



The Self Directed Support Scotland response to the Scottish Government consultation:

‘Self-Directed Support: a public consultation on draft regulations and statutory guidance to accompany the Social Care (Self-directed Support) Act’ (2013)

Self Directed Support Scotland (SDSS) is a national membership organisation which actively promotes Independent Living by supporting, working with, and championing the aims of self-directed support Disabled People's Organisations.

SDSS develop resources, material and training for their member organisations and regularly deliver presentations which show that the social model is at the heart of self-directed support and independent living. SDSS also work with local authorities, voluntary sector organisations, NHS health boards, universities and colleges to influence and guide the implementation of the Social Model within their own policies and programmes.

Tha Taic Fèin-Treòraichte Alba (SDSS) na charthannas a tha a' brosnachadh chiorramach a bhith neo-eisimeileach le taic agus co-obrachadh an com-pàirt le buidhnean chiorramach.

Tha sinn ag obair le ciorramaich a' toirt dhaibh cuideachadh gus buidhnean a chruthachadh a bhios fo an stiùir fèin.

www.sdsscotland.org.uk

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Introduction

Self Directed Support Scotland (SDSS) was established in 2003 to promote independent living through self-directed support in Scotland. Over the last 10 years Scotland has made significant advances towards social care and support that is directed by individuals in a coproduced environment. Securing fairer social care and support for disabled people has always been a priority concern for SDSS and our member organisations.

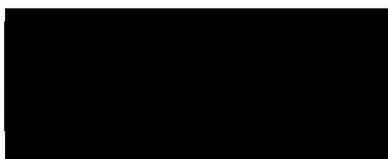
The Self-directed Support Act was a big step forward, which we strongly supported, but we have always been clear that self-directed support is a means to independent living and should afford disabled people the same access to rights, status and options in society, as non-disabled people.

Ten years on, the first self-directed support guidance (2003) has not been a success. Its implementation has clearly not satisfied demands, from disabled people, for a fully equitable social care and support system, which enables independent living.

This response to the Scottish Government consultation: 'The Draft Self-directed Support Statutory Guidance on care and support to accompany the Social Care (Self-directed Support) Act' (2013) sets out what we believe is a comprehensive and convincing case for improving the SDS guidance and regulations.

The SDSS consultation response was written from the collective views of our member organisations and their service users, who are disabled people. SDSS carried out an extensive consultation event with our member organisations - on 30th May 2013 - in Perth Concert Hall. This event was attended by service users.

We hope this response proves useful in informing the deliberations of the Scottish Government and Parliament.



Florence Garabedian
Chair



Jess Wade
Manager

Summary Response

SDSS calls upon the Scottish Government to:

- Give a clear message to local authorities, and professionals in the field of care/support, that information and support organisations have a crucial role to play in the successful implementation of the SDS Act.
- Give a clear message to local authorities that they should develop strategically a co-ordinated approach to and structure of independent information and support so that independent information and support organisations can effectively operate at all stages of the supported person pathway.
- Encourage local authorities to review the actual benefit and actual cost of charging people in receipt of care/support and to seriously consider how care charges discriminate against disabled people and people with long term conditions while undermining any policy towards Independent Living, including SDS.
- Improve the overall guidance to show the link between human rights and self-directed support. This can only ensure individuals are empowered in their care and support.
- Make very clear in the guidance that people in receipt of care and support must be involved in self-directed support training for social workers so that it creates a real culture shift to empower service users in their care and support options.
- Advance the slow implementation of SDS services for children and young people. This is an urgent matter which requires further attention and direction by Scottish Government.

Consultation Questionnaire

Draft Statutory Guidance on Care and Support

Consultation Questions

Question 1a: Was this section of the guidance clear and easy to understand? Yes No

Question 1b: How useful did you find this section of the guidance?
Very useful Quite Useful Not very useful Not at all useful

Question 1c: Do you have any further comments on this section of the guidance?

Part 7 - SDSS welcomes the use of a clearly defined pathway through the care/support journey [Table1]. The process will deliver consistency to an individual's social care/support journey across local authority areas.

However, the inclusion of self-directed support organisations in “The Person’s Pathway” at Steps 1 and 2 would benefit an individual further within the process. It would ensure; sustainable outcomes and that the individual has full information to understand the potential support available. In its present form, the table suggests support organisations are involved later in the pathway **and** at the encouragement of social work departments.

SDSS believes the title in [Table 2] “the provider” is potentially confusing and should also read “support organisations”. Disabled people’s Support Organisations are legally distinct to ‘providers’.

Service user and member organisations comments:

- Support organisations need to be involved as early as possible in the supported person’s pathway
- Sustainable packages come from accessing information, the local authority doesn’t have all the ideas
- Communication of the pathway should be accessible and accountable to service users
- Local authority sign posting to SDS support organisations is patchy

Question 2 a: Was this section of the guidance clear and easy to understand? Yes No

Question 2b: How useful did you find this section of the guidance?

Very useful Quite Useful Not very useful Not at all useful

Question 2c: Do you have any further comments on this section of the guidance?

While SDSS agrees Section 3 is clear and easy to read, we believe the section is missing a defined link between ‘the principles of care and support’ and the underpinning values of the 2013 Act, the rights of independent living.

The addition of Section 2 in the 2013 Act was to assert the link between the existing rights of individuals and duties placed on local authorities; the European Convention of Human Rights, the United Nations Convention on the Rights of Disabled People and the Equality and Human Rights Acts.

Although local authorities are bound by these conventions and legislation, we believe adding in this criterion will contextualise the link between the duties of Section 2 and the principals of social care and support. This will afford local authorities a greater understanding of Section 2 and the duties placed on them which underline social care/support.

We believe in its current form, Section 3 of the draft guidance, underrepresents the work of the Scottish Government, partner organisations and the self-directed support national strategy in shifting the culture around care and support.

Service user and member organisations comments:

- A human rights approach to support planning should go hand in hand
- There is a definite link between my rights and the social care I receive
- It is my right to live a life [worth living]
- My SDS outcomes are a human right
- Local authorities need to understand disabled people’s rights, otherwise mistakes can, do and will happen

Question 3a: Was this section of the guidance clear and easy to understand? Yes No

Question 3b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 3c: Do you have any further comments on this section of the guidance?

SDSS believes Part 24, in its current form, does not pose an answer, offer direction or direct an authority as to their role - in appropriately resourcing social care/support packages. We welcome, however, the consideration, given in Section 24, on the challenging subject of eligibility threshold, prevention and early intervention strategies and how these can contribute to funding better overall social care/support systems. **Part 24 would benefit from being redrafted into 2 paragraphs. Firstly an authority's role in a strategic capacity and secondly, the benefit of early intervention and prevention.**

SDSS supports the definitions in [Table 4] Collaboration, Involvement and Informed Choice. We believe that the guidance should contain the definitions of the existing duties on Section 2 and that without the underpinning philosophy; the meaning of [Table 4] is weakened.

Service user and member organisations comment:

- Local authorities need to work with service users and their support organisations equally and respectfully, at present this is not happening

Question 4a: Was this section of the guidance clear and easy to understand? Yes No

Question 4b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 4c: Do you have any further comments on this section of the guidance?

SDSS welcomes a clear and concise approach to support planning. Disabled people have stated their frustration to SDSS and member organisations in the inconsistency within local authorities' support planning methodologies and training that has resulted in poor or insufficient support planning.

We agree with Part 42 (Section 5) that there is a definite “link between the individual’s eligible needs, their outcomes and the support required to meet those needs and outcomes.” Making the support planning process personalised to the individual is essential to achieving a sustainable plan. SDSS would further argue that Part 42 is missing the legal duties the Equality Act 2010 places on a local authority. In discharging their duties authorities should make the support planning process as accessible for the individual as reasonably possible.

5.2 Risk: SDSS agrees with the approach in general to risk as stated in Parts 44 to 46 of “a proportionate approach, spending appropriate time on ...risks”. However we believe that in Part 46 “two parties” should be amended to “participants” as more than two parties; an individual, a family member, a local authority and a support organisation - may be involved in coproducing the support plan.

5.1/5.3 Resources SDSS agrees with the overall approach of the “resource question” in Parts 47 to 51 and particularly “there is no single approach to “resource allocation” prescribed in law, nor any single method recommended by Scottish Government.” As disabled people’s support organisations we have experienced divergent models of resource allocation used by local authorities, which has led to differences in the application of social care/support resourcing across Scotland and resourcing of individual’s support plans. The former deficiency in uniformity and direction was neither fair nor equitable for disabled people and is against the ethos in the Act of self-directing an individual’s support.

SDSS believes Part 51 should be revised to include disabled people’s or SDS support organisations. In Scotland local disabled people’s organisations (DPOs) have been providing services and supporting people to run their own social care since the late 1980s. DPOs can substantially improve choice and control for disabled people and are instrumental in acting as a hub to support disabled people to come together and develop shared insights and support networks freely on their own terms. DPOs can help identify and implement more cost-effective alternatives to meeting an outcome than existing systems would normally make possible. In addition to experiences of improved quality and continuity of care, the involvement of DPOs can lead to a reduction in unplanned care and further productivity gains in the shift from a needs based model to one that is personalised, effective and efficient. This should be clearly stated in the guidance.

Resourcing models have hindered the principles of adequately funding an individual's outcomes in order to serve an alternative purpose for a local authority. In some instances the new resource policy adopted by local authorities resulted in an arbitrary cut in resources across social care budgets¹. Therefore, any resourcing policy should be centred on principles which are both fair and transparent to protect the social care/support funding of individuals.

SDSS is satisfied that the intent of Section 5.3 is to put beyond reasonable doubt; what a resource policy or allocation system is intended to do, and by which parameters the policy should be discharged. However, without a statutory framework in complaints or review mechanisms with a regulatory body², SDSS member organisations tell us a 'great postcode lottery' is emerging across Scotland as a result of the 'localism' approach to resource allocation systems. Some member organisations have told us, the postcode lottery exists within local authority areas, where services are being further restricted by service user groups.

Part 56: SDSS believes the current wording of the guidance creates a conflict of interest with direct care providers. SDSS member organisations have stated to us a potential issue; if a supported person is no longer happy with their provider(s), or the service of one of their competitors, how appropriate is it for the service provider to renegotiate the their own service?

SDSS believes the use of the term 'providers' may lead local authorities to think that support organisations may not be able to play this role. Disabled people's organisations (DPOs) and SDS support organisations are founded and are legally distinct to 'providers'. In addition DPOs have encountered situations whereby parts of a support plan were disregarded by the local authority where third party support was requested.

Part 58: SDSS believes this will ensure a further degree of choice, control and flexibility beyond what would otherwise be available under Option 3 for individuals who do not wish to manage a personal budget. SDSS welcomes the description in Part 59-60 on the use of option three and maintaining a degree of choice and control for an individual and see this as working towards the outcomes of the individual. However, SDSS

¹ <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/52878.aspx>

² http://ajtc.justice.gov.uk/docs/decisions_with_no_appeal_web_final.pdf

believes option 3 should not mean individuals are offered services which service users, with options 1 or 2 do not want. This should be made clear in the guidance

SDSS welcomes the methodology in Part 66 in defining the extreme circumstances where a local authority can restrict the use of an option. However, SDSS disagrees with the proposed complaint mechanism outlined in the guidance. A minority of local authorities operate a consistent complaints review committee (CRC) system; which affords some equity for disabled people, in handling review or complaints of social care/support decisions. Likewise, complaints to the Scottish Public Service Ombudsman can only be made on procedural grounds, not professional judgements.

The Advisory Committee on Administrative Justice and Tribunals in Scotland in its report and advice to Scottish Ministers 'Right to Appeal'³ stated this inconsistent approach was "unsustainable and that there is an urgent need to enable those who are dissatisfied with a community care decision to take it to an independent forum."

SCAJTC therefore recommended the establishment of a new tribunal authority to deal with appeals against care/support decisions, with jurisdiction over all decisions, including professional decisions relating to the assessment of need and the provision of/or payment for services. SDSS believes independent review and sanction can only guarantee disabled people true equality in the social care/support around them and will fulfil the SDS national strategy where individuals "should be able to maximise choice and control over any formal support they require."⁴

Information: Parts 72 and 73; SDSS welcomes the strong language to direct local authorities to provide individuals with the "nature and effect" of the options available. Service users tell SDSS member organisations that these basic tenets of a good social care/support plan have been previously unavailable when requested by an individual.

While SDSS welcomes the clear and concise definitions in [Table 7] we believe Part 74 is not strong enough to reach the stated conclusion of an "appropriate mix of information and support options available in their local area." SDSS is uncertain if this reflects the intended spirit of the 2013 Act or the Minister for Public Health's previous statements to the

³ http://ajtc.justice.gov.uk/docs/decisions_with_no_appeal_web_final.pdf

⁴ <http://www.selfdirectedsupportscotland.org.uk/strategy/>

Scottish Parliament. Therefore, SDSS proposes that Table 7 be replaced with the SDS National Implementation Groups' model diagram developed by the SDS Standards Group. We believe this is a clearer fit for Part 74 (Appendix 1).

Part 75: We welcome the inclusion of the definition of user-led support and information organisations, SDSS believes this will help local authorities in their sign posting to appropriate information and support organisations.

Service user and member organisations comments:

- The local authority needs to approach support planning with consistence in care managers and how they implement their policies

Question 5a: Was this section of the guidance clear and easy to understand? Yes No

Question 5b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 5c: Do you have any further comments on this section of the guidance?

SDSS welcome the clear definition of when an individual or local authority can review their social care/support needs.

Question 6a: Was this section of the guidance clear and easy to understand? Yes No

Question 6b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 6c: Do you have any further comments on this section of the guidance?

SDSS is unclear if Section 7 is intended to cover direct care providers, alone or the term "providers" incorporates support/advocacy organisations. If so, this should be clearly stated.

We welcome the explanation of Section 19 of the 2013 Act. However we believe Part 82 should be enhanced to include the local authority's role in capacity building in their local area. We believe this will fulfil the aspiration of many disabled people who have told SDSS and member organisations their desire for user-led disabled people's organisations in

their local area to support them. This would also accomplish the ethos of self-directing support as stated in the SDS national strategy.

Question 7a: Was this section of the guidance clear and easy to understand? Yes No

Question 7b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 7c: Do you have any further comments on this section of the guidance?

We welcome explanation and clarification of the role of the health service in social care/support. Disabled people have highlighted to SDSS and member organisations instances when discharge from health services has been problematic and disjointed into social care/support.

SDSS notes with importance the need for consistency between the principles of the Act and the Public Bodies (Joint Working) Bill. The integration Bill needs to be reflected in Section 8 of the SDS Act Guidance.

Question 8a: Was this section of the guidance clear and easy to understand? Yes No

Question 8b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 8c: Do you have any further comments on this section of the guidance?

SDSS welcomes the link between the SDS framework used in Part 92 and Part 93 on Getting it Right for every child. This will improve the choice and control offered to children and young people wishing to use self-directed support. However, SDSS believes the short term complexity in the implementation of SDS - combined with children and young people's services not being prepared for SDS - may leave a number of stakeholders without a proper framework to deal with complex and sensitive situations (see our comments on Question 4). **SDSS strongly advises the Scottish Government to advance this matter urgently.**

Question 9a: Was this section of the guidance clear and easy to understand? Yes No

Question 9b: How useful did you find this section of the guidance? Very useful Quite Useful Not very useful Not at all useful

Question 9c: Do you have any further comments on this section of the guidance?

SDSS welcomes the clarification and guidance stated in Parts 105, 106, 107 and 112. This offers greater certainty in what service users have described to SDSS and member organisations as a very complex and challenging period.

Question 10a: Was this section of the guidance clear and easy to understand? Yes No

Question 10b: How useful did you find this section of the guidance?

Very useful Quite Useful Not very useful Not at all useful

Question 10c: Do you have any further comments on this section of the guidance?

SDSS welcomes the clarity of Section 9.3 in defining the support for and role of carers in social care/support. We believe that Parts 116 to 120 offer greater transparency in supporting carers through a carer's assessment. We note that Part 119 should be clearer, as this appears to describe option 3.

Question 11a: Was this section of the guidance clear and easy to understand? Yes No

Question 11b: How useful did you find this section of the guidance?

Very useful Quite Useful Not very useful Not at all useful

Question 11c: Do you have any further comments on this section of the guidance?

SDSS welcomes the clarity and definition of a third party payment in Part 125. Disabled people have stated to SDSS and member organisations that these payments were prohibited by a number of local authorities in Scotland. This direction to local authorities will allow further choice and control with self-directed support option two.

Part 127: SDSS welcomes the inclusion of "a service from the local authority or from another local authority". Disabled people have stated to SDSS and member organisations that this option was previously barred by their local authority.

We believe that the process described in Part 126, 132 to 134 will offer better certainty to all parties involved in social care/support in

understanding the appropriate circumstances when a direct payment should be managed and withdrawn.

SDSS also believes appropriate training must be given to individuals in managing their direct payments in order to prevent; confusion or misinterpretation with their package. Evidence gathered by SDSS member organisations shows where training is undertaken by an individual, support packages are sustainable. SDS support organisations already provide support through training, monitoring and discussing SDS options and Parts 132 to 134 would benefit from the inclusion of this information.

Parts 137 to 139: Our member organisations have highlighted instances, in supporting service users, where all the information from a local authority decision to withdraw support, has not been made available, clearly, to either the individual or their support organisation. These Parts should include a written notice to alter or withdraw support. The notice should state the:

- reasons why the local authority alter or withdraw any SDS option;
- proposed alternative means of support;
- consequences of the proposed action by the local authority.

Part 137 should remind local authorities of employers' contractual agreements with their staff and particularly the need to pay redundancy money when this is due. This addition will ensure individuals have all the available support from the local authority and/or support organisation.

Question 12a: Was this section of the guidance clear and easy to understand? Yes No

Question 12b: How useful did you find this section of the guidance?

Very useful Quite Useful Not very useful Not at all useful

Question 12c: Do you have any further comments on this section of the guidance?

SDSS welcomes the clear and concise definition of re-ablement, immediate care and 'the gateway' stated in Parts – 143 to 145. SDSS member organisations tell us the role of the health professional and services are paramount to successful re-ablement strategies. Member organisations have previously stated their frustration with the lack of thorough health and social care coordination in re-ablement with

flexibility of services and choice. SDSS believes, service users have a right to the maximum say on how the services they need to support independent living are delivered, and we should not put on the face of the regulations anything that may restrict that right. SDSS and member organisations look to the Health and Social Care Integration Bill (Scotland) to bring clarity to future approaches to support for individuals across Scotland.

Residential Care: Disabled people in residential care have told SDSS and member organisations, their frustration in being prevented from the right to choose the support option they want. In most instances this prevents the individual from leaving residential care.

SDSS and member organisations believe all SDS options should be made available to those eligible for social care/support, although it also recognises that it may have a temporary effect on the market place and a cost attached to this.

Charging: Part 149; SDSS and member organisations do not agree with charging any individual for their social care/support services⁵. However, we welcome the Scottish Government's approach to charging that:

“Authorities should consider new approaches to charging – approaches which enable them to charge on the basis of proportion of the supported person's budget as opposed to one form of service or another.”

We believe this Part should include a reference to existing Equality Act Scotland devolved Public Duties; whereby a local authority **must** consult on policy/service changes with disabled people. SDSS and member organisations welcome a co-produced dialogue with the local authorities on revising their charging mechanisms in-line with the intention of Part 149. Charging for community care is unfair – it is unfair that disabled people are expected to plug the funding gap in social care – and they cannot afford to do this. In addition, we think that; given its role in promoting, protecting and supporting the human rights of disabled people; it is unfair that users of community care should be asked to pay towards it. We note that – rightly – some services that are crucial to the rights of citizens; e.g. the NHS, schools and cycle lanes; are paid for by

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http://www.ilis.co.uk/uploaded_files/110908_review_of_cosla_charging_policy_guidance_ilis_response_final.doc

everyone in society, but used by only some. We believe that the decision not to pay for community care in this way is historical and arbitrary and that community care should be paid for by everyone, in the same way the NHS is.

Service user and member organisations comments:

- Disabled people are always the ones to be penalised, I only want to get out of bed, live a life – like everyone else.
- Care managers' knowledge of charging policies is weak, often leading to service users being misinformed and spending money they do not have
- If individuals receive the right information, they do not end up in debt and receive threatening letters

Question 13: Do you have any further general comments on the guidance?

SDSS and member organisations believe the guidance covers all areas of the 2013 Act. However, we also believe that guidance should better reflect Equality Act duties which underpin the ethos of self-directed support and the 2013 Act. Therefore, further links and references should be made throughout the guidance to the 2013 Act. We believe this would better assist local authorities in the discharging of the social care/support duties

Consultation Questionnaire

Draft Regulations

Consultation Questions

Question 1: What are your views on Part 2 of the draft Regulations?

While we welcome a consistent approach to direct payments, as set out in Regulations 3-7, SDSS believes that Regulation 3 should define the parameters whereby a local authority considers an individual has "ability" to contribute to a direct payment. SDSS is concerned that the diverse nature of policies associated with means testing, is hindering access for some individuals to SDS option one.

SDSS welcome the wording and clarity of Regulation 4; that a cash payment should be made net of any charges, unless the individual requires a gross payment.

Our member organisations support Regulation 6, which allows for third party payments via SDS option 2. SDSS member organisations have highlighted issues where local authorities' policies have prevented the use of third party payments, on behalf of an individual. We feel this will put beyond reasonable doubt an individual's right to third party payment in SDS option 2.

SDSS welcomes the clarity of Regulation 7 in clarifying the instances a local authority can terminate a cash payment. We agree individuals should receive a written notice from a local authority stating the reasons for the termination of payment. SDSS believes this notice should also include other information on the options available to an individual.

Question 2: What are your views on Part 3 of the draft Regulations?

SDSS and member organisations welcome and agree with the stated list in Regulation 9. We believe the factors listed in the Part 3 will put beyond reasonable doubt the acceptable instances a family member can be involved in supporting an individual. SDSS note with caution Item (i). We believe that this is an appropriate catch all Item, which may allow flexibility in difficult circumstances, but should only be used as a last resort.

Question 3: What are your views on Regulation 11 which deems individuals who are placed under a variety of criminal justice orders to be ineligible to receive direct payments?

SDSS agrees with the listed exclusions in Regulation Part 11.

Question 4: What are your views on restricting access to direct payments for those who are homeless, those who are fleeing domestic abuse or those who require support in relation to drug or alcohol addiction?

SDSS notes with caution the explicit circumstances local authorities may apply an exclusion or withdrawal of SDS options 1 or 4. We would argue that a local authority should apply proportionality and common sense when assessing an individual's suitability for SDS options 1 and 4 while he/she has access to advocacy.

Question 5: What are your views on restricting access to direct payments in relation to the provision of long-term residential care?

SDSS member organisations and their service users tell us that this is a very complex and emotive subject for individuals. SDSS is of the firm opinion, where reasonably possible, all service users should be allowed real choice in social care. However, research from the 2013 SDSS self-directed support organisations mapping research demonstrates a real lack of choice in SDS support organisations outside of Edinburgh and Glasgow⁶. Therefore, enabled choice, for a range of support services or providers, is not available everywhere in Scotland.

The lack of real choice across Scotland poses a threat to the credible take-up of SDS. Any changes to social care services, contracts or service level agreements, including residential care, should be made in co-production, with a range of parties involved. One decision on SDS contracts, should not be looked at in isolation. There will be an effect across a range of provision, which may affect different service users or groups of service users. Co-production with a range of organisations can mitigate the possible effects contract changes may cause.

⁶ <http://www.sdsscotland.org.uk/imageuploads/Final%20Mapping%20Report%202013.pdf>

Question 6: The draft Regulations do not specify circumstances where the direct payment option should be unavailable for care and support to children/families. Should there be specific restrictions on choice of support in relation to children/families support (i.e. support provided under Section 22 of the Children (Scotland) Act 1995) and should these restrictions apply to the direct payment only or to other options as well?

Member organisations, service users and their families tell us that care and support for children and their social care needs is extremely complex. Flexibility for families and local authorities to allow greater discretion will, in complex situations, support children and their families better.

SDSS believes that all children (including children and young people under Section 22 of the Children Scotland Act) should be eligible for SDS. However, the consequence in the availability of SDS options to all children and young people is beginning to emerge. SDSS and member organisations are very aware that local authorities are struggling with how to apply the four options and are not clear on who is responsible for managing the options. This is unclear from the draft regulations.

Member organisations tell us they are very concerned with the slow development and limited choice of services for children and young people accessible through SDS, and direct payments in particular. SDSS believe further work with all stakeholders, in coproduction, is required to develop SDS options for children and young people, before the Scottish Government make a specific decision in this area. **SDSS strongly advises the Scottish Government to progress the matter urgently.**

Question 7: Do you have any further comments on the draft Regulations?

- No

Question 8 : Do you have any comments on the financial costs or benefits of the Regulations?

SDSS member organisations tell us, support packages are being reduced through the application of SDS. Service users say they are only receiving minimal care/support; to meet 'duty of care' regulations placed

upon local authorities⁷. This is in opposition to the stated aims and ethos of the SDS Act.

Our member organisations are concerned about the lack of consistent resourcing for SDS support organisations. Funding for SDS support organisations is a mixture of time limited funding by; service level agreements from local authorities or grant-in-aids from the Scottish Government. SDSS member organisations tell us the current SDS funding for the majority of SDS support organisations will end during or just after the commencement year of the SDS Act. Our member organisations tell us this ultimately affects their ability to adequately support a service user's outcomes and prevents investment in services. SDSS believe this will ultimately affect the take-up and the sustainability of SDS support packages across Scotland. **SDSS calls upon the Scottish Government to examine the inconsistent resourcing of SDS support organisations in order to meet the SDS national implementation strategy objectives.**

Question 9 (a): Do you have any views on the impact of the Regulations on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

By “equality impacts” we mean whether or not, and in what ways, the Regulations will affect certain groups, and whether they will impact on those groups in a positive or a negative way. In considering the impacts you may wish to consult the Equality Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act 2013, available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/9876>

We plan to update the Equality Impact Assessment in light of this consultation.

⁷ <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/52878.aspx>

Question 9 (b): Do you have any views on the impact of the Regulations on human rights? For more information about human rights please see the Scottish Human Rights Commission's website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

Our member organisations tell us; for many disabled people, community care/support is one example of the practical assistance needed to; eliminate discrimination, promote equality of opportunity and protect human rights. Without it, many disabled people cannot; participate in society on an equal basis to others; they cannot enjoy the right to a family life or to live free from inhumane or degrading treatment; they cannot live their life in the way they choose, at home, at work and in the community or live a productive life.

All of the rights protected by the Equality Act, European Convention on Human Rights (ECHR), in the Human Rights Act and in subsequent human rights conventions, belong to disabled people. The United Nations Convention on the Rights of Disabled People (UNCRPD) strengthens and contextualises these rights. It also recognises the role of community care/support in doing so: Article 19 of the UNCRPD states that; to ensure disabled people equally enjoy the rights laid out in the ECHR states must ensure; "disabled people have a right to live in the community, with the support they need and can make choices like other people do". In addition, at Section 2, the SDS Scotland Act 2013 further recognises the role of community care in supporting such rights to participate in society.

Independent living and community care/support is therefore necessary for and underpinned by the human and civil rights of disabled people.

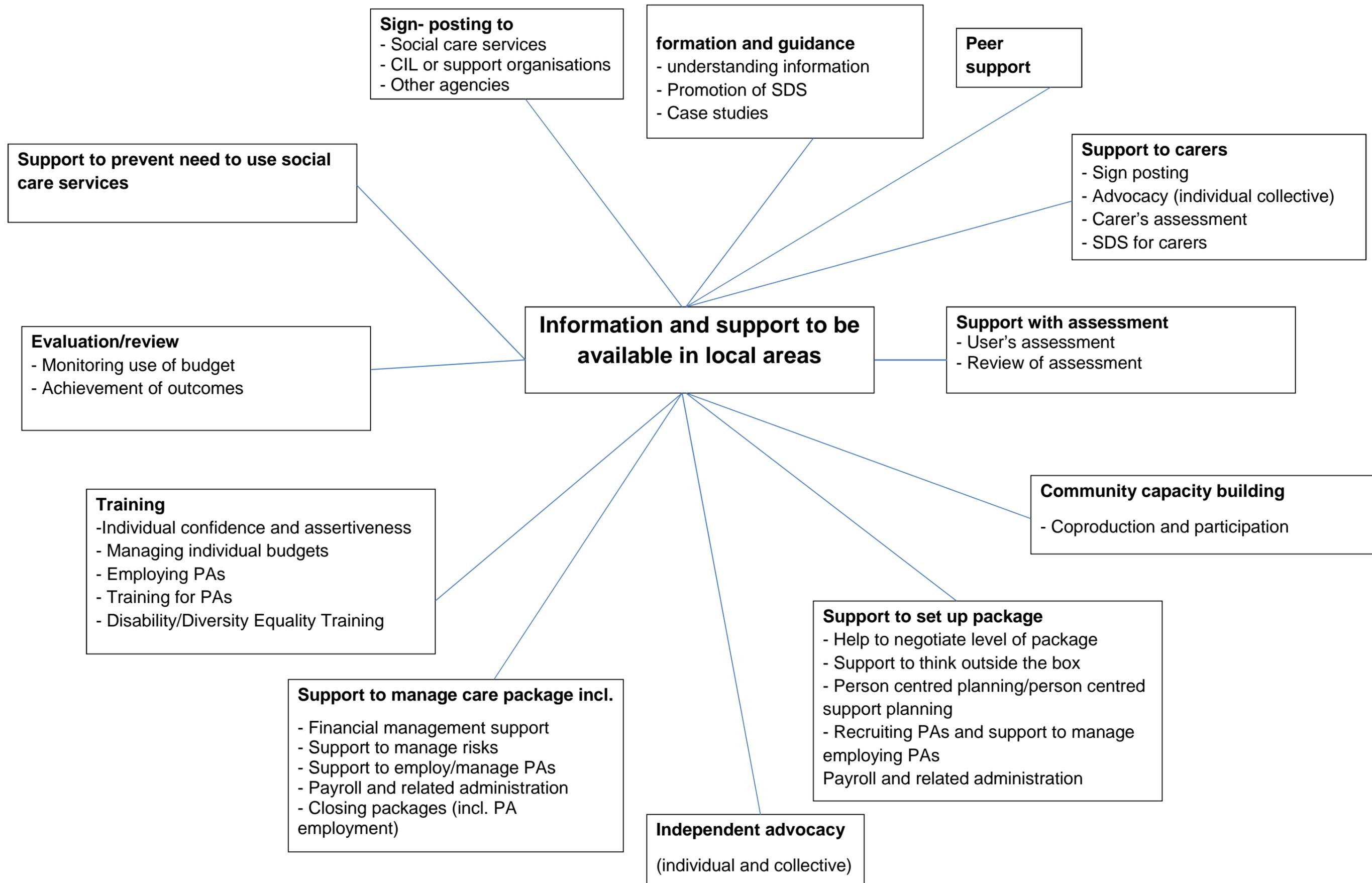
Government and local authorities must not act in ways which are incompatible with these rights. Charging for crucial support to make human rights a reality for some people in our society is therefore considered at best, unusual, and at worst, a contravention of the rights laid out in law for disabled people.

Charging for community care/support is unfair – it is unfair that disabled people are expected to plug the funding gap in social care – and they cannot afford to do this. SDSS member organisations and their service users tell us; that the community charges advocated by the regulations:

- are a breach of the civic and human rights of disabled people – to live an independent life, free from discrimination; and to enjoy their possessions and their home
- are a double form of taxation that places an intolerable burden on disabled people and are an inefficient way of providing additional revenue for care services

In addition, we think that; given its role in promoting, protecting and supporting the human rights of disabled people; it is unfair that users of community care/support should be asked to pay towards it. We note that – rightly – some services that are crucial to the rights of citizens; e.g. the NHS, schools and cycle lanes; are paid for by everyone in society, but used by only some. We believe that the decision not to pay for community care in this way is historical and arbitrary and that community care should be paid for by everyone, in the same way the NHS is.

Appendix – Support organisations





This consultation response was written by:
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