

Consultation on the draft statutory guidance and regulations to accompany the Social Care (Self-directed Support) (Scotland) Act 2013



A collaborative response from people who use services, their families, their networks and service providers

The following organisations collaborated on this report



Acknowledgments:

We would like to thank and acknowledge all those who attended the Collaborative event on the 6th June. Coming from a wide range of background, organisations and from across Scotland they contributed their energy, enthusiasm and ideas to a day which we hope you will agree when you read the report was fruitful and productive.

We would also like to thank the two originators of the event, Yvonne Stewart, Alzheimer Scotland and Donald Macaskill, Scottish Care. Their conviction of the benefit of bringing people together greatly contributed to the day's success. We would also want to recognise the range of volunteers who made this event possible including the facilitators who enabled the discussion to occur and the scribes who recorded the ideas and comments which folks offered. Further thanks to the event organiser Kirsty Wilson from Alzheimer Scotland who arranged and organised a dynamic environment which fostered creative thought and contribution.

The day was creatively chaired by Kate Fearnley, Deputy Chief Executive, Alzheimer Scotland, whose sensitive handling of the debate kept the discussion focused and meaningful.

Our thanks to Michelle Drum of IRISS who recorded the event and created an IRISS.FM show available online at <http://irissfm.iriss.org.uk/episode/047>

Our last thanks go to the Scottish Government Self-directed Support Team for funding the Collaborative event and for offering on-going support and advice.

This report was written and compiled by Michelle Shaw of Alzheimer Scotland who successfully achieved the not insignificant task of collating the wide range of ideas, viewpoints and perspectives from the many discussions held throughout the day.

We trust the words and ideas in this report will help shape the Guidance and Regulations and contribute to achieving real choice and control for the women, men and children who use social care services in Scotland.

June 2013

Foreword

Self-directed support presents an opportunity to fundamentally change the way that people who need services are supported, empowering them to shape and manage their own support in the way that best suits them. I think I can safely say that everyone participating in this consultation event warmly welcomes the new legislation, and that the 100 or so people in the hall were all there in a spirit of genuine positivity, seeking to contribute their considered thoughts about the guidance and regulations.

This was an unusual event, bringing together as it did both those who use services and carers, and representatives of service-providing organisations. This report details the outcome of their joint deliberations, and I commend it to you as a positive contribution to making sure that the guidance and regulations on SDS are as effective and helpful as possible.

Kate Fearnley, Chair

Deputy Chief Executive, Alzheimer Scotland

Introduction

This report outlines a collaborative response from people who use services, their families, their networks and independent and third sector service providers to the draft statutory guidance and regulations to accompany the Social Care (Self-directed Support) (Scotland) Act 2013. On the 6th June 2013 in the Carnegie Conference Centre, Dunfermline nearly 100 individuals who receive services, family carers and a range of organisational representatives discussed the guidance and regulations and contributed their thoughts. These have been collated and presented in this report. Individual organisations will also be presenting their own organisational responses to the consultation.

This document details our agreed comments and views on the following sections or themes:

- Knowing where to go – covering rights, support, independent advice, information and advocacy
- Assessment and support planning
- Supported decision-making and circles of support
- The four self-directed support (SDS) options
- Monitoring and reviews
- Carers
- Children and young people
- Proposed exclusions in the draft guidance

Each section also contains direct quotes and verbatim comments from those participating in the consultation.

Knowing where to go

The values and principles detailed in the guidance are warmly welcomed and viewed as a positive opportunity for people. Understanding and navigating SDS can be complicated, particularly as the language at times in the guidance is not always accessible and includes jargon. However, with the correct support and information throughout the process, people can make decisions that will lead to personalised solutions for them. We do have a number of concerns about the right information reaching people who need it at the right time. Although a great deal of information exists it is not yet getting to the people who require it. This includes a lack of information being cascaded down to frontline workers. There is much variance in the existence of localised services to provide independent information and support, which must be addressed if equity is to be achieved.

In addition we feel that service providers should actively market their services, combined with a signposting approach from local authorities. However, frameworks such as approved provider lists can be restrictive, limiting choice and undermining the ethos of choice and control. This in turn raises concerns regarding the links between commissioning and particular providers. Furthermore there is a potential conflict of interest regarding the availability of choice if the information is given solely by a service provider/social work professional.

Collaborative working will be vital and the local authority must provide people with written information on resources and their choices. Individuals must be enabled to know what options they have and also how to challenge decisions with which they do not agree. We are concerned that the SDS rhetoric and the reality on the ground are very different.

“Should there be a SDS awareness week? With local events, national focus and user / provider / ‘commissioner’ community engagement.”

Assessment and support planning

We welcome that the emphasis is on outcomes for the individual and on collaboration to identify and achieve those outcomes. However, we feel there needs to be a greater recognition of the scale of cultural change that is required, implemented through a change management programme. This change involves an exchange of power and there needs to be detail on how this aspirational collaboration will become a reality, rather than remaining solely an aspiration.

This should in turn lead to greater consistency of implementation across local authorities. There is genuine concern that the spectre of financial constraints could be used by local authorities to excuse not fulfilling their obligations and responsibilities. This will require a robust monitoring and audit process to ensure there is accountability, transparency and consistent implementation and delivery of SDS throughout local authorities in Scotland.

Implementation would in turn be helped if there were many case studies and examples. We feel this requires a co-ordinated initiative to gather those case studies. Examples should be provided at each stage of the guidance for illustration including examples where things do not work as well in order to explore what can be done or learnt to get back on track again.

We believe that there is a need for universal access to independent advocacy as a key part of the SDS process and are also concerned that people will be left on their own as many already struggle to make contact with their social worker or care manager in a timely manner. A final point in this section of the guidance is that we feel the language of risk enablement is lacking and could be more strongly supported within the narrative.

“If everything is going to go through the prism of social work approaches then how is this going to turn out differently from the way it turned out in the past? It’s about owning budgets still so unless we can support social work departments to meet this challenge then things won’t change. So should there be something in the guidance about that?”

Supported decision-making and circles of support

We feel that this section requires significant rewriting in order to make it more accessible, informative, empowering and representative of the complexity of the issues. It is not written in a manner that is underpinned by the core values and principles outlined in section three of the guidance. The guidance is at times woolly and not person-centred in nature with too great a focus on the challenges faced by the professional and their sole responsibility in deciding whether an individual requires assistance and what “reasonable steps” to take to support decision-making.

The guidance needs to be stronger on circles of support both in relation to what they are, how they operate, who is responsible for their facilitation and how they can support people with decision-making. A very prescriptive definition is not necessarily required but illustration and examples are needed as many of the key professionals in this situation may have limited or no knowledge or experience of circles of support or how in combination with person-centred planning tools they could support decision-making.

Paragraphs 112 - 113 on the supported person lacking capacity also require a significant rewrite. The guidance makes limited mention of the Adults with Incapacity (Scotland) Act (AWI) 2000 and no reference to the principles and responsibilities inherent in this for guardians and attorneys. The supported person is completely absent from the narrative and there appears to be no expectation or requirement for a proxy decision-maker to utilise circles of support as a way of involving the supported person or retaining them at the centre of the process. Indeed people lacking capacity appear to be completely excluded from the guidance in relation to circles of support, which causes us great concern.

Furthermore this section does not reflect the complexity of capacity and the fact that the capacity to make decisions is not “all or nothing”. A minimum requirement would be hyperlinks to the AWI 2000 and good practice guidelines. A significant level of knowledge has also been assumed in relation to Advanced Statements, the legal limits to whom they may apply and the role of the Mental Health Officer. Much more clarity and detail are required here, as is general cross referencing with other relevant legislation. The guidance also needs

to be clearer that the involvement of a Mental Health Officer in itself will not address the issue of capacity.

We strongly feel that this section should detail a role for independent advocacy. Furthermore paragraph 111 delineates assistance with communicating decisions and making decisions too strongly as there may well be cross-over issues and should have mention of assistive technology and communication tools such as Talking Mats.

“This is a pivotal issue in SDS and the guidance needs to be clearer. The AWI 2000 principles need to be included for those who are not knowledgeable – especially that there is an ongoing duty to seek the person’s views, wishes and feelings. The guidance is quite exclusionary in terms of people deemed to lack capacity – the antithesis of SDS.”

The four SDS options

Option one

We feel this is a particularly positive option for people as it affords more choice and control and is less restrictive than the original direct payment (DP) scheme. However, there is potential for confusion between these and therefore, the guidance would benefit from detailing the mechanism for changing from the traditional DP to SDS option one. The guidance could do more to encourage people to try option one, especially considering the historically low uptake of DPs in Scotland. The following steps could encourage people to select option one:

- The security of trying option one and knowing they can switch to another if it is not working (being an employer can be stressful).
- A fixed review after three months to ensure it is the best option.
- Case studies of real life examples detailing creative and positive experiences.
- Clearer commitment to developing more support systems for those selecting option one, such as Centres for Inclusive Living and brokerage.

We are concerned that option one is not being made accessible enough for people. Social work staff require training and social work systems are not geared up for this option. A lack of understanding will directly impact on how each option is communicated to individuals, as will current frameworks such as preferred provider lists. Both of these will impact on the individual’s level of choice. We feel third sector agencies should be involved in information provision, otherwise we are concerned that displayed leaflets will be considered an adequate measure. More information is required on support for using option one to clarify issues such as whether people will be able to use their budget to cover brokerage costs, without jeopardising meeting support needs. Furthermore we feel the guidance lacks clarity on the third party issue and more discussion is required around words like ‘capable’. We recognise that there are more risks associated with this option and that other options will be perceived as less risky. This highlights the need for close and robust monitoring systems.

Option Two

Paragraph 56 contains a conflicting message where it advises that individuals will be informed of a resource that will be made available to deliver their support plan. This implies that the person's choice is being restricted. If people opt for option two then we must ensure that they still have the same level of choice and control as they would under option one. The guidance needs good case studies to highlight this option's benefits and drawbacks.

There are concerns that people with learning disabilities, on reaching the age of 65 will be treated differently. We are also concerned about a 'postcode' lottery in terms of the way the guidance will be interpreted across local authorities; the application of eligibility criteria depending on availability of resources in the area; and differences between rural and urban areas.

Option Three

There is a very presumptuous and leading statement suggesting most people will opt for this option. We strongly feel this statement should be reworded or removed or as there is no evidence to support it and it raises concerns that some local authorities may use this as an easy option to maintain the status quo and thereby protect their own interests. There is a definite need for clear and accurate information to ensure informed choice for each individual. We feel there will be a direct link between option two and option three in terms of how they are communicated to individuals.

We feel that as part of the monitoring and reviewing process, information on how each option is presented to the person should be gathered and informed choice should be evidenced. Local authorities should be asked to routinely gather evidence of the information sharing and decision-making processes they have in place.

Option Four

We feel that option four has great potential to be used as a 'testing option' and people could use this to gradually take more control. We feel that option four gives people more security and flexibility and could be used as a stepping stone to move towards option one – assuming clear review processes are embedded. We would suggest the guidance could present this option more favourably and would again benefit from clear case examples of how this option has been utilised successfully.

General Issues

We feel that the Care Inspectorate should have a role in monitoring SDS to ensure people have been offered all options. Furthermore an independent person or broker should be involved when the options are being offered to individuals. We are concerned that in house structures like day centres or housing may impact on the choice offered to the person. If less people attend then the cost per head multiplies which could impact on the level of choice being offered. In addition there is not enough detailed information in the guidance for people who have fluctuating needs. If people do not use their full budget there are concerns they will have a reduced budget the following year, which could cause anxiety and directly impact on a person's health. In addition better integration with health is required and more case studies would facilitate this.

We are concerned that people are not been giving the correct level of choice as commissioning processes are not aligned with the SDS options. Micro organisations opening up are affected by local authorities having preferred provider lists. Finally on the four options, the power of veto or duty of care undermines power sharing and individuals' expertise regarding their own needs. There will be variation in professionals' views on what is appropriate or reasonable. Indeed much of the document is open to interpretation.

“I’m shocked by the number of social workers I’ve met who say, “I don’t know anything about this”.”

“Option 3 alarmed me a little bit – the guidance assumes large numbers of people will stick with this option, almost encourages this. The wording should be changed.”

Monitoring and reviews

We feel that section six of the guidance is very brief in comparison to the assessment section and therefore appears tokenistic. The guidance requires more detail as this is one of the most crucial and integral parts of the process to ascertain if outcomes have been met and for people to voice their opinions and make changes. Furthermore, time frames and the processes involved in making changes, such as a change of SDS option or budget change, should be covered.

The values and principles set out earlier in the guidance need to be more explicit in this section regarding the individual choosing who is involved in the review and influencing when and where it occurs. The choice regarding others' participation must lie with the individual, even where there may be a vested interest, such as a personal assistant being present, despite this potentially relating to their continued employment. The guidance requires more detail on good practice in this area in relation to the frequency of reviews, roles, responsibilities and format. For example, very formal reviews can be intimidating for individuals and this requires flexibility and an enabling approach. To ensure good practice, governance arrangements and robust monitoring processes of local authorities must be identified. We also firmly believe that there needs to be a change and a move towards independent advice and advocacy.

We are concerned that local authorities will not be able to meet the pressures on resources to facilitate reviews in a timely and appropriate manner as many people already wait considerable lengths of time for reviews. This in turn again underlines their lesser status in comparison to the initial assessment stage. These entire processes should also feed into identifying gaps in services at an early stage and directly inform local authority's community planning and commissioning responsibilities, particularly in rural areas. Changing an option and how long that should take should be detailed in the guidance.

“Our experience in Glasgow is where people have been creative it’s led to cost saving and part of the budget being taken back at review – a perverse incentive to stay with traditional services.”

“Who should be involved in reviews? I know of a situation where a local authority felt a PA couldn’t be in the room “because of vested interest”,

even though the individual wanted him to be there as the person who knew him best. Ironically they were prepared for a service provider to be there. Respect includes respecting people's judgement and trust, as well as safeguards.

Carers

We support and agree in principle with the proposed lay regulations which would waive all charges for support to carers. However, this may be complicated in reality as short breaks and holidays can benefit both the supported person and the carer. In addition we are concerned that it may result in unintended consequences as there do not appear to be additional resources to meet this commitment. Therefore there is a real risk of a tightening of the eligibility criterion in response to this, which in turn will potentially lead to less preventative services and more focus solely on crisis responses, despite the guidance's discussion of the importance of preventative support. A further significant concern relates to the local authority's capacity to provide replacement care for the cared for person at the time it is required for the carer to utilise their own personalised support option.

We are also concerned that this section of the guidance has an implicit expectation that family members will provide care without taking into account issues such as family dynamics, history and the sometimes competing needs of the cared for person and the carer. This is particularly true in the wording of the expectation that replacement care when the carer is having a short break or holiday will normally be provided by family or friends at the person's home in the draft Carers (Waiving of Charges for Support) (Scotland) Regulations 2014. However, family members may not have the necessary skills or there may be cultural, gender or vulnerability issues. There may be intimate care and complex needs that would be inappropriate for another family member or friend to address. Furthermore this does not allow the carer to have a short break in their own home as there may be essential equipment that could not be moved to another setting.

Finally in relation to the employment of relatives, there are many positive examples of people employing family members and this section would benefit from case studies of when employing a relative has worked well, possibly with reference to language or cultural needs or in a rural setting.

The guidance is unclear on how 'capable' to meet the needs of the supported person will be determined or the vetting processes involved. Safeguards are required to ensure the person has the same opportunities, for example, regarding independence when a family member is employed. Clarity on what checks would be in place would be useful.

“There's too much perception that there's always people/family around to help.”

Children and young people

We feel that the needs of children and young people should be included throughout the guidance with the relevant children's sections alongside the adult sections and thoroughly

cross referenced throughout the document. There is too great a distinction between children and adult services, whereas it would be more useful to regard growing up as a pathway, with a greater emphasis on the transition to young adult life. SDS can be used to help young people to take on new responsibilities as they prepare for independent living and will require support to develop the necessary skills and knowledge to do so.

We believe that strengthening the language in the guidance is required to ensure local authorities fulfil their responsibilities. For example social workers must (not ‘should’) listen to what children want during the assessment process. There are separate outcomes systems for children and adults services. The guidance links well with children’s frameworks, however more attention is needed to show how these interlink with adult services throughout the transition process. This will require staff from both sectors to understand both frameworks to make the move between them seamless. The review process will be an important part of this.

Children and young people should have access to Children’s Rights Officer. They should know their rights, particularly concerning risk management strategies and decisions about healthcare and navigating between children and parental rights. There should be more emphasis on peer support for young people. We are also concerned that statutory requirements regarding a duty of care may result in risk-averse decision-making. It should also not be used as a way to prevent more creative uses of SDS.

As it relates to children and young people, there is a discrepancy with the general understanding of circles of support in a person-centred planning context. The circles of support should be there to support young people through their journey, not just decision-making. The young person should wherever possible agree to this and decide who is involved. It should be the responsibility of the ‘Named Person’ to ensure a circle of support happens when needed. This will take a greater commitment from those who are members. The guidance should be clearer about decision-making responsibilities and the need to involve all young people in decisions in line with the AWI 2000.

“Paragraph 16 only refers to s.23 of the Children (Scotland) Act 1995, suggesting SDS only applies to children affected by disability. Section 8(1) of the 2013 Act – SDS applies to all **children in need** (s.22 1995 Act).”

Proposed exclusions

We fundamentally disagree with the nature of the blanket exclusions within the regulations in relation to both exclusions of people from DPs and of services from DPs. We believe this is in direct opposition to the ethos of choice and control, the spirit of the Act and the person-centred philosophy underpinning self-directed support. Individuality as a principle is mutually exclusive with blanket exclusions. In particular such exclusions fail to recognise the fluctuating nature of some conditions. Without reservation this is an equality and human rights issue and without justification.

We do recognise that there may need to be restrictions regarding some individuals receiving DPs. However these restrictions should be permissive rather than restrictive. There are potential options to mitigate including double sign off, phased or graded access to DP monies and third party sharing or managing of a DP. Indeed we feel that access to DPs could have an

incentivising and empowering role for some individuals. The starting point must be open to all and thereafter restrictions put in place for the benefit of the individual and others.

Furthermore assessment, support planning and monitoring are crucial issues in this regard. Excluded and vulnerable individuals are under constant and regular monitoring therefore monitoring could easily occur to ensure appropriate conduct if granted a DP. However, it is important that people are monitored in a way that supports them and that improves their health and recovery. There are individuals who are included in terms of eligibility but who are excluded in terms of choice and quality of life in practice. We need to have a light touch in relation to punishments for misuse otherwise there will be no incentive to improve.

We are gravely concerned by the exclusion of residential care. In effect many people will be excluded solely on the grounds of their age, which is clearly a discrimination and equality issue. Without DPs choice will be limited to what is offered by existing providers and establishments without a reasonable argument and evidence base for doing so.

Furthermore we are concerned about funding issues in relation to DPs. There must be safeguards that access to DPs for anyone is not just tokenistic and that individuals will be able to access the full amount they are assessed as requiring and the same amount as an individual currently gets rather than a reduction directly dictated by funding issues and budget cuts. For self-directed support to work in general and DPs in particular there needs to be a significant culture change in the way assessments are undertaken and in professionals' relationships with people. If the culture of an organisation like a local authority is restrictive and the professional is unable to think creatively, we are concerned that there is little likelihood that this will translate to giving real choice and passing real control over to individuals.

“We need to change the culture and our way of thinking to make SDS work.”

General

A number of recurring themes throughout the guidance merit individual note:

- The values and principles set out at the start of the guidance are very warmly welcomed but do not consistently flow throughout the narrative of the remainder of the document.
- The language is at times woolly, inaccessible, orientated towards professionals and unnecessarily includes jargon.
- Access to independent advocacy and advice is fundamental throughout the pathway and SDS process.
- A significant culture change needs to occur if the spirit of the Act is to be upheld and the Statement of Intent met. This must be underpinned by a change management programme.

- There must be transparent and independent monitoring and audit of the implementation of the Act to ensure accountability and consistency across statutory bodies.

The remainder of the report documents a number of individual comments that were echoed through the consultation.

“The person needs to be at the centre of everything.”

“The language is all wrong.”

“Guidance appears to have been written by several people without joined-up thinking.”

“There is no space for fixed frameworks within SDS.”

“Let’s not lose the individual in SDS commissioning.”

“Free up money for SDS from the NHS.”

“Don’t let this wither on the bough like local area co-ordination.”

“It’s a postcode lottery as to how the legislation is interpreted and I don’t think anything in the guidance will stop that happening.”

