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Response to the Scottish Government Consultation on draft Statutory Guidance and Regulations to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

1. Introduction

- 1.1 Glasgow Disability Alliance supports and echoes the responses submitted by Self Directed Support Scotland and Inclusion Scotland, along with Disabled Peoples Organisations who are working towards making Independent Living a reality for disabled citizens of Scotland.
- 1.2 Self directed support is a mechanism towards Independent Living, and this is a step forward for disabled people. . It is therefore vital that the Regulations and Guidance ensure that the principles and philosophy of the SDS Act, a milestone in the history of the disability movement, are fully upheld and interpreted as they were enacted.
- 1.3 Glasgow Disability Alliance is running a project called Self Directed Support Road Testers, which is funded through the Scottish Government's SDS Strategy. This project is about providing information to wide populations of disabled people who might otherwise never hear about the

SDS option, sharing learning and supporting champions around self directed support. One other component is 'My Choices, A Vision for Self Directed Support', which is currently working with 18 disabled people to enable them to experience choice and control in their lives and develop innovative and creative ways of providing good outcomes for supported people within tight budgets. My Choices is a demonstration project and we wish to clearly show that those with lower levels of impairment should not be excluded from the SDS process: even a little support can make a life changing difference to a disabled person's quality of life and personal outcomes. Likewise we wish to show that those with complex needs can also have choice and control over their lives, given the right support.

2. Section 2: The Supported Person's Pathway

2.1 It is welcome to have a clearly defined pathway through the care and support journey. Understanding and navigating SDS is complicated and the language can be confusing for the supported person. We have concerns about the right information reaching people who need it at the right time and the correct stage of the process. This also includes correct information being distributed to front line workers, including local authority workers and voluntary sector workers. Scottish Government should also consider how this can include a joined up approach to other relevant strategies, for example the Autism Strategy and a potential Independent Living Strategy. Due to the variance of localised services to provide independent information and support, it is vital that there is a structured process included in the Regulations and Guidance and that that this process is consistent in each local authority area.

2.2 There is a gap in Table 2 in that it does not specifically include disabled peoples' organisations and support organisations. In the present draft third sector organisations are included under The Provider section. This confuses disabled peoples organisations and support organisations with local authorities, the NHS, or third sector organisations who are providing an SDS service which supported persons are purchasing. It is common at this time to forget that DPOs are part of a community of interest i.e. in this case disabled people and this is a position accepted by the Scottish Government's own definition of community e.g. the national Standards for

Community Engagement and draft wording in proposals for the Community Empowerment and renewal Bill.

2.3 Section 5.5 paragraph 75 states that “The professional should point the supported person towards other sources of information out with the authority. This may include independent organisations or user led organisations.” However these organisations are not mentioned in Table 2. Disabled people’s organisations and support organisations who are independent of the local authority and who are not providers, i.e. not trying to sell a service to the supported person, are absolutely crucial in the pathway. In particular, we can evidence that peer support is a vital element in building the understanding, capacity and decision making ability of disabled people. Thus support from DPOs should be an integral component of any SDS pathway. This should be made explicit in Table 2 and separated out from providers who are potentially trying to sell a service to include a section ‘support organisations’ in Table 2 which specifically mentions disabled peoples organisations and support organisations independent of being a provider.

3. Section 3: Values and principles

3.1 Whilst this is an important section and is vital to include, it fails to make the connection between the principles of care and support and the right of independent living, which is the fundamental basis of the 2013 Act. Self directed support is a mechanism towards independent living, and the values and principles which independent living represents should be a fundamental part of this section.

3.2 The inclusion of Section 1A in the 2013 Act was to make the link between the rights of individuals and the duties placed upon local authorities by international conventions that the UK is a party to. There should be an explicit reference to human rights, and information should be provided on which human rights obligations the local authority has. These include:

- The Human Rights Act
- The European Convention on Human Rights

- International Convention on the Elimination of All Forms of Racial Discrimination
- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social and Political Rights
- Convention on the Elimination of All Forms of Discrimination Against Women
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
- Convention on the Rights of the Child
- Convention on the Rights of Persons with Disabilities

4. Section 4: Eligibility and Assessment

4.1 In the process of assessment, there must be genuine collaboration and co-production between the supported person and the local authority to ensure a fair and satisfactory process as well as outcome. The assessment processes used by some authorities are not clear on how much weighting they give to the supported person's self assessment. It has been reported to GDA that one authority has a questionnaire with two tick boxes side by side. The supported person completes one column and the social worker the other. This is then put forward to identify the resource. It Disabled people who have experienced this process, state that this has not felt like genuine collaboration or co-production. In fact, it is unclear as to whose column gets the most weighting, what the outcome is if there are differences in the answers between the supported person and the social worker, or how the supported person can challenge things that they do not agree with. Furthermore, the questionnaire and related criteria on which the form is based were not developed in coproduction with disabled people- we understand that there was some early input but this was unable to be continued due to time pressures. Therefore we feel that this process is fundamentally flawed regardless of how the scoring framework is implemented.

4.2 Paragraph 24 states that: "A local authority can take into account overall resources when determining eligibility criteria." This goes against the entire principle of self directed support that it should be based on the person's needs, not the authority's budget. This is incompatible with the

guidance which states that once it has been established a person requires services, then the local authority cannot refuse to meet those needs because of budget restraints. We already have a lot of evidence suggesting that local authorities are delivering finance based SDS rather than personal outcome based SDS for disabled people.

4.3 The effect of this is that local authorities will change their eligibility criteria based purely on budgets, and Self Directed Support will become a post code lottery. This presents major problems, not least around issues of equal treatment. The situation will arise where two people with very similar support needs, will received different SDS outcomes, with one receiving SDS and the other not , simply because they live in different local authority areas in Scotland.

4.4 This will also present major challenges to the mobility of disabled people to move and live around Scotland, which will have serious human rights implications. With different local authorities having different assessment criteria for SDS, disabled people in receipt of SDS will not know if their package will be the same should they move to another local authority area, whether for work, family or any other reason they wish to move for. The portability of packages is a critical concern and this section of the Guidance and Regulations simply serves to create a post code lottery of self directed support in Scotland.

4.5 Within the assessment process, the supported person should be considered not as the service user but as the commissioner. SDS is about changing the balance of power toward the individual and enabling choice and control in their lives. In this respect, SDS provides the supported person the financial resources to direct their own support, and therefore they are both the commissioner of the service, and the end recipient.

4.6 SDS can be used in many creative ways to enable choice and control in disabled people's lives and work towards positive outcomes. See the Case Study: SDS and Art at 4.7

4.7 C and M are two young disabled girls who both share a keen interest in art. They met through a Glasgow Disability Alliance summer

programme for young people and developed a strong friendship. Through the 'My Choices, A Vision for Self Directed Support' section of the SDS Road Testers project, they have been able to work together towards something they both enjoy. The two girls pooled their budgets and were able to employ a personal assistant. Together, they planned a programme of activities to go out and take part in art classes, go to galleries and museums, and are planning a visit to the Edinburgh Festival. With a small amount of resources, working collaboratively and creatively, the girls were able to take advantage of many of the free art classes and exhibitions that are going on in Glasgow that they wouldn't have been able to access without a personal assistant. Because C and M were able to direct the agency they employed the personal assistant through, with support from GDA, and decide on what activities they wanted to do, they have been able to experience a great deal of choice and control in their lives, have new experiences and develop a greater interest in something they are both passionate about. This has wider implications as they are both now actively exploring studies and careers in art which otherwise would have been disregarded. In this instance, the pooling of budgets was an active and positive choice for the disabled people concerned and we would wish the option to pool budgets to be supported. However, we must caution against the potential of local authorities to see this as a cost – saving measure. This is an example of a situation where peer support or advocacy, independent of local authority and providers is imperative.

5. The four options

5.1 **Option 1** – 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.

5.2 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, and in particular peer support organisations / DPOs. Otherwise we are concerned that displayed leaflets will be inadequate in terms of supporting and encouraging people to pursue this option. 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 as well as independent advocacy, capacity building to raise aspirations and peer support.

5.3 **Option 2** - 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.

5.4 There are concerns that people with learning difficulties, 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.

5.5 **Option 3** - 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.

5.6 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.

5.7 **Option 4** - 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 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. With this in mind, it should be made clearer that moving to a different option is a possibility should an individual's personal capacity develop or simply if the personal choice to change one's mind is exercised.

6. Support Planning

6.1 It is a good thing that there is a clear and concise approach to support planning. Disabled people have repeatedly expressed their frustrations to many organisations about the inconsistency within the local authority's support planning methodologies and training that has resulted in poor or insufficient support planning.

6.2 Fundamental to the principles of choice and control which is the aim of SDS, individuals need to be aware of the effects of all the options, and need to have accessible and freely available information to be able to make an informed choice about what is best for them. Individuals must be able to change between options, and for people with fluctuating conditions, this must be factored in to their support plan.

6.3 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. We would further argue, together with other DPOs, 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.

6.4 We would like to see Part 51 revised to include disabled people’s or SDS support organisations. Local disabled people’s organisations (DPOs) have been providing services and supporting people to run their own social care since the 1970s. 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. Innovative community development models such as GDA’s SDS Road Testers project can evidence this.

6.5 We agree 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, advocate and a support organisation - may be involved in coproducing the support plan.

6.6 As a disabled people’s support organisation we have had reports of 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 was against the ethos in the Act of self-directing an individual's support.

6.7 Resourcing models have hindered the principles of adequately resourcing 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 budgets. Therefore, any resourcing policy should be centred on principles which are both fair and transparent to protect the social care/support funding of individuals.

6.8 Regarding Part 56, a fundamental issue on this as providers of direct care will have a conflict of interest under this particular guidance. If the supported person is no longer happy with their service(s), or the service of one of their competitors, how appropriate would it be for the service provider to renegotiate the service? Secondly and in any case we would advise not to use the term 'providers' as it may lead local authorities to think that support organisations may not be able to play this role. In addition to this DPO's have encountered issues whereby parts of a support plan were disregarded where third party support was requested.

6.9 We believe that Part 58 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.

6.10 We welcome 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 individual outcomes of the individual. However, GDA believes option 3 should not mean individuals are offered services which service users, with options 1 or 2 do not want.

6.11 Whichever option the individual chooses however, they should not lose their independence or the right to change their mind.

6.12 GDA welcomes the methodology in Part 66 in defining the extreme circumstances where a local authority can restrict the use of an option. However, GDA disagrees with the proposed complaint mechanism

proposed by the guidance. A small 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.

6.13 The Advisory Committee on Administrative Justice and Tribunals in Scotland's in its report and advice to Scottish Ministers 'Right to Appeal' 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."

6.14 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. GDA 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."

6.15 Information: Parts 72 and 73; GDA welcome the strong language to direct local authorities to provide individuals with the "nature and effect" of the options available. Disabled people tell GDA that these basic tenants of a good social care support plan have been unavailable when requested by an individual.

6.16 Whilst GDA 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." It is uncertain if this reflects the intended spirit of the 2013 Act or the Minister for Public Health's previous statements to the Scottish Parliament. Therefore, we propose that Table 7 be replaced with the SDS National Implementation Groups' model diagram developed alongside the SDS standards. We believe this is a clearer fit for Part 74.

6.17 Part 75: We welcome the inclusion of the definition of user-led support and information organisations, we believe this will help local authorities in their sign posting to appropriate information and support organisations. However the language is not strong enough to ensure that user-led support and information organisations will actually be actively involved in the process. It should be far stronger than simply the “professional should point the supported person towards other sources of information out with the local authority.” There should be a duty upon the local authority to actively involve disabled people-led support and information organisations who are independent and not trying to sell the supported person services.

7. Monitoring and Reviews

7.1 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.

7.2 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.

7.3 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.

8. Circles of Support

8.1 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: it does not appear to be a human rights based approach. 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.

8.2 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. GDA suggests that friendships and natural circles of support which emerge as a direct result of peer support are more beneficial: GDA has abundant evidence from disabled people and externally conducted evaluations to support this.

8.3 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.

8.4 Furthermore this section does not reflect the complexity of capacity and the fact that the capacity to make decisions is not “all or nothing”. We suggest a minimum requirement to 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. “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 on-going 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.”

9. Charging

9.1 We do not agree that disabled people should be charged for social care services. 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 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.