

# Consultation Questionnaire

## Draft Statutory Guidance on Care and Support

### Consultation Questions

Section 2 : Values and Principles

**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"/>	<input type="checkbox"/>	<input type="checkbox"/>	<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?*

Comments

It would useful to include welfare guardian and the legal rights of welfare guardians.

## Draft Statutory Guidance on Care and Support

### 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?*

Comments

Table three (page 11) – should include the necessity of welfare guardian involvement and participation in the assessment and support planning process.

The rationale being – for individuals with profound and multiple learning disabilities (PMLD) the legal rights of family carers as welfare guardians must be acknowledged to enable the underlying principles of the act to be successful.

**Draft Statutory Guidance on Care and Support**

**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 checked="" type="checkbox"/>	<input 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 checked="" type="checkbox"/>	<input type="checkbox"/>	<input 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

Page 14, section 20 - we would suggest including the term **learning disability**.

Table 4, (page 18) – again this section should include reference to welfare guardians to enable meaningful collaboration for people with PMLD.

## **Draft Statutory Guidance on Care and Support**

### **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 checked="" type="checkbox"/>	<input 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

Page 23, section 42 – for family carers of people with PMLD the support planning process should be approached with extra sensitivity and understanding. Please see attached case study.

Page 24, section 44 – family carers/welfare guardians must be included in any discussion around risk management/assessment.

Page 25, section 47 – please see case study for an example of individual needs verse financial resource allocation.

Page 30, section 66 – PAMIS is pleased that the right to complain about any decision made in relation to the person's assessed needs is transparent, clear and concise.

## **Draft Statutory Guidance on Care and Support**

### **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 checked="" type="checkbox"/>	<input 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 checked="" 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?*

Comments

Page 36, (78) – the length of time taken to reflect on the choices made and the support provided should be discussed and agreed by all parties. This will enable true coproduction between all involved in the decision making process and allow any unforeseen problems to be identified in a timely fashion.

## **Draft Statutory Guidance on Care and Support**

### **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 checked="" type="checkbox"/>	<input 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?*

Comments

Page 38 (81) – there are limits to the choices available for people with PMLD. This group are historically excluded from opportunities within the community, due to lack of facilities that meet their physical and intellectual disabilities.

In order for people with PMLD to successfully access their community, lack of access to basic requirements such as fully accessible changing places facilities must be addressed. PAMIS through The Changing Places Campaign continues to promote the need for such facilities. Additionally, the majority of people with PMLD have complex health needs and therefore require support from carers who are able and with the relevant skills to support their particular health needs.

## **Draft Statutory Guidance on Care and Support**

### **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 checked="" 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?

Comments

Page 41, (85) - Individuals with PMLD have a high level of health care needs. Therefore, in order for a person with PMLD to have achievable outcomes, it is imperative that health has an active contribution to any agreed care package.

## **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 checked="" 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 checked="" 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

Page 49, section 103 – It has been our experienced that some families were advised that there was no legal requirement to obtain welfare guardianship. PAMIS is pleased to see the inclusion of welfare guardianship of this section.

## 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 checked="" 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 checked="" 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?*

PAMIS is pleased that the relevance of welfare guardianship is acknowledged and that support of the person with guardianship to make decisions on behalf of the person who will be in receipt of direct payments, has been made. PAMIS agrees with the requirement of professionals to include support collaborate with the supported person's guardian in all decisions.

## 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 checked="" type="checkbox"/>	<input 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

PAMIS is pleased that the needs of carers in their own right, have been considered within this guidance. Also the reference to support for carers out with the formal assessment process. PAMIS also values the document's acknowledgement of the huge cost savings made by unpaid carers.

**Draft Statutory Guidance on Care and Support**

**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 checked="" 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?*

Comments

Page 62, section 127 – PAMIS would like clarification as to whether the physical “thing” referred to within bullet point 3 can include the purchase of pieces of equipment that would enable an individual with PMLD outcomes to be achieved. For instance, hoists, tilt table, wheelchair power-pack, communication aids etc.

Page 62, (130) – PAMIS feels the responsibilities as listed at the third bullet point should be placed in a separate section, with more explanations and examples of each point raised.

For example, the guidance needs to provide more detailed information on each

point raised:

Disclosure... **and also PVG checks along with the process involved.**

Employment Law...**and also signposting to relevant organisations for support in this area e.g. SPAEN.**

Payroll... **again signposting of relevant organisations.**

Staff development and training...**the guidance should clarify the funding strand that will enable development and training to be included in any support package.**

Provision for regular training updates should be included.

With the responsibility of becoming an employer, there is a need for family carers to have an understanding and knowledge of the legal duties placed on them e.g. the need to understand the Adult Support and Protection Act (Scotland) Act 2007. As already mentioned, it is also necessary for family carers to have an understanding of employment law and access to organisations that offer specialised support such as SPAEN and other similar supportive groups.

## **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 checked="" type="checkbox"/>	<input 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 Page 67 - PAMIS believes other organisations are better placed to give comment on re-enablement and intermediate care where this type of intervention care is related to a person's ability to regain confidence and independence.

PAMIS does however recognise the value of offering families additional support to

avoid hospitalisation of a person with PMLD where their family carers are for example ill, injured or needing additional help to enable them to continue to care.

Consultation issue:

Choice and control would be welcome in all aspects of community support

## **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?*

PAMIS would like to acknowledge that this consultation document was well written and written in a way that was easily understood.

#### 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.*

As with the response to Direct Payment Regulation 9 and 10 we feel that single parents of a child or adult with Profound and Multiple Learning Disabilities and complex medical needs will be faced with discrimination due to the rules around guardianship. (Please see response to Part 3 of the Regulations which considers the employment of family members)

### **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>

It is a human right to realise your full potential. In order to do so people with PMLD must be able to access their community and take part in their community. Regulations, guidance and promotion of self-directed support will be limited if the fundamental problems regarding accessing and participating in community activity is not also considered.

The individuals carrying out eligibility criteria should be knowledgeable about people with PMLD. They should know what equipment is required by individuals with PMLD and should state what type of equipment is necessary to allow someone with PMLD to have the same basic human rights as everyone has.

## **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)?**

**Means testing** – where possible any person considering direct payments should have the requirement to pay a contribution of the cost of care, based on their financial ability to pay, clearly explained before the process of accessing direct payment begins.

Where a means test is carried out after a direct payment has been made the person or the person acting as guardian for the user of the direct payment should be given this information with written explanation that in the event that it is assessed that a contribution should be made from the recipient's funds the assessed money due will have to be returned to the local authority.

## **Payment Net or Gross - comments**

**DP by instalments** - PAMIS welcomes the flexible way payment can be made

**Third party direct payments** – PAMIS welcomes the ability for direct payment users to have payments paid directly to a third party while at the same time maintaining the person's guardian control of how the money is spent. This ensures that family carers remain involved in the decisions around care for their relative yet by- passes much of the paperwork involved in hiring carers directly.

**Circumstances where a direct payment may be terminated** – Where a local authority decides to terminate a direct payment the person should be informed of this decision, and the reasons for making this decision, in writing.

PAMIS is pleased that the regulation addresses the need to consider contractual agreements, made in relation to employment law, when decisions around terminating any direct payment are being made. The high level of care a person with PMLD requires should also be considered and the time necessary to secure alternative care for what are often exceptionally complex social and health care needs should also be taken into account.

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

PAMIS welcomes the recognition that in particular circumstances, family members are best placed to provide care and when necessary should be paid appropriately. However, in regard to the statement that a family member named as the person's welfare guardian should not be able to provide care and receive payment, single parent family carers may face discrimination. Many family carers of a person with PMLD are single parent carers. In this situation and where the single parent is the welfare guardian and no-one else is able to be appointed as welfare guardian, these parent carers will be unable to provide care and receive payment due to this anomaly.

Also, which professional has the discretion to allow employment in certain circumstances?

E.G. Someone with PMLD who has complex health care needs and the parent has provided suctioning and gastrostomy care for a number of years. The family feel that until staff are competent in the communication and healthcare of someone with PMLD that the mother or competent adult caring for the child/young person with PMLD should be allowed to provide the care if necessary, otherwise in these circumstances the local authority or personal assistant could be seen as negligent and it is inappropriate to have untrained carers working with individuals with PMLD.

The parents of someone with PMLD would often be the Legal Welfare Guardians but this should not prevent them from providing care if appropriate staff are unavailable.

**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?

Others are better placed to comment on regulation 11

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

Others are better placed to comment on question 4

**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.

There are a number of people with PMLD living in long term residential care and this should not prevent them having access to direct payments if this will enhance their lives and help support their outcomes. The reasons for this are that for many the reality of residential living means very little stimulation, boredom and inappropriately trained staff. A direct payment would give the residential resident more choice and control therefore why should this be denied them on the grounds that they are living in residential accommodation.

**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?

It is not clear in the Regulations if equipment ie wheelchair, hoists etc will come from an agreed budget between health and social work.

## **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.

Comments not at this time

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.

Again in relation to single parent carers who are also appointed welfare guardians. The regulations on direct payments and family carers do not accommodate the single parent carer looking after a child who has reached adulthood and has no other appropriate person to take the role of guardian. This can have negative

financial implications and can restrict access to the most appropriate care i.e. a parent carer who is best placed to care for their son/daughter with PMLD.

Additionally, the impact of the regulations on a family caring for a daughter/son is enormous. The family have to learn all that is involved in making a choice from one of the available options. If they decide to choose personal assistants they have to learn about staff recruitment and gain an understanding of employment law.

**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>

It is a human right to realise your full potential. In order to do so people with PMLD must be able to access their community and take part in their community. Regulations, guidance and promotion of self-directed support will be limited if the fundamental problems regarding accessing and participating in community activity is not also considered.

The individuals carrying out eligibility criteria should be knowledgeable about people with PMLD. They should know what equipment is required by individuals with PMLD and should state what type of equipment is necessary to allow someone with PMLD to have the same basic human rights as everyone has.