strategic context for the implementation of SDS, but there appears to be no appetite to move beyond strategic monitoring to hold authorities accountable for the quality of the significant aspects of implementation for which they are responsible.

It is also apparent that, despite the universal intent of the legislation, there is limited access to SDS for some groups of people in some local authority areas, as we also discussed earlier in this paper. There appear to be a number of reasons for this, ranging from genuine misapprehension about the universal intention of the Act, through to conscious decisions to begin the implementation of SDS with ‘easier’ groups, where the application of SDS is intuitively seen as more appropriate and less demanding. People with learning disabilities are especially vulnerable, on reaching the age of 60 or 65, to a form of age discrimination that would have them reclassified as ‘older people’ for whom the ‘going rate’ of social care funding is then significantly reduced, with some form of residential care then presented to them as the only alternative, or indeed the norm. The enduring challenge will be the ability of local authorities to establish a methodology for ceding increased autonomy to individuals who, from time to time, require measures of control to ensure their own wellbeing, and the wellbeing of others. This clearly flags up one of the more challenging areas of SDS implementation, where the Scottish Government could provide more effective guidance.

It is therefore unsurprising that at an individual level, SDS remains (for some people) something to be wary of; many are cautious that they may lose services that were long and hard won, even if they do not meet the needs and wants of the person or their family. Such as one mother in a Scottish city who recently described not really wanting to use the four hours per week support allocated to her and delivered by a provider organisation, but concerned that if she asked to have more control and choice over using that small resource a reduction in the budget might result; and worried about what that would mean for her and her family.

There are still great variations in the levels of choice and control that people are ‘permitted’. Some workers have managed to maintain a focus



that encourages people to describe what they want and need to achieve. Yet major inconsistencies persist across different council areas and sometimes between different groups of people in the same area (e.g. in one local authority where people with mental health needs have reported greater restrictions than other people; or with older people or people who have accessed local authority home care services, it is often reported that the options offered are restricted). Some areas have also reverted to a more prescribed and restrictive list of what can and cannot be done with individual funding.

There is still only limited exploration and expansion of the flexibility afforded by option 2, the most innovative aspect of the SDS legislation. This is in part accounted for by a cautious resistance to change, but is compounded by contractual confusion, anxiety about sub-contracting, and the reticence of public bodies and service providers to trust each other fully. In these circumstances, option 2 often represents little more than an attempt to manage budgets slightly differently within the local authority. We believe there is considerable unfulfilled potential to develop the flexibility and person-centredness which option 2, uniquely, represents, and by means of which people could truly enjoy greater personal choice and control over their own lives.

In addition, the prevalent methodology used to calculate individual budgets remains outdated and unsympathetic to the values and principles inherent in SDS. As outlined in our introduction, using the concepts of 'hours of support' and 'hourly rates' to determine, increase or reduce the size of the budget leads to considerable rigidity, and removes much of the creativity that can take place when people are given an annualised budget that they are encouraged to use flexibly. There is also evidence of the use of the concept of 'capacity', not to ensure that the processes of choice and control are administered safely, but rather to reduce the range of choices available to individuals and to families, and in some instances to deny choice completely.

The problematic complexity of the current implementation of SDS at local authority level is underlined by the fact that there are, across the country, thirty-two separate versions of the processes required to facilitate SDS at the level of the individual or family. This directly undermines its national implementation. In part this is because of the inconsistencies apparent between local authority areas, reflected in the varying permissions and prohibitions which dictate who is considered 'eligible', how and when resources are allocated, how funding is made available, what level of financial 'contribution' is required of the individual, how expenditure is accounted for, and on what items money can 'legitimately' be spent. Thus, despite legislation and Statutory Guidance (not to mention CIPFA guidance)



there is no coherent narrative emerging nationally about what SDS actually represents, but instead a series of fragmented and often contradictory stories. It also means that individuals and families who direct their own support face an enormous challenge when they wish, or require, to move to another part of the country.

Going forward, the legislative and policy push to achieve a level of integration between social work and health through the Public Bodies (Joint Working) (Scotland) Act 2014, which came in the wake of the SDS Act, has tended to overshadow SDS implementation and to deflect attention from it. This may be a short-term effect, and in the longer run SDS implementation may benefit from integration, but the feeling persists that, by comparison, SDS is a peripheral concern. However, despite SDS appearing to be pushed to the side-lines, the opportunities it affords continue to be relevant precisely because of the strictures outlined here. Even in the face of an almost total lack of official autonomy for care workers, many organisations are continuing to explore how they can offer more choice and control to the people they support. Even beyond the static resources of social care, there is a considerable, if fragmented, hinterland of informal carers (friends, family, neighbours) and community resources (clubs, associations, anchor organisations, preventative local third sector delivery mechanisms,) which could be harnessed more imaginatively to ensure sustainability of care for future generations. By utilising a bold and innovative combination of the not inconsiderable amount of money spent on social care, the untapped creativity of individuals seeking and delivering care, and the resources of local communities, Scotland might realise an as yet untapped potential for inclusive economic growth within local communities.

## 5. Recommendations

**It is clear that, irrespective of the human rights that underpin the Social Care (Self-directed Support) (Scotland) Act 2013, or the potential for radical change that legislation affords, the implementation of Self-Directed Support (SDS) in Scotland has been deeply problematic. Its criteria and delivery are widely inconsistent across local authorities; public understanding is almost non-existent; individuals continue to face a struggle to access SDS (access to information, access to all four options and, for some groups, access to any options); there is little evidence of a substantive power shift towards the individual and the continuation of outmoded approaches to assessment and delivery leave social care workers with no autonomy in support, involvement or engagement.**

SDS should not be like this. Our paper shows it does not have to be like this. In light of huge public concern around the sustainability of social care, SDS (in its envisioned form) is still our best long-term option. It is the only option that recognises the needs of the individual in a holistic sense, as well as their right to choice, power and control. It also offers a clear way of reaching out to and re-motivating social care workers; engaging them as vital participants in the SDS process.

### **Recommendations:**

- 1.** We recommend that the Scottish Government ensure that all partners develop a human-rights based approach to the implementation of SDS and a human-rights based monitoring of the implementation of SDS. We further recommend that the Scottish Human Rights Commission be resourced and supported to undertake an assessment of this human-rights based implementation.
- 2.** The accountability of local and national government for implementing SDS must be enforced.
- 3.** Local authorities must move away from the time-allocation method of care assessment and delivery, which will always be at odds with any effective or meaningful implementation of SDS.
- 4.** The use of electronic and other contract monitoring systems need to be examined in relation not only to fiscal savings but the negative impacts these have upon the well-being of the workforce and the dignity and

rights of those receiving support. A rights-based approach to SDS has to be based on reciprocal trust and mutual respect rather than suspicion and distrust.

5. Access to information, and to all four SDS options, must be made available consistently across local authorities and in an independent, non-discriminatory way.
6. The Fair Work Framework should be used as a method of ensuring that individual workers' rights are reciprocated and protected. This framework should be implemented and used by commissioning bodies, organisations and individual employers.
7. Greater focus needs to be placed on developing models of care and support that give autonomy, control, choice and decision-making to frontline workers and those whom they support rather than commissioners and contract managers.

## ABOUT THE AUTHORS

**John Dalrymple** has spent his career as a leader, manager, innovator and developer of services for people with learning difficulties, working both in the statutory and voluntary sector. He currently works both as Director of Neighbourhood Networks and as Chief Executive of In Control Scotland. He has a particular interest in rights based approaches and practices and how in particular this applies to people directing their own support.

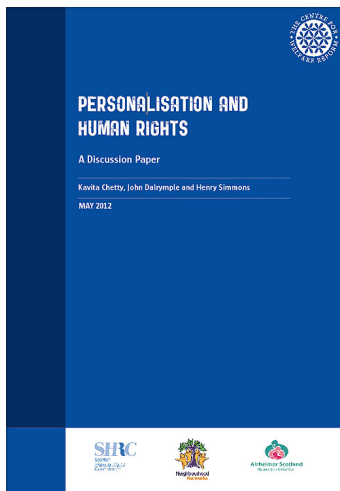
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