



ENABLE Scotland

Leading the way in learning disability

Draft Statutory Guidance on Care and Support
A Public Consultation on draft Statutory Guidance to
accompany the Social Care (Self Directed Support)
(Scotland) Act 2013
Scottish Government

ENABLE Scotland Response – July 2013

About ENABLE:

ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with around 4000 members in 46 local branches and via individual membership. Around a third of our members have a learning disability. ENABLE Scotland campaigns to improve the lives of people who have learning disabilities and their families and carers. ENABLE Scotland provides social care services to more than 2,000 people across Scotland who have learning disabilities or mental health problems.

ENABLE Scotland's service provision and branch members extends across 29 local authorities. In our experience there are various degrees of enthusiasm from, and interpretations by, local authorities about the introduction of self-directed support, making effective Guidance in this area important.

To inform this consultation response, we:

- Held a consultation discussion with our Parents and Carers Committee and our Young Families Support Committee on Saturday 4th May 2013
- Provided a drama performance outlining the principles of self directed support and personalisation for our members at our National Conference on Saturday 11th May 2013, and held two further workshops that day on elements of the draft Guidance – the Supported Person's Pathway, and Staying Safe/Managing Risk
- Collaborated with a range of partners including Alzheimer Scotland, Quarriers, Association for Real Change, Scottish Care, the Alliance, PAMIS, CarersNet, Fair Deal to develop a joint response (submitted separately) and run a Collaborative Workshop on the draft Guidance for Self Directed Support in Scotland in Dunfermline on 6th June 2013

We were heavily involved in the development of the Social Care (Self Directed Support) (Scotland) Act 2013, supporting the passage and scrutiny of the Bill through the Scottish Parliament, and promoting practice with service providers on the ground. ENABLE Scotland remains absolutely committed to supporting the implementation of Self Directed Support, ensuring that it remains true to the original ethos and principles of choice, dignity and control, and are delighted to be able to provide constructive comment on the draft Guidance.

Consultation Questions

Section 2: The Supported Person's Pathway

Question 1(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 1 (b) How useful did you find this section of the guidance?

- Very Useful
- Quite Useful
- Not very useful
- Not at all useful

Question 1 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

ENABLE Scotland welcomes this section as an important and valuable representation of the process for individuals, and commends the Scottish Government on placing the supported person's needs at the heart and start of the Guidance.

We are concerned that there are two elements of the pathway missing, and feel that a linear representation of the pathway is perhaps not the most appropriate visual tool to describe the process.

In the first instance, we feel that there is a pre- Step 1 stage required which reflects the requirements of local authorities to promote awareness of the rights to request assessment and support. For an individual or a carer to get to the stage that they recognise that they 'need support', they must first know that a) support is available, and b) know where they can go, and who to make contact with.

Many of the ENABLE members who contributed their views to this consultation process, particularly younger families, or individuals with lower level care or support needs, did not think that 'self directed support will apply to me'. ENABLE recommends therefore that a paragraph is inserted after paragraph 7 which makes clear the duties on public authorities to promote awareness of the rights to request information and assessment of need. In the presence of that information, it is likely that more individuals and or families would then proceed to Step 1.

Step 3 focuses on the assessment of the **needs** of an individual, and we would recommend that the language be altered throughout this step to reflect that the assessment process must consider and establish a person's **aspirations and wishes**, with their support needs flowing naturally from that.

We would recommend that the language in Step 4 is amended to be clearer on the difference between needs and outcomes. The current language used focuses, in our opinion, on the inputs required to make a support plan work, rather than the aspirations of the individual, and we recommend that a bullet point be added to Step 4 which makes clear that identifying the aspirations of the individual is the first step of the planning process.

The next element of the process which we feel is missing is prior to Step 5. Prior to any decision being made about the final shape of the support plan, a process of brokerage must take place. In order for this to be a meaningful and effective process for the individual and/or family, there is a

requirement on the professional to ensure that the individual and/or family has access to independent advocacy, plenty of opportunity for discussion, and sufficient information about the options on the table. This is a crucial part of the process and therefore ENABLE recommends that either a further step be inserted titled 'Decision Making' which makes clear that there will be room for discussion, brokerage and negotiation around the content of a person's support plan prior to the stage where the supported person and the professional agree or 'sign off' the plan. This is reflected elsewhere in the Guidance, namely under *Section 4 Eligibility and Assessment*, and it would seem sensible to reflect and enhance the element of co-production within the supported person's pathway here.

In light of the themes of discussion and review, and to reflect that the needs and aspirations of an individual will change over time, ENABLE Scotland feels that the Scottish Government may wish to consider a cyclical model to represent the supported person's pathway, rather than a linear table.

Finally, in table 2: Roles and Responsibilities, we are concerned that the 'professional' should be the first individual role listed, and we would rather see the 'supported person' and the 'unpaid carer' at the top of the list, to promote further the ethos of the legislation placing individuals at the heart of the process.

Further, within the defined responsibilities of the 'professional' we are concerned that the text attributes the role of the professional only to social work or health professionals. One further professional group which is completely missing from the Guidance is Local Area Co-ordinators. Whilst we acknowledge that their role differs dependent on the local authority they are operating in, they will have a role to play in the supported person's pathway, most likely in the initial pre-Step 1 phase referred to above, and in some cases, in the support planning process. Their role therefore requires to be reflected in this section of the Guidance.

Section 3: Values and Principles

Question 2(a) Was this section of the Guidance clear and easy to understand? Yes/no

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

- **Very Useful**
- Quite Useful
- Not very useful
- Not at all useful

Question 2 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

ENABLE Scotland welcomes the Values and Principles as set out in Section 3. We are particularly supportive of the directive language used, and believe that this will help to avoid ambiguity in implementation of the policy into practice.

We believe that there is a need to make explicit reference to the SHANARRI wellbeing indicators for children and young people under Paragraph 10:

- Safe
- Healthy
- Active
- Nurtured
- Active
- Respected
- Responsible
- Included

These indicators are proposed as the key wellbeing indicators in statute in the forthcoming Children and Young People (Scotland) Bill, and are well established in practice via the Getting it Right for Every Child framework. To promote the application of the principles of the Self Directed Support Act in the assessment of a child or young person's social care needs, a reference to SHANARRI within the text of Section 3 is essential.

Section 4: Eligibility and Assessment

Question 3(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 3 (b) How useful did you find this section of the guidance?

- Very Useful
- Quite Useful
- Not very useful
- Not at all useful

Question 3 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

ENABLE Scotland commends the Scottish Government on the importance it places in this Section on involving individuals and service providers in the development of local eligibility criteria.

We note that paragraphs 19 and 20 direct local authorities to consider the application of Sections 12 and 12 A of the Social Work (Scotland) Act 1968 in assessing eligibility criteria for adults. We believe that it would be helpful for the guidance to be explicit here about the application of the Children (Scotland) Act 1995 and indeed the Education (Additional Support for Learning) (Scotland) Acts 2004 & 2009 as it relates to an assessment of a child's eligibility for social care support.

In general, we feel that this Section should be absolutely explicit in the expectation that the assessment process focuses on outcomes rather than a professional judgement of a person's need. Whilst we appreciate that the eligibility criteria necessitates a judgement of need prior to the assessment process, the two concepts are used interchangeably throughout this Section, and indeed, the Guidance document, and this must be rectified.

We welcome the affirmative language used in paragraph 24 around duties to provide support to meet needs as assessed, and the clear direction given to local authorities to take a strategic approach to the application of eligibility criteria in partnership with wider partners including the health board, providers, user groups and carer groups.

Prevention and anticipatory care – we are still concerned that applying eligibility criteria means that lower and moderate care needs fall beneath the threshold, and so the system runs counter to the stated national aims of early intervention and preventative care. Within the context of the current economic climate, families are finding it harder to get support. We feel that it is becoming increasingly apparent that more investment in community activities is needed for people who require less support to achieve their personal outcomes, and are therefore pleased with the direction that paragraph 24 gives to local authorities to consider their strategy for investing in preventative services and supporting professionals to direct an individual to alternative sources of support in their local communities.

ENABLE Scotland has an example of best practice to offer the Scottish Government to help illustrate how this can happen:

The Community Connections project was delivered by ENABLE Scotland in the North Lanarkshire area. The project had four aims:

- ***to develop a network of local organisations in North Lanarkshire who provide***

activities for people with learning disabilities;

- **to map what organisations in North Lanarkshire have to offer people with learning disabilities;**
- **to develop an understanding of what needs to be put in place so that people in North Lanarkshire can achieve their outcomes as identified in their Outcome Based Support Plans;**
- **and to assist the business development of local providers by increasing their knowledge of the services people with learning disabilities may want to purchase.**

The research team spoke to thirty organisations and two hundred individuals with a learning disability in the North Lanarkshire area. The team found that the individuals they spoke to wanted the same things as most people namely meaningful relationships, interesting and purposeful things to get involved in. Many people prefer to access 'mainstream' activities rather than rely on segregated services. The team learned that North Lanarkshire is an area that has many activities, groups, providers and opportunities. However many people with a learning disability still appear to be unaware of the opportunities available for them. The team discovered that this is due to the limited amount of accessible information about local services and activities. The team found that services and activities were more concentrated in the south and centre of North Lanarkshire with fewer services and activities in Cumbernauld and the north. The team identified that there is a significant gap in services for young people transitioning to adult services. The team found that people have a distinct lack of knowledge and understanding about how personalisation and self-directed support can impact on their lives and the way they meet outcomes in the future.

Recommendations include the provision of better accessible information to people with learning disabilities about services and self directed support processes; the provision of a collaboratively and co-productively designed and delivered service bringing together people interested in pooling resources in the pursuit of outcomes; better support for people and families in transition between children's and adult services. These recommendations have already impacted on pipeline projects within ENABLE Scotland, specifically plans to deliver interactive informative events around SDS to people who use services; and plans to work in collaboration with other providers in the North Lanarkshire area to develop a one stop information service for people deciding how to use their personal budgets.

Paragraph 26 needs clarity in so far as the focus needs to be on both needs translating into personal outcomes, and personal outcomes translating into needs. This dual element of the assessment process should be pulled out in the Guidance more clearly.

Paragraph 38 on self assessment is welcome and important, but we feel that it could usefully be presented earlier in the Section, and should have a higher prominence as an important tool within the wider assessment process, as opposed to an entirely separate process.

Paragraph 40 is an important point, and perhaps needs expanded upon further to give clarity on the triggers for on-going review of a supported person's outcomes, being clearer that this can, and should, be conducted at the instigation of the individual, with their retaining as much control and choice within the process as possible. This clarity in Guidance will be helpful in avoiding ambiguity or criticism over the motivating factors for review, particularly where this results in a reduction in support.

Section 5: Support Planning

Question 4(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 4(b) How useful did you find this section of the guidance?

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 4 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

As a general observation, this section of the Guidance will be so critical to informing a change in culture and practice, and in shaping the new rights of individuals to be at the heart of their support planning process, we feel that it would be helpful to have more case studies throughout.

On support planning, we are pleased to see the emphasis on outcomes throughout the section on outcomes and working together, but are concerned that the Guidance doesn't perhaps go far enough to recognise the degree of transformational change required to put Section 5 into practice.

ENABLE Scotland can offer a best practice example to highlight how a change management programme around Self Directed Support can be designed and implemented:

Changing Support, Changing Lives is a partnership of five organisations (ENABLE Scotland, The Alliance {previously the Long Term Conditions Alliance}, IRISS, In Control Scotland and SCLD) who have come together to support providers through the transformation to self-directed support. The partners all play different roles, but the overall aims of the project are to develop:

- ***Increased understanding and knowledge of SDS***
- ***Increased innovation and diversity in what is available for people directing their own support***
- ***More flexible ways of supporting people***
- ***Different ways of working with people who access support***
- ***Capacity to respond flexibly and implement cultural and organisational change***
- ***More effective commissioning***

This 3 year project was funded by the Scottish Government and commenced in April 2012. So far ENABLE Scotland have delivered 46 learning events across the country, bringing together more than 1300 people from a range of organisations – including statutory, voluntary and independent sector providers – as well as people who use services, their carers and supporters. Attendees have listened to speakers, taken part in workshops, exchanged ideas and joined in conversations about self-directed support. We have continuously developed the range and scope of events, we take a co-productive approach and always ensure that the voice of the people receiving support is at the centre of everything we deliver. At every conference event a local authority representative is invited to make a keynote speech, and to engage with the audience at a Q & A session at the end of the day. Thus we are ensuring that dialogue between all stakeholders is a key focus of the conference, in the expectation that a range of views will ultimately inform commissioning strategy and practice.

We would be happy to work with the Government to develop this case study further.

We feel that the language around Section 5.2 and Risk presents a rather risk-averse approach, and would encourage more practical modelling of risk management and assessment. Given the shift in power and control which must happen, practical examples of risk assessment from individuals within the Guidance will be important. As one of our members explained to others:

“I have used aids to assist me manage the risk around cooking – it was trial and error but I now have something that works for me.”

Another carer commented that:

“Risk will be minimised if people have really good support to do things the way they want to do”

“People should be encouraged and enabled effectively to take healthy informed risks”

A wider comment reflected that the transformational change required around the implementation of Self Directed Support goes wider than managing the risk around the individual's social care support package:

“The local authority has a responsibility around making communities safer as individuals will be utilising assets that exist in their local communities instead of necessarily tapping into services” “ A change in culture needs to happen – people need to get on board with this.”

We feel that Section 5.4 which outlines the Options of SDS requires further attention. In the first instance, we feel that the table after paragraph 53 would benefit from including the summary titles of each option, instead of numbers, as used elsewhere in the guidance, i.e.:

Option 1: the direct payment

Option 2: the supported person directs the available support

Option 3: the local authority arranges support for the supported person

Option 4: “mix and match”

Real life case studies demonstrating each of the options in practice would help bring the concept to life, and we feel that it would be particularly helpful to include case studies which demonstrate where the process has not worked so well but participants have worked together to achieve a positive outcome in the end. We also strongly recommend a case study which demonstrates how children and families can or could access any of the four options.

Our joint submission with Alzheimer Scotland, Quarriers, Association for Real Change, Scottish Care, the Alliance, PAMIS, CarersNet, Fair Deal and Outside the Box details on pages 5 and 6 our recommendations for revision of this particular section on the four options.

In addition, we would recommend that a more detailed explanation of a professional's “duty of care” discretion within paragraphs 65 and 66 would be helpful in avoiding ambiguity and guiding individuals to understand what this is and why it might be applied.

In Section 5.5., we believe that the role of independent advocacy should be offered much higher prominence, and feel that paragraphs 71 and 72 could make more explicit the requirements for a professional to offer completely impartial information and that they therefore must share information about other providers in order to truly empower the individual with choice and control over their support.

In addition to providing impartial information about other service providers, it is vital that professionals have a very clear understanding of the principles of SDS, and that this is reflected in a national change programme as referred to elsewhere in this response which includes standardised training and resources across all 32 local authorities to ensure consistency of approach. We would further recommend that the Care Inspectorate process be aligned to SDS, and that ensuring that all people are offered all options is a minimum performance indicator. We note that whilst the duty is on the local authority/health board to provide information about the choices and assessment process, it may be helpful for the Scottish Government to consider produce standard information resources to promote consistent application of self directed support throughout Scotland.

On Informed choice – guidance states (section 5.5, para 71, pg 31) that “the professional must provide any assistance *that is reasonably required* to enable the supported person to express a view on the choices available to them, and to make an informed choice in terms of the 4 options.” Concern is that this is open to interpretation as to what is meant by “reasonably required.” This should be made clearer in Guidance e.g. does it apply to the use of assistive technology for communication?

We also strongly recommend that the Guidance makes clear that individuals should be provided with information about the level of budget which has been assessed as required to meet the supported person’s outcomes in advance of their making a decision about which of the four options to select.

How will people know what support is available to them? Guidance states that “the professional should point the supported person towards other sources of information out with the authority...” (para 75, pg 33). At present, some local authorities appear have a lack of knowledge about what support and information services exist in their area. This will need to change if appropriate, effective information and support around SDS is to be given to service users.

In best practice, we would recommend that the Guidance reflects the important role of independent advocacy in this initial process of sharing information and discussing options, and we would make a practical suggestion that paragraph 76 moves higher up this section, and express concern that the Guidance is recommending that a professional provide an individual with information about independent advocacy services only “where they consider it appropriate to do so”. Whilst we appreciate that funded advocacy organisations must prioritise people who have a statutory requirement for advocacy, it strikes us that this information about availability of independent advocacy is something which should be provided to the individual as a standard part of the information sharing process to promote the individual’s right to direct the process.

Section 6: Monitoring and Review

Question 5(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 5(b) How useful did you find this section of the guidance?

- Very Useful
- Quite Useful
- **Not very useful**
- Not at all useful

Question 5 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

Given the critical importance of the monitoring and review cycle in terms of ensuring that a support plan achieves the intended outcomes for a supported individual, we feel that this section of the Guidance is too short, and requires expanding.

We also consider that individuals should be supported to change their minds about the option of support planning and delivery they have opted for, and that professionals should be directed to encourage and accept this as an appropriate and desirable part of the review process. It may be worth considering adding the word 'Flexibility' to the title of Section 6 to remind all involved that the selection of a support option is not a one-off event, and that individuals can change their mind.

We believe that this section should usefully contain more detail on embedding the values and principles of SDS within the review process, i.e. ensuring that the individual is at the heart of directing the monitoring and review process, and provide clarity and suggestions on roles, responsibilities of the people likely to be involved, as well as suggestions on the format, reflecting that one approach will not suit all individuals.

As with other elements of the practice required by the Act, ENABLE Scotland would encourage the Scottish Government to liaise with the inspectorates to ensure that governance arrangements and robust monitoring of local authority review processes are in place before formal commencement.

Where possible, we would recommend that this aligns within existing inspection arrangements and to this end would highlight that the language and timescale for review as set out in paragraph 79 recommends this as something which local authorities should aim to conduct on an annual basis, whereas the current Care Inspectorate requirements clearly state that review should happen every 6 months.

We believe that it would be helpful for this section also to guide local authorities towards a maximum time frame for the review process to complete from start to finish.

Finally, we would recommend that the Guidance should make explicit the link between information extracted at review about the suitability and/or availability of local services to meet needs, and the local community planning and strategic commissioning processes outlined in Section 7.

Section 7: Facilitating Choice

Question 6(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 6(b) How useful did you find this section of the guidance?

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 6 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

ENABLE Scotland welcomes the focus on providing advice on the strategic commissioning of services which best meet the emerging social care needs of individuals within their local communities, as directed by them.

It is highly likely that smaller and independently funded providers and services will wish to be reflected in the body of options for support and so it will be important for local authorities to be clear on the resource they may need to allocate to mapping services available in their area which exist to meet the needs of identified client groups. We would refer again to our experiences with the North Lanarkshire Community Mapping project for further practice examples of how to deliver on this.

We are not keen on the title of this section, and would make the suggestion that it should perhaps change to 'Enabling Choice' to reflect the active role of the individual and the authority's role to support the choice. 'Facilitating' brings connotations of the local authority having the more active role in the process.

Finally, we would expect this section of the Guidance to have reference to the forthcoming Public Bodies (Joint Working) (Scotland) Bill and be clear about how Strategic Commissioning for Self Directed Support will relate to the integration plans required by that process. For example, the Bill as published makes clear the expectation that integration plans must be underlined by the following principles:

- Decisions about integration of functions must take account of the principle that services are to improve the wellbeing of people who use that service
- Integration happens from the viewpoint of people using services, taking account of different needs and different parts of the areas in which the service is provided
- Services are planned and led locally by the community and local professionals
- Services anticipate and prevent needs from arising
- Services make the best use of the available facilities, people and other resources.

Section 8: The Role of the NHS and the NHS Professional

Question 7(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 7(b) How useful did you find this section of the guidance?

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 7 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

We are pleased to see a section dedicated to providing guidance to the NHS professionals, and believe that this is an important inclusion in the Guidance.

Again, we would only seek to point out that this section points helpfully towards implementation of the Public Bodies (Joint Working) (Scotland) Bill, both at individual level and service planning level, and would encourage the Scottish Government to ensure that the final version of the Guidance at least refers to the proposed legislation and recognises the links.

As with social care professionals, we believe that there is a considerable training and information requirement for health care professionals in order to adopt this joint approach successfully in practice, and would encourage the Scottish Government to consider the training and information needs of health care workers, particularly those in the allied health professions, in any change management programme.

Our members also felt that they would like some clarity in the Guidance about what happens when there is a conflict between a health board and a local authority over the provision of support. The wider concept of mediation support and dispute resolution is missing throughout the Guidance, and we feel that this is an omission which should be rectified in the final version.

Section 9: Further Guidance

9.1 Children and Families

Question 8(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 8(b) How useful did you find this section of the guidance?

- Very Useful
- Quite Useful
- **Not very useful**
- Not at all useful

Question 8 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

Whilst we are delighted to see a section devoted to the requirements of children and families, we are concerned that perhaps it would be more effective to present Guidance about the implementation of Self Directed Support for children and families throughout the Guidance document, and not in a standalone section. This would emphasise the fact that the SDS Act applies to all eligible people of all ages, and would help challenge the wider public perception amongst children and younger families, as expressed to ENABLE, that: '**Self Directed support doesn't apply to me; my child is too young**'.

We are concerned that links to other relevant support frameworks, such as the Education (Additional Support for Learning) (Scotland) Acts 2004 & 2009 are not explicit, and more work is required within the Guidance to support parents and young people to navigate their way through both support planning and assessment frameworks, to identify under what circumstances will it be appropriate for a parent or young person to pursue options 1, 2 or 4, and to consider any potential unintended consequence of working across both frameworks. For example, a parent who chooses to opt for a direct payment and employ their own support worker for their child may risk making their child ineligible for a Co-ordinated Support Plan (CSP) under the ASL framework as they are effectively removing a statutory service which requires co-ordination across agencies. With the loss of a CSP comes the loss of routes of redress, and so this could present a significant unintended consequence for children and families.

There is a further significant pressure point at the Transitions planning stage, where young people are moving from one set of eligibility criteria under ASL to a completely different framework under social care. The strategic commissioning of services to provide support to young people leaving school and entering into independent living is something which needs to be reflected in this document, but also across the suite of new Guidance over the next 12-18 months to accompany the Children and Young People Bill and the Public Bodies (Joint Working) Bill.

Clarity on what young people cannot use their direct payments for is required in Guidance, as some of our members have highlighted challenges with local authorities disagreeing that direct payments can be used to meet transport costs to facilitate a young person attending their college course of choice. As a result of the Post 16 Bill and the move to regionalised delivery of courses, a young person who has a learning disability may now increasingly find that the most suitable course for them at college is not now delivered in their local college, but in a neighbouring town, which brings a transport requirement. This is a particular challenge which could be exemplified in a case study format.

From the age of 16, a young person could be directing their own support, which brings with it significant responsibilities, and it will be important that colleagues in education are working to prepare young people who have social care needs for this, and educate them about their rights.

Finally, we believe that the language in paragraph 104 should be more directive and read that authorities 'must' take steps to promote SDS for children and young people, as detailed elsewhere in the Guidance as a duty for *all* people, and not just that they 'should'.

9.2 Supported Decision Making and Circles of Support

Question 9(a) Was this section of the Guidance clear and easy to understand? Yes/no

Question 9(b) How useful did you find this section of the guidance?

- Very Useful
- Quite Useful
- Not very useful
- **Not at all useful**

Question 9 (c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

We refer to the joint submission for more detailed comment on this section, and endorse the opinions reflected therein; namely that this section is weak and would benefit from a considerable rewrite.

However, for individuals who have a learning disability, this section of the Guidance is absolutely critical to ensuring that they retain choice and control over directing their support. We therefore believe that this entire section should better sit as a sub section of Section 2, The Supported Person's Pathway, or at least cross referenced to it.

Illustrative case studies of Circles of Support in practice would be helpful; the language used currently is very theoretical and would not help a professional who is unfamiliar with the process.

We are concerned with the focus of this section on directing professionals to legal routes for managing ownership of the decision making process, either under the Adults with Incapacity Act 2000 or the Mental Health (Care and Treatment) Act 2003.

We would recommend that the Guidance should be explicit here about the expectations of legal guardians or attorneys to utilise the principles of Circles of Support when working within a SDS context on behalf of a supported person. We would also recommend that the Guidance cross references the requirements placed on legal guardians or appointees under the AWI Act to retain the individual at the centre of the process. The current wording assumes a lot of knowledge on the part of the reader around existing legal frameworks.

In general, given the complexity of the situation for adults with incapacity, a detailed section which outlines the following would be a helpful practical addition to the Guidance:

- Legislative and policy framework

- Existing guidance under the AWI of the role of guardians and/or attorneys
- The role of each person involved in the process (e.g. the supported person, the professional, the guardian/attorney, the Mental Health Officer, the wider family, independent advocate, etc.)

Finally, the role of independent advocacy in this section is a notable and concerning omission within this section, and we suggest that this be rectified in the final version.

9.3 Carers

Question 10(a) Was this section of the Guidance clear and easy to understand? Yes/no

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

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 10(c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

We are pleased to see such a focus on carers in the Guidance, and we broadly welcome the proposed regulations which will waive all charges for support to carers. We would like to sound a note of caution over instances where short breaks will also benefit the supported person, and believe that the Guidance will need to be very clear on the charging arrangements in such instances.

We note that there is no additional resource to meet the commitment to waive carers charges, and encourage the Guidance to make a clear statement which ensures that eligibility criteria for funded carer support does not become tighter and lead to more crisis interventions as opposed to preventative spend.

Working via carers groups and other routes to people who are providing care to promote the options and applicability of Self Directed Support will be another important element of the implementation of the Act. We believe that it would be helpful for the Guidance to make clear its expectation on public authorities to share information across carers networks and via individual caseload. We feel that this will be particularly important across education networks, where the greatest involvement of family carers of children with social care support needs will be found, and where, on the basis of feedback from our Younger Families membership, there is limited understanding of the applicability of SDS.

We welcome paragraph 122 and 123's focus on lower level support for carers, and would suggest the inclusion of some case studies in this section to bring this concept to life.

We further believe that it would be helpful for the Guidance to make a clear statement on the provision of emergency planning pathways as part of carers assessment, where the carer is an older carer and the cared-for individual has on-going support needs, such as individuals with

learning disabilities. We would refer the Guidance team to the recently published Scottish Government Learning Disability Strategy *Keys to Life* (2013), which commits the Scottish Government to continue work to improve access to emergency planning pathways via the Carers Assessment, and suggest that reflecting this commitment within the SDS Guidance on Carers is a critical step in making this a reality across Scotland.

9.4 Direct Payments

Question 11(a) Was this section of the Guidance clear and easy to understand? Yes/no

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

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 11(c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

Our first observation is that, whilst an important section, this section seems to be in a strange position, and we would recommend that it be moved higher up the Guidance document, perhaps even as a subsection of the 4 options section.

The number of people with learning disabilities in Scotland who receive a direct payment has increased steadily, from 32 in 2001 to 1,249 in 2011 (Scottish Government, 2011d, 2010d, 2010e). However, this still represents only a small proportion of the numbers of people with learning disabilities. (SAY Review 2012). Families tell us that they are put off as they think '**it is just one more thing to work at**' (ENABLE 2013).

We believe that the Direct Payments option under the SDS framework is a positive option for people, and is less restrictive than the original direct payments scheme. We strongly recommend that clarity is provided in the Guidance about the status of Direct Payments as directed by the Community Care (Direct Payments) Act 1996 – for example, is the intention that the 2013 SDS Direct Payments system will replace the 1996 Direct Payments system entirely, and will individuals currently in receipt of a Direct Payment be reassessed as part of a transitional programme? Either way, if it is likely that both Direct Payment systems will work alongside each other for some time, the Guidance should reflect clarity on this. Otherwise, the use of the term 'Direct Payment' to mean *either* a payment under the 1996 Act, *or* under option one of the SDS Act inevitably leads to confusion.

We believe that any information for individuals around the Direct Payments option needs to promote the fact that direct payments don't always need to mean employing someone directly; that individuals can commission a service provider to develop a support package which meets needs associated with personal outcomes, or can commission a brokerage service to negotiate and design a package of support for them. ENABLE are concerned with ensuring clarity on whether the cost of a brokerage service would eat into the money available for support. We believe that it would be helpful for the cost of brokerage to be considered separately from the amount available for support, and that this is an important point in the implementation of the new Direct Payment

system which we need the Guidance to be explicit on.

Families have also told us that they would like the Guidance to be clear on the duty of care, and they want to know '**who is responsible for what if someone takes on a direct payment?**' They also wanted to know "**Is it means tested?**" Neither of these points are clearly stated within Section 9.4

Families have also told us that: "**we need clear information if someone decides to employ their own personal assistant –**

- **what support is available to you?;**
- **how can families know where to go?;**
- **do all local authorities have support organisations in place?; and**
- **is there a duty on local authorities to provide support or fund support organisations?"**

We note that there is reference to this under paragraph 130, but only insofar as it guides the professional to take steps to provide information about the employment of a personal assistant to the supporter person and/or guardian. We feel that it would be helpful for the Guidance to be clearer on what this option will mean for individuals.

9.5 Wider legal duties and strategic responsibilities of local authorities

Question 12(a) Was this section of the Guidance clear and easy to understand? Yes/no

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

- Very Useful
- **Quite Useful**
- Not very useful
- Not at all useful

Question 12(c) Do you have any further comments on this section of the Guidance?

(Please provide your suggestions for improvements or additions to this section. Are there any further topics that you would like to see included, any changes that should be made, or any other comments you'd like to make?)

Within paragraph 141, we believe that risk enablement should have a higher prominence to promote further the intention of supporting individuals to live the life they want to live.

We agree that re-ablement and intermediate care may not be the most appropriate time to introduce an individual to the concept of SDS. Under those circumstances, an individual is likely to be experiencing a challenging time in their life, and may not feel robust enough to be considering such issues. However, this is a considerable assumption, and it would be better for the Guidance to make a statement which allows for the professionals to promote that SDS may be an option for them in the longer term, and to encourage conversations about personal objectives and support planning, led by the wishes of the individual. Whilst not formally offering Options 1 and 2 of the SDS framework, this would help introduce some flexibility into the assessment and planning process which places the needs of the individual at the centre, and would prepare the individual for engagement in a process which may follow the period of re-ablement interventions.

We believe that residential care should not be excluded. ENABLE Scotland has concerns about the unintended consequences of such a move for younger adults with learning disabilities who are in Group Homes. Policy elsewhere (namely the Same As You 2000 and 2012 review; and Keys to Life) directs the phasing out of this practice in favour of supporting individuals to live independent lives, and we would be against any younger adult with a learning disability being excluded from the Self Directed Support system by virtue of their current placement. This would be a terrible unintended consequence of the current regulations. We would welcome further discussion with the Scottish Government on how to manage this issue. We also feel that a blanket exclusions policy is unhelpful in general; as individual circumstances change, there should be a continuum of options available to individuals; will help transitions planning into a new phase of life for the proposed excluded groups on page 70.

On Charging, we again feel that there is need for clarity on the situation for younger adults who have a learning disability and who may be currently placed in a residential group home. eSAY data shows that In 2010, 28% of adults with learning disabilities lived in accommodation with other adults with learning disabilities, of whom a third lived with more than 5 other adults with learning disabilities (Scottish Consortium for Learning Disability, 2011). According to Scottish Government data the number of adults with learning disabilities in care homes has fallen by nearly a third from around 3,100 in 2001 to around 2,100 in 2010².

At present, the Guidance reflects only the circumstances of people aged 65 or over, and where existing policy makes clear that personal and nursing care support be provided free of charge. If a young person who has a learning disability inherited a large sum of money, would their personal contribution to their personal and nursing care needs be means tested as a result of their changes circumstances through the assessment process?

We are concerned that the needs of this vulnerable group of people have not been fully considered in the development of this Guidance to date, and would welcome further discussion on this prior to the final version of the Guidance being published.

General Questions

The Guidance document as a whole

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

For example, are there any gaps in terms of the topics covered by the guidance? Are there any major changes that you would recommend? Do you have any comments on the style and layout of the guidance, or the language used in the Guidance?

We are committed to the values and principles of Self Directed Support, and welcome the Guidance and the intent behind it. Our position on improvements within the Guidance and wider suggestions around successful implementation of SDS can be summarised:

- The values and principles set out at the start of the guidance are very warmly welcomed but do not consistently flow throughout the narrative of the remainder of the document.
- The language is at times woolly, inaccessible, orientated towards professionals and unnecessarily includes jargon.
- There are no links across relevant Government policies directed at vulnerable groups, e.g. the Keys to Life 2013 has a five page section on Self Directed Support and makes 5 recommendations about the implementation of Self Directed Support as it impacts on people who have a learning disability.
- Access to independent advocacy and advice is fundamental throughout the pathway and SDS process.
- Recognition of the potential role of mediation when supporting negotiations across family members, carers, the local authority and the individual is missing, and should usefully be linked to independent advocacy provision, or existing mediation services
- The role of the Local Area Co-ordinators must be made explicit in the Guidance.
- Information on applicability for children and families needs to be woven throughout the Guidance, and not presented as an additional section.
- An information campaign for individuals and families will be required, and there may be benefit in Scottish Government considering a national, independent, information helpline/resource to guide people through the process. The ENQUIRE helpline for Additional Support for Learning, run by Children in Scotland, is a good example to look to.
- Younger adults who have learning disabilities and who live in a Group Home setting need to be reflected in the Guidance alongside older people in residential care settings.
- A statement guiding local authorities to include access to emergency planning pathways for older carers should be included within Section 9.3 Carers
- A significant culture change needs to occur if the spirit of the Act is to be upheld and the Statement of Intent met. This must be underpinned by a change management programme.
- There must be transparent and independent monitoring and audit of the implementation of the Act to ensure accountability and consistency across statutory bodies.

We believe that there is a need for the Scottish Government to be absolutely clear about who the intended audience of the document is – it is perhaps trying to cover too many bases. There is a real need for further guidance and/or information to be directed at individuals, families, and professionals in health and social care who will be supporting and signposting individuals through this. The Guidance document gives a helpful overview; but as a first port of call for individuals, whether professionals, carers or supported persons, it is unlikely to meet those basic information

needs.

As one parent/carer asked us during a recent consultation event about Self Directed Support:

“What is it?”

Individuals, families and professionals alike need to understand the new system clearly in order to successfully implement the legislation and embed the ethos of choice and control. A training and information programme, across agencies, will be required to accompany this Guidance and support individuals and services for the implementation of Self Directed Support. The Guidance paper, whilst helpful and necessary, will not achieve this on its own.

For more details on any element of this response, please contact:

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