



Consultation on Self Directed Support – draft Regulations

This response is submitted by the Independent Living in Scotland project. We gratefully acknowledge the input of our allies, in particular Self Directed Support Scotland.

July 2013

Introduction – about the Independent Living in Scotland (ILiS) project

- The Independent Living in Scotland project aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM). It is funded by the Scottish Government Equality Unit to make the strategic interventions that will help to make independent living the reality for disabled people in Scotland.
- It is hosted by Inclusion Scotland, a consortium of Disabled People's Organisations and steered by disabled people's organisations¹. DPO's are organisations led by and for disabled people. You can find out more about them in the ILiS publication "It's Our World Too", available at www.ilis.co.uk.
- The ILiS project is part of a wider Independent Living Programme, a partnership programme which seeks to mainstream the principles and practices of independent living within the general economic and social policy of Scotland. The shared "Vision for Independent Living" (<http://www.scotland.gov.uk/Publications/2013/04/8699>), sets out the Scottish Government, CoSLA, NHS Scotland and the Independent Living Movements shared aspirations for independent living in Scotland.
- **Independent Living means:**
 - “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life” (Definition developed by disabled people and adopted by the ILiS project).
- For many disabled people, this practical assistance and support (such as access to the environment, advocacy, personal assistance, income, and equal opportunities for employment), underpinned by the principles of independent living, freedom, choice, dignity and control is essential for them to exercise their rights and duties of citizenship, via their full and equal participation in the civic and economic life of Scotland.

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- Without it, many disabled people cannot; enjoy the human rights they are entitled to² on an equal basis to others – as set out in the Human Rights Act and the European Convention of Human Rights, to live free from discrimination and harassment, as promoted by the Equality Act 2010, nor contribute to a wealthier and fairer, healthier, safer and stronger, smarter and greener Scotland³.
- Independent living thus promotes a modern understanding of disability and disability equality that can support policy and practise to protect the human rights of disabled people. It achieves this by recognising the essential role of “material support” in ensuring disabled people can “participate in society and lead an ordinary life”.
- The role independent living plays in protecting the human rights of disabled people is recognised and underpinned by international human rights and equalities obligations to which the UK and Scotland are party to; including the recognition that all of the rights outlined in the ECHR and Human Rights legislation belong to disabled people, and that these are further strengthened and contextualised by the rights set out in the UNCRPD.
- We gratefully acknowledge the work of our allies in producing this response, particularly Self-Directed Support Scotland.



Jim Elder-Woodward OBE, Convenor

² ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

³ ILiS; “Response to the SDS Strategy in Scotland”, 2010

Our response

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

- 1.1 **ILiS does not agree that disabled people should pay towards their social care or support.** We make this point in our response to the Statutory Guidance. Not-with-standing this, we believe that the regulations must go some way to determining what is 'reasonable' to expect a disabled person to pay, as opposed to their 'ability' to pay. 'Reasonableness' has been defined elsewhere in law (e.g. in the Equality Act 2010).
- 1.2 Elsewhere in our response to the draft Guidance we say that consistency across local authorities is necessary to avoid a post-code lottery. Whilst we understand and respect the devolved relationship between Scottish Government and Local Authorities, we are more keenly aware of the discrepancies in contributions towards care to be made by disabled people across Scotland, and the disparity of impact this has on their lives depending on where they live.
- 1.3. in relation to Regulation 4, we believe that payments should *automatically be made gross of any contribution, unless the payee elects to receive it net.* This is a reversal of the order as currently shown in the draft regulations. We believe this is a fairer way of paying as the user will may not be in a position to pay for care or support at the outset. Whilst we recognise that they can elect to change, we believe that issues will impact on this in reality; for example not every system will change readily or not every payee will recognise the need. As a result, they could end up in arrears to their service providers.
- 1.4 Regulation 5 as it stands is too weak. The regulations need to;
- 1.4.1 set parameters for when this could happen, and how, and
 - 1.4.2 require the local authority to both inform and gain the permission of the DP user in the first instance.
- 1.5 We welcome the inclusion of third party direct payments. We have included a request for guidance on Part 6.A(b) of the regulations to be covered in the Statutory Guidance
- 1.6 We welcome the clarity of Regulation 7 in setting out the instances a local authority can terminate a direct 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. However, we also recognise that there will be extenuating circumstances e.g. at Part 7(1)(b) which could be use of the money for a necessary support, other than the one for which it was 'awarded'. We would ask that the Regulations support this.

In addition, the Regulations (and or the guidance) should ensure that even is direct payments are stopped and the supported person is still eligible for support, that the person is still supported.

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

2.1 We 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. However, the list of family members is restricting in that it does not, for example, take account of today's 'blended' families including step-parents and brothers/sisters. This would be a useful addition given that the list is prescriptive.

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?

3.1 We cannot understand the reference to Regulation 8(c) made at Regulation 11(1)(e). There does not appear to be a Regulation 8(c) in our copy of the regulations.

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?

4.1 We note with extreme caution the explicit circumstances local authorities may apply an exclusion or withdrawal of SDS options 1 or 4. We would argue that the

Regulations should expect the Local Authority to take account of the supported person's views. We would strongly argue for the removal 12(2)(d) and (e). At the very least, parameters should be set for use of these options as a (defined) temporary solution, and that restrictions be set to limit the time spent in these circumstances.

Further, are very doubtful that support available under 12(2)(a) to (c) is likely in all cases to provide the support and accessibility standards required for to meet the needs of very many people who require social care and support. We would ask that the Local Authorities are required to ensure that all needs and not just e.g. needs in relation to domestic abuse, are met.

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

5.1 ILiS believes that all service users should be entitled to choice, with support in place to enable decision making and enablement of choices made. This is a Human Rights issue.

5.2 Also, research from SDSS (2013) which looked at mapping self-directed support organisations evidences a real lack of choice in SDS support organisations outside of Edinburgh and Glasgow⁴. This lack of support and choice is likely to have a negative impact on the uptake of SDS across the country. Any changes to social care services, contracts or service level agreements, including residential care, should be made in co-production with disabled people and their own organisations (Disabled People's Organisations – DPOs).

⁴ <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?

6.1 We are conscious that issues around care and support for children and their social care needs are complicated. Flexibility will be key to enable local authorities support children and their families better. We believe that all children should be eligible for SDS and that guidance should be made available for local authorities, providers, families and indeed young people themselves to support them.

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

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

8.1 Social care is notoriously under-funded. This is bad enough in isolation but disabled people are increasingly facing financial hardship from welfare reform, job losses and rising costs, when their living costs are already higher than the norm. In addition, we are aware that support packages are, controversially, being reduced through the application of SDS and increasing numbers of people are now receiving only minimal care/support which met the local authorities 'duty of care' obligations⁵. This is in opposition to the stated aims and ethos of the SDS Act.

⁵ <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/52878.aspx>

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.

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>

9.1 We know that community support is one example of the practical assistance needed to for independent living. Without it, many disabled people cannot; participate in society on an equal basis to others; enjoy the right to a family life or to live free from inhumane or degrading treatment; 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. These rights apply in Scotland and to all Scottish legislation.

9.2 The United Nations Convention on the Rights of Disabled People (UNCRPD) strengthens and contextualises these rights as well as recognising 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.

9.3 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. We are disappointed that the regulations permit charging, and worse, charging that is capricious and inconsistent across the country.

Heather Fiskin

Project Manager, Independent Living in Scotland project



Email: heather@ilis.co.uk

Website: www.ilis.co.uk

Facebook: [@independentlivinginscotland](https://www.facebook.com/independentlivinginscotland)

Twitter: [@ilisproject](https://twitter.com/ilisproject)



Consultation on Self Directed Support – draft Guidance

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Our response

- ILiS welcome the draft Statutory Guidance and are pleased to contribute to the consultation. There is much in the draft Guidance to be welcomed and our comments which follow are intended to support the direction of the guidance towards a fair, supportive and transparent system which embeds the key overarching principles of the Act and supports independent living.
- We also gratefully acknowledge the opportunities to participate in the development of the legislation, guidance and regulations which have been extended to us to date and are pleased to recognise the work of the SDS team in the Scottish Government in respect of this involvement and in relation to the draft Guidance now being consulted on.



Jim Elder-Woodward OBE, Convenor

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Consultation Questions

Section 2 – The Supported Person’s Pathway

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?

- 1.1. ILiS welcomes the incorporation of Table 1 ‘The Person’s Pathway’, at Part 7 of the Statutory Guidance and in particular the list at step 2 which highlights a number of diverse ‘first contact’ points.
- 1.2. **We strongly support the point made by Self-Directed Support Scotland (SDSS) in their response to this consultation, that the inclusion of self-directed support organisations at both steps 1 and 2** would benefit individuals in the process. This would ensure that the supported person (or person who requires support) would have impartial information and support to understand that information.
- 1.3. Again, we support the inclusion of the helpful table (Table 2) and we note the following elements and make suggestions for improvements;
 - 1.3.1. that the use of the term ‘may’ as in ‘may give voice to a supported person’s wishes’ and especially, ‘They may arrange for some additional assistance...’ wrongly imply that these actions are optional. Certainly in the latter case above, it would be expected within the principles of the Equality Act that reasonable adjustments would be made. Without the participation and input by the supported person, including with support if required, the outcomes are unlikely to be either the right outcomes or sustainable outcomes.
 - 1.3.2. that the section relating to ‘unpaid carers’ should emphasise proportionality of input to the process i.e. where the table highlights that unpaid carers have different degrees of authority, this must be reflected proportionately in their input to this process. Carer’s perspectives and their aspirations for the supported person should not be given undue onus in decision making and this needs to be made clearer in the table.

- 1.3.3. that the reference to 'the provider' could be misleading as that it should be expanded to include 'and support organisations' as the latter are distinct from 'providers' but in the context of this table of roles and responsibilities, belong in the same section.
- 1.4. It would be helpful if this section also highlighted that the 'person's pathway' is promoted and explained to people. Otherwise, there is a risk that it will become something that is 'done' to people rather than with them. Professionals will naturally become immersed in the process and very familiar with it; the person newly requiring support will not have that benefit.

Section 3 Values and Principles

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?

- 2.1 We agree that Section 3 is clear and succinct, however we are deeply concerned at the omission of distinct and visible link between those principles included here and the underpinning values of the 2013 Act, i.e. the rights to independent living.
- 2.2 In addition, these missing rights should themselves be positioned in the context of human rights and the Convention on the Rights of Persons with Disabilities and other rights enshrined in the Equality Act 2010. This was the premise for the inclusion of Section 2 of the 2013 Act. (Please see our introductory section above for more detail on the UNCRPD).
- 2.3 It is essential that these elements are clearly captured by the Statutory Guidance as this is the document that those listed in Table 1 will most likely make reference to. To omit these elements from the Guidance would create a chasm between the principles of the Act and the delivery of the Act.

- 2.4 We feel that the Guidance could be improved upon, and have greater effect, by giving wider recognition to the cultural shifts (and also the lexicological, structural and other shifts) required to reach the starting point for this guidance to take effect. Cultural shifts could be addressed in this section.
- 2.5 In Part 9 of Section 3, the somewhat bald and out of context reference to 'independence' could be improved upon by either the inclusion of 'and independent living', or changing the whole to 'inclusive living'.
- 2.6 In Table 3, the reference to communities being assisted to play an active role in commissioning seems somewhat disjointed to the process here. The need for such a reference is dubious unless it relates to the supported persons SDS package taking account of their involvement in the community and support to play a part in Commissioning services alongside others in their community.

Section 4 Eligibility and Assessment

Question 3a: Was this section of the guidance clear and easy to understand? Yes (in parts) 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?

- 3.1 ILiS supports SDSS's assertion (see their response to this consultation) that Part 24 of Section 4, 'does not pose an answer, offer direction or direct an authority as to their role - in appropriately resourcing social care/support packages'. As with SDSS, we do however welcome the consideration given to eligibility threshold, prevention and early intervention strategies and how these can contribute to funding better overall social care/support systems. We would like to see obligations relating to equality and human rights being included within the framework of considerations suggested at this part also. Part 24 would be more helpful if redrafted as two paragraphs setting out 1. an authority's role in a strategic capacity (which could include the authorities roles and responsibilities in relation to equality and human rights and the part

that eligibility for social care plays within these and, 2. the benefit of early intervention and prevention.

- 3.2 Following on from themes around support for involvement highlighted above, we feel Table 4 needs to make reference to support for involvement (as opposed to 'any assistance that is reasonably required to enable them to express their views'), this could take the form of professional communication support for a deaf/blind person or support from an advocacy organisation, which is quite distinct from 'assistance' to 'express'.
- 3.3 We welcome the balanced guidance in relation to risk, set out in Parts 22 and 23, including recognition of risks to a person's independent living.
- 3.4 Part 25 should include guidance on making the published eligibility criteria available, including in alternative formats as required. Whilst this could be said to be implicit, it is clearly better to make these references explicitly. As with Part 24, this Part should also include reference to equality and human rights obligations in relation to the authorities response to need.
- 3.5 The diagram setting out the Exchange Model of Assessment needs to be clearer and more accessible. (Figure 1).
- 3.6 Part 34 lists suggested personal outcomes. These are in the whole quite paternalistic and un-aspirational. They do not for example, include the opportunities that others enjoy such as learning, qualifying, working and earning income. The list would be much improved, and a better illustration on behalf of many people, with the inclusion of some everyday outcomes and goals such as those offered above.
- 3.7 Part 38 (and elsewhere) makes reference to the 'provider'. As before the definition in Table 2 (and indeed throughout the Guidance where references to 'provider' currently exist) should be extended to include 'support organisations'. Indeed, in the context of this Part, it would be particularly beneficial as 'providers' as opposed to 'support organisations' may have their own priorities for care and outcomes.

Section 5 Resources

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?

- 4.1 There is much to commend in Section 5 of the draft guidance however, it is crucial that readers are reminded at Part 48 about the content of the preceding pages in the guidance, the underpinning principles of the Act, and specifically their role in achieving outcomes.
- 4.2 We suggest that reference be made, at paragraphs 44 – 46, to the understandings of ‘risk’ that are detailed earlier within the guidance and that make reference to the risks to independent living (as defined within the statement of intent).
- 4.3 We agree with the link made at Part 42 Section 5.1, between ‘the individual’s eligible needs, their outcomes and the support required to meet those needs and outcomes.’ However, and as mentioned at 3.4 above, we would suggest that a reference is inserted here which highlights the legal duties in the Equality Act 2010 to make adjustments for equal access, including to information in spoken (which is missing here), as well as written formats.
- 4.4 Also, whilst the content of Part 47 is not inaccurate, many of the listed attributes require financed support to see the light of day. This point needs to be made including by (but not solely by) re-siting Part 47 elsewhere in Section 5.3 and not at the top, which implies a hierarchical importance.
- 4.5 In addition, and most importantly, it is vital that the onus on personal assets is not accredited undue weight. Many disabled people require to make the most of their personal assets. The guidance in this particular section seems to take a very unrealistic view of the reality of disability for many people. Community ‘hubs’ might be physically accessible, but not if you are not supported to get out of your house or suffer from depression and other conditions. We strongly advise redrafting this section. We suggest that specific reference to the definition in the statement of intent of independent living; in particular the

aspects of this around the role of 'practical assistance and support to lead an ordinary life'; is made within this section. We also suggest the section makes clear that resources should not form part of an assessment but could, with the persons express permission, be taken into account – some disabled people may try to upscale their assets and downsize their needs from force of habit, or culture.

4.6 In relation to Part 49, we strongly believe that a standard, national system for resource allocation – which could include the 'equivalence mode;', applicable to all local authorities, would reduce inconsistencies in the system and ensure that supported people do not experience significant barriers when moving from one authority to another. This would also ensure more transparency as well as more effective involvement of DPOs in creation of such a system and enable monitoring and improvement.

4.7 ILiS recommends that Parts 5.1, 5.2 and 5.3 are extended to include disabled people and Disabled People's Organisations. Scottish DPOs have a wealth of direct experience of trying to achieve the supports for independent and inclusive living across the breadth of Scottish demographics, geographics and the variables of 32 Local Authorities. DPOs have been instrumental in driving forth changes which we now take for granted such as accessible busses and dropped kerbs and the presumption of mainstream education, but which were radical when first touted. They are a resource which can only assist in identifying and implementing changes which offer alternatives to the current systems.

4.8 In particular we support SDSS's assertion in their response to this consultation, that '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' and we agree that this should be clearly stated in the guidance. We suggest that; to support the close working between DPO's and Local Authorities; a link be inserted in the guidance to; "All Together Now", a guide to working in coproduction with DPO's, published by ILiS and available at www.ilis.co.uk.

4.9 We feel that the guidance begins to disconnect from the principles of the Act in this Part and that the guidance needs to include a visible demonstration

here to emphasise the need for the principles of the Act to be embedded within the resourcing systems used. Ideally, evidence of how the principles of the Act were embedded within resourcing systems, would need to be shown. Without this, we reluctantly expect that we will see systems which have been revised in favour of Local Authority budgets and not in favour of the principles for social care in the Act. Whilst we recognise the extremely difficult financial environment in which Local Authorities are operating, we also recognise that effective and personalised care and support works preventatively across a range of other budgets.

- 4.10 ILiS shares the concerns of others at the lack of a statutory and independent framework for appeals, complaints and reviews. Without such frameworks there is not even a basic system for addressing concerns, unfairness or even every day mistakes – and righting them.
- 4.11 ILiS acknowledges the processes at Part 66 which describe the circumstances where a local authority can restrict the use of a particular option, where it is 'clear' (which implies that this is to be an objective and not a subjective assertion) that that option will not meet the eligible needs. However, with others, we disagree with the proposed complaint mechanism outlined in the guidance. The guidance should make reference to the complaints review committees operated by a number of local authorities. These allow some equity for disabled people, in handling review or complaints of social care/support decisions. It should be made clear in the guidance, and be passed on to the supported person, that complaints to the Scottish Public Service Ombudsman can only be made on procedural grounds, not professional judgements.
- 4.12 We note that the Advisory Committee on Administrative Justice and Tribunals in Scotland's report 'Right to Appeal'⁴ highlighted that 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." **We believe that a new and independent authority charged with addressing appeals against all elements of care and**

⁴ http://ajtc.justice.gov.uk/docs/decisions_with_no_appeal_web_final.pdf

support decisions, including assessment, provision and payment is the only and right way forward.

We do however recognise that this consultation on draft guidance is not the locus for such an appeal. Rather, we would ask that this point be noted within Scottish Government including in the published analysis of responses and that the guidance makes clear that no complete and independent route to appeal and redress exists. The guidance will be referred to by supported people, carers and support organisations too so and so it is crucial that they are fully informed.

- 4.13 Along with SDSS, we welcome the prescription in Part 72 that professionals should 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.
- 4.14 However, we do not think that the guidance to ‘tailor communication’ goes nearly far enough in ensuring that the supported person has the right level of accredited support to hear, understand and respond to and engage with the professionals, and others, in this context.
- 4.15 ILiS are happy to support SDSS’s suggestion 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.
- 4.16 We welcome the inclusion at Part 75, of the definition of user-led support and information organisations. We believe that this will encourage local authorities to identify and sign post supported people and carers to appropriate information and support organisations. However, it must be said that many local and regional support organisations are currently under-funded and face an unstable future – this is something that Local Authorities, along with other funders, need urgently to address.

Section 6 Monitoring and review

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?

5.1 SDSS welcome the clear definition of when an individual or local authority can instigate a review of social care/support needs and that periodic reviews should be sought as a matter of course, based on outcomes.

Section 7 Facilitating choice

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?

6.1 We welcome the explanation of Section 19 of the 2013 Act in this Section 7 of the guidance however we feel that as a whole it would benefit from a more in-depth description to emphasise and demonstrate the breadth and source of the variety implied here. In particular the inclusion of Disabled People's Organisations and support providers.

6.2 As above in paragraph 4.13 of our response, we recognise that Local Authorities, along with others, have a role to play in financing and supporting local provision, including disabled people's organisations and support providers. It would be helpful to include a note of this here.

Section 8 the role of the NHS and NHS professional

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?

- 7.1 ILiS notes the progression of the Public Bodies (Joint Working) Bill and the planned for correlation between SDS and the integration of health and social care. Reference must be made in this Statutory Guidance. Recognising that the situation with the PB(JW) Bill is evolving, as well as complex, this could be achieved through cross referencing to a 'timed' annex and its replacement with a supplementary annexe once the Bill has passed..
- 7.2 We welcome explanation and clarification of the role of the health service in social care/support. There are many well-documented examples of disabled people's experience of the challenges and added grief presented by discharge from health care and transfer to social care stay.
- 7.3 The case study at this section (Parts 85 and 90) is helpful and we would welcome further use of this tool throughout the guidance, where useful.
- 7.4 Training for health professionals and manager in the ethos of this Act is going to be pivotal to the success of the duties. Ditto effective joint working involving disabled people and their organisations.

Section 9 Further guidance

Section 9.1 Children and young people

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?

- 8.1 The further guidance section is useful and we welcome the link between the SDS framework and the Getting it Right For Every Child framework. This will improve the choice and control offered to children and young people wishing to use self-directed support.
- 8.2 Transition from children's to adult support services, as dealt with in Part 101, is traditionally a very difficult phase. ILiS is concerned that the complexity and the different degrees to which LA's are prepared for SDS will mean that some young people are particularly disadvantaged at this time if this is to be the time at which they transit. This is also a time when young people may opt to leave home in order to live, work and or study in a different Local Authority area. It is particularly important that any disadvantage is negated by the strongest application of the principles of this guidance.
- 8.3 We also support SDSS's advice to the Scottish Government to advance this matter urgently.

Section 9.2 Supported decision making and circles of support

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?

- 9.1 ILiS queries the inclusion of a concept as mis-understood, fraught with potential mis-use and paternalistic connotations as 'circles of support' in Statutory Guidance. We recognise that the term enshrines many things, some of it good, and is included as a way of illustrating informal support and would therefore make a case for circles of support to be replaced with a less contentious and clearer reference to informal support/s.
- 9.2 Several forms of communication support should be provided by qualified and registered providers. These are professional services and not informal support as suggested by the coloured box at the top of Section 9.2.

- 9.3 Providers need to be aware that informal support, for example, a regular carer or a family member may interject their own views on any decision, whether or not intentionally and even when in the belief that they 'know best' and are doing so in the best interests of the supported person. Providers need to be aware of this and know how to identify and address this.
- 9.4 Paradoxically, the Statutory Guidance should make reference to the costs for some types of support and the paucity of it, which can impact on when meetings can take place e.g. deaf/blind interpreters are a particular case in point.
- 9.5 ILiS strongly advises that stronger links to the rights to advocacy to support decision making should be included in this section.
- 9.6 ILiS suggest that Scottish Government confirms with the Royal College of Speech and Language therapists the reference to them supporting an individual in this context to communicate is appropriate (Part 111).

9.3 Carers

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

See our comment, 9.3, above.

Section 9.4 Direct payments

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?

- 11.1 ILiS welcomes the clarity and definition of third party payment in Part 125. We are aware that such payments were prohibited by a number of local authorities in Scotland in the past and we hope choice and control for disabled people will follow from this direction to local authorities. However, we would wish to see more guidance on this matter including how the Local Authority will satisfy itself that the direct payment user will retain total control over how the money is spent, and how they will monitor this. The current draft only makes reference to the direct payment user being made aware of their 'right' to retain control.
- 11.2 We also wish to highlight the need for this Section to include references to appropriate and on-going training for supported persons to help them to manage and understand and to gain the most from, their direct payments. We are aware of evidence via SDSS of increased sustainability of support packages where training has been given.
- 11.3 We are aware of individuals being called to Employment Tribunals where a partner has died and their Personal Assistants are seeking redundancy which is not currently covered by the direct payments. To ensure that Local Authorities are delivering the ethos of this Act, they need to take account of all the realities of being an employer for a supported person.
- 11.4 We support SDSS's assertion that the guidance must include direction on withdrawal of support and the form that could take. SDSS write; '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.'

Section 9.5 Wider legal duties and strategic responsibilities

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?

- 12.1 ILiS welcomes the references to re-ablement, immediate care and ‘the gateway’ stated in Parts – 143 to 145. We are conscious that positive outcomes can and will be hindered by any gaps in the communication and failure to take effect joint action across health and social care models and professional groups.
- 12.2 We are aware that disabled people currently in residential care have told DPOS of 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.
- 12.3 We 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.
- **ILiS does not agree that individuals should be charged for their social care/support services (Part 149).** Community care (including that which is provided via SDS) should be free at the point of delivery. Charging for support that is essential to the equal participation in society of one group of people – who share the same protected characteristic – could amount to discrimination, challenges their equal enjoyment of human rights and as such, undermines positive agendas to progress these, such as SDS. Disabled people and their families face unprecedented hardship at this time. They are ill-equipped to contribute financially to the shortfall in social care funding. Even with support in place, most are failing to achieve equality of opportunity in line with their non-disabled peers and are simply paying to exist. We strongly attest that social care should be paid for by everyone as a collective contribution to achieving a wealthier and fairer, smarter, safer and stronger and healthier Scotland.

Whilst recognising this, we recommend that Local Authorities work in coproduction with disabled people and their organisations to develop any revised charging policies and approaches charging policies consider these new approaches. We strongly advise that Local Authorities and other relevant public bodies, listed in regulations as being subject to the specific duties of the Equality Act 2010, are reminded of these duties in the Guidance, especially the duty to equality impact assess new and revised policies.

The Guidance as a whole document

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

- 13.1 We believe the SDSS and member organisations believe the guidance covers all areas of the Act. However, we feel that more attention could be given to timeframes and encouraging providers and others to set timeframes for completing stages. These should of course be published so that the supported person can know what to expect, when.
- 13.2 We would be encouraged to see any moves that would allow the supported person to 'try out' the options. It is idealistic to think that people will be comfortable making 'permanent' decisions without experiencing them and making themselves familiar with the pros and cons. Whilst it may be possible to have an idea what these could be, it must be recognised that it will not be possible to identify issues for all individuals and their lifestyles and other factors which can impact.
- 13.3 More guidance is required on training and recognition of the further work required to recognise and embed the principles of this Guidance throughout the systems and staffs of organisations. This applies equally to finance managers, Councillors etc. as to social workers.

Heather Fiskin

Project Manager, Independent Living in Scotland project



Email: heather@ilis.co.uk

Website: www.ilis.co.uk

Facebook: [@independentlivinginscotland](https://www.facebook.com/independentlivinginscotland)

Twitter: [@ilisproject](https://twitter.com/ilisproject)