

Consultation Questionnaire

Draft Statutory Guidance on Care and Support

Comment on guidance as a whole

Consultation Questions

Section 2 : **THE SUPPORTED PERSONS PATHWAY** This was listed as values and principles but does not correlate with the order of the guidance. Sect 2 is the pathway.

Question 1a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/> for professionals	<input type="checkbox"/>	<input checked="" type="checkbox"/> not so for individuals	<input type="checkbox"/>

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

Some advice to help you to answer this question – 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?

The use of the word professional rather than social care or health professional is unhelpful for people with dementia and carers.

Step 1 This is quite simplistic in respect of people with dementia. Often they don't acknowledge or recognise the difficulties they may have and as a consequence of fear and stigma many people will not seek help

Step 2 Needs some explanation about what initial screening is. Individuals are often unaware that initial screening is taking place. Needs more openness to explain that screening is taking place.

The pathway is helpful but may work well as a flow chart or other graphic format was used. It appears very linear in current format

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Consultation Questions

Section 3: Values and Principles

**Question 2a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Some advice to help you to answer this question – 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 welcome the values and principles section as underpinning self directed support. We would like to have seen a reference to human rights and equalities legislation.

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Consultation Questions

Section 4: Eligibility and Assessment

Question 3a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input checked="" type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Some advice to help you to answer this question – 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?

Comments This section makes a good attempt to explain a complex process. However, some of the language is unhelpful (de facto, critical thinking and constructive challenge, exchange model) the section needs to be much clearer, avoiding jargon if it is to be helpful to and accessible to

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Consultation Questions

Section 5 : Support Planning

This section of the guidance covered:

- general guidance on support planning

- risk
- resources
- the choices that must be made available to the supported person and
- information and support

**Question 4a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 4c: 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?

Comments

Welcome the personal outcomes approach. However, there is a need to try and promote risk enablement. There is too much emphasis.

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Consultation Questions

Section 6 : Monitoring and Review

**Question 5a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input type="checkbox"/>	<input checked="" type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 5c: 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?

Again some of the language here is unhelpful. Some of it is overly wordy and could do with some plain english

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Consultation Questions

Section 7 : Facilitating genuine choice for individuals

**Question 6a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 6c: 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 note the intention to populate the guidance with good practice guides. We support this and argue for the inclusion of a good practice guide for people with dementia. Such a guide should concentrate on ensuring people with dementia have access to supported decision making.

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Consultation Questions

Section 8 : The role of the NHS professional

**Question 7a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 7c: 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?

that are more appropriate for statutory guidance rather than Regulations?

Again the guidance here is helpful but needs some careful editing and re writing to meet plain English standards/

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.1 : Children and Families

Question 8a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 8c: 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?

Comments

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.2 : Supported decision-making and circles of support

Question 9a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 9c: 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?

Comments

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 9.3: Carers

**Question 10a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 10c: 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?

Comments

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Consultation Questions

Section 9.4: Direct payments

Question 11a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 11c: 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 before – the whole document needs careful editing

Draft Statutory Guidance on Care and Support

Section 9.5: Wider legal duties and strategic responsibilities

Question 12a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

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

Very useful	Quite Useful	Not very useful	Not at all useful
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 12c: 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?

Comments

Draft Statutory Guidance on Care and Support

Consultation Questions – 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?

Alzheimer Scotland welcomes the opportunity to comment on the draft statutory guidance.

We welcome the explanation of the status of statutory guidance but would have liked to have seen greater clarity. Paragraph one of the introduction states that the professional “must have regard to the guidance”. It then goes on to say “they must the letter and the spirit of the guidance”. This is confusing, having regard for the guidance is not the same as following the letter and spirit. Having regard should be removed as it creates confusion. Also, some explanation is needed as to what constitutes good reason for departing from the guidance.

We note that the guidance is considered of interest to health and social care professionals and a range of groups and individuals. We are not confident that the guidance will be useful to individuals. There is a great deal of technical information particularly around the legal frameworks. For people with dementia and their carers a plain English version would be helpful.

As a general comment we think that the guidance needs some editing. There appear to be a number of different writing styles throughout the guidance which make the document less easy to read.

The costs and benefits arising from this guidance

Question 14: Do you have any comments on the financial costs or benefits of the requirements set out in the guidance?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the guidance. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

Comments

The equality and human rights impacts of the guidance

Question 15 (a): Do you have any views on the impact of the guidance 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**

Some advice to help you to answer this question - By “equality impacts” we mean whether or not the guidance will affect certain 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 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 the comments and information from this consultation.

Comments

Question 15 (b): Do you have any views on the impact of the guidance 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>

Comments

Consultation Questionnaire

Draft Regulations

Consultation Questions

Question 1: What are your views on Part 2 of the draft Regulations (calculation, payment and termination of direct payments)?

Comments

Question 2: What are your views on Part 3 of the draft Regulations (appropriate/inappropriate circumstances for the employment of close relatives)?

We are satisfied with this provision.

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?

For example, is it appropriate to impose the exclusions listed in Regulation 11? Are there any persons not listed in regulation 11 to whom it would be inappropriate to offer the option of a direct payment?

Comments

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?

We do not agree with this provision which discriminates against some of the most at risk groups.

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

This question was raised during the initial consultations on a draft SDS Bill. The Scottish Government would like to invite detailed views before making a final decision prior to the laying of the Regulations before the Scottish Parliament. Should the restriction be removed from the final regulations, thereby allowing direct payments for residential care? Or should it be retained? Please provide reasons as to your support or opposition to requiring authorities to provide direct payments for residential care.

SDS should not exclude people in care homes from having greater choice and control over their care and support.

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?

Comments

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

For example, are there any gaps in terms of the topics covered by the Regulations? Are there any major changes that you would recommend? Are there any topics that are more appropriate for statutory guidance rather than Regulations?

Comments

Draft Regulations

Consultation Questions – General Questions

The costs and benefits arising from these regulations

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

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the Regulations. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

no

The equality and human rights impacts of the regulations

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.

No

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>

No We see SDS as a way of promoting Human Rights. The right to greater choice and control over where, when, and where receive their social care is a fundamental human right.

Response to Scottish Government's consultation on draft statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

Introduction

There are an estimated 86,000 people in Scotland living with dementia¹ many who live with their condition without a formal diagnosis.

Since 2009/10 statistical information has been available from the Scottish Government to monitor the take up of direct payments amongst people with dementia. In 2009/2010 there were only 97 people with dementia in receipt of a direct payment, which increased to 151 in 2010/2011 and with a further increase to 244 in 2011/2012. While this still represents a very small minority of people with dementia who use formal social care services we are pleased to see the level of uptake increase year on year. However we are concerned that there remain significant barriers for people with dementia and their families to overcome to access self-directed support which we know can and does lead to a better quality of life for people with dementia and their families.

The following report contains information gathered from small focus group consultations with 52 individuals in a variety of locations (details below).. We also encouraged people who could not attend the events to submit their individual comments for inclusion in this response. We focused in these sessions on the "Statement of Intent", "The Supported Persons Pathway" and section 9.2 of the draft Regulations and Guidance "Supported Decision Making and Circles of Support".

We would like to thank everyone who attended the collaborative event and the individual focus group sessions or who sent in their comments/suggestions individually and gave freely of their time to give their views.

East Dunbartonshire Consultation

Date: 3rd June 2013

Numbers: 7 attendees (4 family members/3 professionals)

East Renfrewshire Consultation

Date: 16th May 2013

Numbers: 18 attendees (9 people with dementia, 9 family members/supporters)

Ayrshire Consultation

Date: 17th June 2013

Numbers: 8 attendees (6 family members/2 professionals)

Renfrewshire Consultation

Date: 30th May 2013

Numbers: 14 attendees (5 people with dementia, 9 family members/supporters)

Individual responses

Numbers: 3 (1 person with dementia, 2 family members)

SDWG Consultation

Date: 24th June 2013

Numbers: 2 attendees (people with dementia)

General

A number of issues were raised that were not specific to any particular section of the guidance but rather, crucial points for professionals to consider throughout the process of working collaboratively or supporting a person with dementia. We hope that this information will help to inform good practice guidance when supporting people with dementia and their families through the SDS process.

There was a general feeling that too much emphasis is placed on the professional's assessment and lead in the provision of assistance should this be required by the person with dementia.

Proposed exclusion of residential care from Direct Payment option

Concerns were raised that the proposed exclusion of care homes limits choice and control and would therefore be very disempowering. It was generally

agreed that flexibility on this issue would positively promote the ethos of choice and control and should be reconsidered by the government.

Staff training

The issue of professionals being ill-informed about SDS was strongly highlighted. This was backed up with examples where people were given the wrong information or professionals' lack of knowledge made the entire process more difficult. An example of this involved a family being informed that accessing SDS would mean they would have to become employers. This suggests that more staff training will be required to implement the legislation effectively.

Language used in the guidance

The language in the guidance was criticised as using unnecessarily obscure terminology and phrases such as “disabled people” with which not all people with dementia would identify and which would perpetuate the stigma associated with the condition.

It was strongly perceived that the guidance was written for professionals and therefore not accessible, clear or comprehensible. It was suggested that a guide should be written for people with dementia and their supporters, speaking directly to them about what this might mean for them and outlining their rights, responsibilities and entitlements.

Stigma associated with dementia

People with dementia and family members raised the issue of the continuing stigma associated with a diagnosis of dementia. People felt this influenced professionals' erroneous negative judgements about the abilities of a person with dementia or as one individual with dementia phrased it “we're not stupid”. The importance of language and the judgements associated with labelling were identified. This suggests that professionals need to consider their own preconceptions or continuing stereotypes that may exist regarding dementia in order to support full involvement and participation.

Dementia knowledgeable professionals

The importance of professionals and particularly social work staff being knowledgeable about dementia was highlighted. This will again be

fundamental to support involvement and participation but will also play a part in the professional's assessment and analysis of needs and risks. This in turn links to workforce developments such as the Promoting Excellence Framework.

It is important for professionals to consider throughout the process the aim of working collaboratively or supporting a person with dementia.

Stigma associated with accessing social work services

People with dementia and family members also identified an additional layer of stigma associated with accessing social work services. They advised that this created an additional barrier for them in seeking such support which did not equivalently exist for them in relation to their conceptualisation and accessing of health services and support. This suggests that social work services require a more positive presence or image generally in the community and the need to communicate more clearly their potentially supportive role regarding people with dementia.

Political c concerns

A small number of people raised concerns that the proposed changes were linked to a wider political agenda of privatisation of social care and health services, as well as concerns regarding the potential impact upon the direction of travel should Scotland become an independent country as a result of the independence referendum in 2014.

Resources

The lack of resources was strongly highlighted as a major issue, with the potential to derail the intended changes. It was felt that local authorities will only deal with crisis situations as this is all they have the time and money with which to deal. It was generally agreed that preventative support will be omitted, which in turn would lead to the delivery of "too little, too late". Resources were also seen as a barrier to relationship-based practice which takes time on the part of the professional.

Open to interpretation

It was felt that the language in the guidance is open to interpretation. As it is not prescriptive this raised concerns that there will be a lack of consistency across the local authorities regarding implementation of the Act.

“The primary role of the unpaid carer is to provide care and support to a family member or friend.” This does not recognise the relationship between the carer and the supported person and may lead to over professionalization of the unpaid carer role which is first and foremost based on love, companionship and trust.

Statement of Intent

People were generally positive about the *Statement of Intent*. In particular the inclusion of concepts such as dignity and control were warmly welcomed. People felt that it set out a grand ambition that was an appropriate starting point and felt that it sounded good “in theory”. However, a few concerns were raised that this section was rather wordy and did include some language that may be perceived as jargon or “government speak” and was therefore less accessible to everyone. Indeed some people reflected that it was only through discussion of the statement and what it meant that they developed a more positive view of it. Furthermore some concerns were raised about the phrase “disabled people” as this was not a label or definition with which they identified themselves or people with dementia.

The Supported Persons Pathway

“If you don’t understand the system then “we’re going to do a review or an assessment”, what is that? What does it mean?”

This section of the guidance elicited both positive and negative comments.

The aim to support people with dementia fully in decision-making was very warmly welcomed. However, it was highlighted that to do so required a comprehensive understanding of the individual nature of a person’s experience of dementia.

Most people felt that the pathway was a good step forward and an opportunity to change how social care and community health services are arranged and delivered. For some people with dementia, not yet involved with formal social care service provision, the pathway was reassuring in relation to seeking support for themselves in the future. Within the 4 options regarding SDS, the flexibility of the mix and match option 4 was viewed positively.

People were positive about the change to an outcomes based assessment and the explicit requirement to support the involvement of people with dementia and the significant others in their lives.

Assistance during assessment and support planning

“We need knowledge and to know our rights.”

The main themes in this section related to ensuring people have adequate, clear and comprehensive information as soon as possible in the process. The potential important role for advocacy services was also identified or at very least having the involvement of a professional who understands the choices and options available and has the time to impart this information to people with dementia and their families in an accessible unbiased way.

Step 1 – some concerns were raised regarding whether the person with dementia or the carer would be listened to if there was a difference of opinion regarding whether there was any need for help and in situations when people with dementia do not acknowledge or are not aware of their need for support and what this means in relation to the pathway progressing? Many people were not aware that they could directly approach social services when they or a family member needed help and believed this step required action on the part of a professional. Individuals recounted their own experience of chance playing a part in the process when they were ultimately signposted to social work services, rather than robust referral or signposting systems. A number of people voiced their belief that health services have a much greater signposting and information provision responsibility to meet as they are likely to be the initial point of service involvement for people with dementia. Furthermore health professionals are likely to encounter individuals at an earlier stage when future planning or accessing of support could potentially have an even greater positive impact. This could be pivotally important as there was a strong consensus that accessing social work services and support currently depended on an individual’s own knowledge and their connections.

Step 2 – will the views of the person with dementia would be respected if they refused this first contact. In addition terminology such as “screening” was not

perceived as intuitive or accessible the pivotal position of health professionals to be more involved in this step was highlighted.

Step 3 – this step seems to involve a number of assessments being carried out – initial screening, decision regarding eligibility and full assessment concerns regarding shared understanding of the eligibility criterion were raised as was the potential negative impact of a lack of financial resources.

Step 4 – the language of a support plan was unfamiliar as opposed to the more traditional language of a care plan. There was also some concern regarding who has access to and ownership of support plans.

Step 5 – the choices were warmly welcomed but who ultimately decided which was the best option for a person with dementia and whether the choices were given equal weighting which would question the assumption that most people will choose option 3.

Step 6 – questions were asked regarding the time frames for the implementation of support after the previous steps had occurred.

Step 7 – People raised the issue that although this section sounded good in theory the reality is that reviews currently only occur once every few years. This again raises resource implications as more time and staff would be required to achieve appropriate time frames on the frequency of reviews. what are the time frames for reviews and who ultimately made the decisions regarding whether a support arrangement was working or not, particularly in relation to the deteriorating nature of dementia and therefore the potential need for more frequent reviews.

Those involved in this consultation, including the individuals detailed identified the followed measures that would assist with this process:

- Someone who has a dedicated role to support with the SDS process
- The process of getting information not feeling such a struggle
- Being given the right information in a comprehensive and accessible format at the outset to enable choice and control
- Being put in touch with a direct payment or SDS support group

- Formal services, especially health services such as the rehabilitation team explaining the process properly rather than just focusing on equipment
- Explaining and ensuring people's rights are upheld
- More SDS training for all staff in different sectors and settings
- Flexibility throughout the process as a "one fit plan" does not suit everyone
- Being involved with the assessment and provided with a copy and an opportunity to discuss it in order to understand it properly
- Much clearer information and guidance on how a direct payment can be spent
- Clearer sign-posting to carers' support organisations
- A simple, straightforward guide to accessing support and explaining the eligibility criterion would be particularly useful.
- People with dementia need empowered via knowledge. It was suggested that an accessible guide be written with written and visual information and a variety of case scenarios (dementia specific).

a simple, straightforward guide to accessing support, explaining the eligibility criterion and the choices offered by the four options would be particularly useful for people with dementia and their family members/supporters.

Lack of consistency in social work process

People raised the issue that there was a lack of consistent support from social work services. Examples were provided where individuals or families were required to go through the entire process again with different practitioners if they wished to make changes or access self-directed support. Concerns were also raised about the difficulty of navigating social work systems such as the duty system and overall the negative impact of these issues on the quality of the support provided.

Relationship-based practice

A strong theme from people with dementia and family members is the need for relationship-based practice carried out by skilled social work and other professionals. People identified that it was very difficult without building a positive relationship to trust and work in partnership with the professional throughout this process. Furthermore it was identified that people with dementia, for a variety of well documented reasons, may not initially provide a comprehensive picture of their difficulties or abilities. Only through getting to

know the person will the professional be able to exercise skilled and accurate judgement. Again this leads to a question of adequate resourcing as relationship-based practice requires time.

Supported decision-making and circles of support

“It would upset me if I didn’t have a say in what happened to me.”

Lack of emphasis on the supported person

People felt that the introductory paragraph of the guidance section 9.2 placed too much emphasis on the challenges faced by the professional when there are support needs in relation to decision-making. The guidance needs to include the challenges for the person with dementia or supported person and their family in this paragraph.

“The thought of a professional, somebody who doesn’t know me, that worries me.”

Legal measures

A number of people suggested that legal measures under the Adults with Incapacity (Scotland) act 2000, such as powers of attorney should be given more prominence in this section. This particularly related to informing individuals of their options early in a situation where the condition deteriorates, such as with dementia.

Assistance during assessment and support planning

The importance of professionals having enough time to carry out these stages in partnership with the person with dementia was highlighted. It was also identified that person-centred planning tools such as PATHs would facilitate the involvement and participation of the person with dementia more fully than traditional processes. The clear underlining that assistance could not be imposed on individuals and that assistance was not about appointing proxy decision makers were positively received. The potential important role for advocacy services was also identified.

The following good practice measures were identified as fundamentally important to support people with dementia with decision-making:

Information – this needs to be provided in **clear, accessible and plain language** and not “professional to professional” language. It was highlighted that professionals often do not change their language to assist people to understand. The language used in the guidance was described as difficult to read and understand, even for family members who were in a related profession and did not have a diagnosis of dementia. There was a strong feeling that an underlying assumption that people with dementia did not need to fully understand everything was condescending and significantly impacted on the individual negatively.

Processing information – the importance of providing information in manageable and digestible chunks was highlighted, alongside the need to take regular breaks to enable full participation. Professionals need to take account of this when planning to meet people with dementia, the suggestion being that they met more regularly for shorter periods of time.

Don’t assume shared meaning – it was reiterated a number of times that if people are not knowledgeable on social care and health systems then words such as assessment, screening, review etc... must be clearly explained.

Assisting with memory issues – professionals need to take account of the effects of dementia by providing people with more help and support such as written information to assist with memory difficulties. Examples such an explanation or synopsis of the purpose of visits, the discussions that occur and any agreed decisions should be provided in writing. Furthermore an opportunity to review and discuss any issues with this written record must be provided.

Skills – professionals need to utilise communication skills such as reflective listening to ensure and demonstrate that they are both listening to and understanding what the person with dementia has said. This will also act as a safeguard regarding checking the person with dementia has understood the discussion.

Relationship based practice – the importance of the professional getting to know the person with dementia was strongly emphasised. This is necessary in order for the person with dementia to build trust and equally for the professional to make personalised assessments, whether in relation to risk or support. This is particularly true when the person with dementia is initially reluctant or unable to acknowledge the difficulties they may be experiencing.

Circles of support – Most people had no experience of using circles of support (nor did they know what they were) for those participants who had experience of circles of support and person-centred planning felt it was very positive and viewed as a supportive decision-making arrangement in conjunction with person centred planning tools. Concerns were raised regarding circles of support as an arrangement to support decision-making in circumstances where a person with dementia does not have family or close friends and what alternative support would be provided.

Capacity – Capacity is not an all or nothing scenario but the way the guidance is written may lead some people to believe it is. The use of advanced statements should be promoted to ensure proxy decision makers are acting as much as possible on the wishes of people with dementia. People highlighted the need for safeguards to be in place to identify when this is not happening. In addition those involved did not perceive any valid reason circles of support could not be used when an individual lacks capacity, in order to maximise their involvement in the process. This puzzled and concerned as to the reasons for the apparent exclusion of people lacking capacity from the possible empowering support arrangement of circles of support.. There was mixed knowledge on the provisions and responsibilities inherent within the Adults with Incapacity (Scotland) Act 2000, suggesting much more explanatory detail is required in section 9.2 and details of the McMillan principles should be included and not assumed that people will know about these or use the links provided to do their own further research.

Supporting decision-making

The carers identified how difficult they found it to promote decision-making with people with dementia. This was particularly in relation to the changed nature of their relationships due to the condition and their lack of understanding regarding how and where to access support. However they identified the following measures as supporting decision-making:

- Clear explanations without the information being too detailed
- Clearly and simply explaining the consequences of various decisions
- Having the time to have these discussions slowly and at the individual's pace

- Involving other people such as other family members or friends to help the person with dementia make better decisions (the example cited was in relation to taking medication)
- Crucial for advocacy services to be involved
- The fundamental importance of positive relationships to support involvement and participation
- Support for the carer particularly in circumstances where they have their own complex health needs
- Using assistive technology, prompts and aids to support communication such as timelines and life story work

Overall people were concerned that due to the above discussed issues there was the potential for the government's visionary transformation of social care services to flounder unless these issues were addressed.

Personal Experiences of SDS

Experience of SDS

Case 1

Mr D described the positive impact for him as a carer and for his wife when they accessed SDS in relation to her support needs, articulating that SDS had “given him back his life” and “saved his life”. He utilised SDS to employ a PA with the administration of employer responsibilities undertaken by an agency. The PA was an individual who was known and trusted by the family and with the right knowledge and skills to support his wife. Mr D described the first evening he left his wife in the company of the PA. He was able to pursue his own social interests for five hours, which had been an impossibility for a number of years. He returned home to find his wife relaxed and content with her PA. His wife was generally very agitated but with the right support from the right person she became very relaxed. This had been achieved through the use of SDS. Mr D identified the flexibility of SDS as the reason it was such a positive measure in his family's circumstances. He had no interest in becoming an employer but could still utilise a direct payment to employ as PA as the paperwork responsibility was undertaken by a company. With time the direct payment increased to reflect his wife's increased support needs.

Case 2

Mr A discussed his incredibly difficult experience of accessing SDS for his mother. He highlighted the lack of knowledge and awareness of key social work professionals at this time on SDS and talked about the social worker needing to continually seek clarification from the service manager on a wide variety of issues. He raised concerns regarding RASG processes and the experience of the social worker repeatedly needing to return to the committee to argue the case and secure a budget. Mr A raised the need for SDS training and resources for staff as “the troops on the ground don’t know about it”. The entire process was combative requiring input from lawyers to fight for his mother’s rights and took almost one and a half years to secure SDS, describing the experience as a “massive fight to get it”. He highlighted the need to know the right person to make the right things happen during the process.

Despite the significant barriers to accessing SDS Mr A was incredibly positive about the impact of SDS upon his mother’s quality of life due to the choice and control it offered. Indeed he clearly articulated that, “Because of SDS my Mum is still alive” and that “SDS had allowed his family to have some freedom”.

Case 3

Mrs B described accessing SDS to support her mother as traditional home care did not meet her mother’s needs. Mrs B’s mother does not fully recognise her need for support and did not want a variety of staff in her home. Mrs B was put in touch with the SDS advisor in November and by February the direct payment was in place, with which she purchased Alzheimer Scotland services to meet her mother’s personal care and social stimulation needs. Mrs B stated that she finds the personalised service very positive and as it was not feasible for her to take on the responsibilities of an employer in relation to a personal assistant, purchasing services works well, although her mother is still resistant to any changes in staff.

Mrs B’s concerns related primarily to issues with financial services such as the bank in their dealings with her as the enacted continuing power of attorney. She cited a catalogue of difficulties including the bank misplacing the power of attorney documentation and problems with invoices.

Case 4

Mrs C's mother currently is in receipt of traditional services. Mrs C described her experience of the social work assessment process and related issues. Mrs C was unaware of the SDS options available and did not feel these very clearly explored or explained at any time during the process. Furthermore the family were not clear on the outcome of the assessment and never received or read a copy of the completed assessment and identified outcomes and had no awareness of their rights regarding this or the choices available. Mrs C clearly identified the need for improved and comprehensive information to be provided regarding both the individual's choices and their rights.

Case 5

Ms F described her experience of accessing SDS to meet her mother's support needs and achieve her personalised outcomes. In her words:

"We were turned down initially for 12 hours SDS and offered another day of day care instead which my Mum did not want and I could not have got her ready for – it fitted in with nothing. The social worker agreed so we asked for this time as SDS instead. We now have 6 hours allocation per week. We use 3 hours regularly weekly and I bank the rest so we can have a full day or extra 1-1 time as fits with all our family's needs. All I had to do was set up a new bank account and make sure I keep the invoices to show money in and money out."

Ms F identified the flexibility offered by SDS, particularly regarding banking hours and utilising them when required, as especially positive. However, Ms F also highlighted that in the first instance they were not offered SDS and instead she had to request it. This suggests that more training is needed for professionals regarding their SDS knowledge and responsibilities. Ms F also suggested that clear signposting to local support organisations that can assist with navigating the SDS process is vitally important.

Case 6

Mr E a person with a diagnosis of dementia for 7 years discussed his recent experience of raising the possibility of accessing SDS with his local authority to enable him to continue his role in campaigning, training and maintain his self management activities such as going to the gym to maintain his quality of life. Mr E identified that the response of his worker to consider giving up these activities felt like barriers to being an equal and valued citizen. He cited examples such as being unable to operate the washing machine and difficulty

organising tasks and activities and the need to follow unfamiliar processes and the likelihood that his support needs would not be great enough to meet the higher categories of the eligibility criteria. But without support his life would transform to one of isolation and despair.

“I want to keep my independence as much as possible.”

ⁱ Alzheimer Scotland prevalence rates