

Dear Sir/Madam

SELF-DIRECTED SUPPORT: CONSULTATION ON DRAFT STATUTORY GUIDANCE ON CARE AND SUPPORT

Responding to this consultation paper

We are inviting written responses to this consultation paper by **10 July 2013**.
Please send your response with the completed Respondent Information Form (see "Handling your Response" below) to:

E-mail to: selfdirectedsupport@scotland.gsi.gov.uk

or

Adam Milne
Self-directed support Team,
Room 2ER,
St Andrew's House,
Regent Road,
Edinburgh,
EH1 3DG

If you have any queries please contact Adam Milne on 0131 244 5455

We would be grateful if you would use the consultation questionnaire provided as part of the Respondent Information Form or could clearly indicate in your response which questions or parts of the consultation paper you are responding to as this will aid our analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at <http://www.scotland.gov.uk/consultations>.

The Scottish Government has an email alert system for consultations, <http://register.scotland.gov.uk>. This system allows stakeholder individuals and organisations to register and receive a weekly email containing details of all new consultations (including web links). It complements, but in no way replaces SG distribution lists, and is designed to allow stakeholders to keep up to date with all SG consultation activity, and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register.

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the Respondent Information Form attached to this letter as this will ensure that

we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly. All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Next steps in the process

Where respondents have given permission for their response to be made public and after we have checked that they contain no potentially defamatory material, responses will be made available to the public in the Scottish Government Library, and on the Scottish Government consultation web pages by **7 August 2013**. You can make arrangements to view responses by contacting the SG Library on 0131 244 4552. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next?

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us consider any amendments or additions to the guidance. We aim to issue a report on this consultation process along with our response to it during Autumn 2013.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the address given above.

Yours sincerely

Adam Milne
Scottish Government
Self-directed Support Team

Response by the National Deaf Children's Society

About us: NDCS is the national charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence.

NDCS believes that the family is the most important influence on a deaf child's development. NDCS supports the deaf child through the family as well as directly supporting deaf children and young people themselves.

NDCS estimates that there are around 3,500 deaf children in Scotland. 90 per cent of deaf children are born to hearing parents with little or no prior experience of deafness.

We use the term 'deaf' to refer to all levels of childhood deafness, including deafness in one ear only and temporary forms of hearing loss such as glue ear, and to include all communication methods, including British Sign Language.

Summary:

NDCS Scotland is supportive of the underlying principles and values of the Social Care (Self-Directed Support) (Scotland) Bill and its accompanying Statutory Guidance. We welcome efforts to encourage the principles of involvement, informed choice and collaboration within the provision of social care for children and young people. NDCS Scotland is hopeful that these provisions will support:

- Nurturing of deaf children's development
- Deaf children to reach their full potential
- Diminishing of barriers and removing risks posed by deafness to the child's health, safety, intellectual development and overall welfare.

While NDCS Scotland welcomes these proposals, we have a number of suggestions as to how the Guidance can be strengthened to improve its overall impact. To summarise we recommend:

- That it is acknowledged in Guidance that to deliver care and support for deaf children, young people and their families, specialist knowledge on their needs and communication requirements is essential. This should be reflected in local authorities prioritising workforce training and up skilling staff to ensure services have the capacity to deliver services to this group.
- On the basis of this deaf awareness and understanding, authorities should pay careful attention to the communication requirements of deaf children young people and their families. They should take real, active steps to meet these requirements in all consultation and engagement with, and information distributed to, this group.
- NDCS Scotland has a number of concerns regarding deaf young people who are 16 to 18 years old. We welcome provisions to allow access to Direct Payments for this group, but we recognise the need to offer them additional support in order to manage this responsibility.
- We welcome provisions to allow family members to be employed by supported people, as this reflects the reality of many deaf children and young peoples' support provision. However, we note concerns around the need to financially safeguard our children and young people.
- With a view to end the postcode lottery of care and support for deaf children and young people in Scotland, we welcome further information on how the Scottish Government intends to oversee the implementation of the Self-Directed Support system, the timescales involved for authorities and the expected sanctions imposed for those failing

to meet these.

Consultation Questionnaire

Draft Statutory Guidance on Care and Support

Consultation Questions

Section 2 : The supported person's pathway

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

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

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

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|--------------------------|-------------------------------------|--------------------------|--------------------------|
| 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 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?

NDCS Scotland broadly welcomes the proposed supported person's pathway and its focus on the individual service user and their support needs. NDCS Scotland sees the supported person's pathway as being largely underpinned by the experience of adults. We note that the pathway does not reflect how children frequently require more varied and in-depth support from statutory services. NDCS Scotland recommends that the Scottish Government consider making the remit of the pathway explicitly broader by including how education are expected to fit into the proposed care pathway.

Third sector organisations play a key role in delivering support, in particular, providing information and advice, post-diagnostic support, signposting families to appropriate services and highlighting self-help and peer support. This input is invaluable and NDCS Scotland recommends that the position of third sector organisations is made clearer within the Guidance as a whole, but particularly within the supported person's pathway.

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)

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|-------------------------------------|--------------------------|
| 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 type="checkbox"/> | <input checked="" 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?

NDCS Scotland is supportive of the underlying principles and values of the Guidance and efforts to encourage involvement, informed choice and collaboration. NDCS Scotland is hopeful that under these provisions, support for families with deaf children will enable them to:

- Nurture their child's development
- Help the child reach their full potential
- Diminish barriers and remove risks posed by deafness to the child's health, safety, intellectual development and overall welfare.

NDCS Scotland is also hopeful that the principles will lead to greater involvement from individual children and their families to ensure they have a direct say on the type of support they want.

NDCS Scotland also acknowledges the importance that local authorities consider these values when conducting assessments and delivering service. However, it is also essential that staff in these services understand how these values apply to deaf children and young people, and how they can enable independence and freedom within these individual and specific contexts.

NDCS Scotland strongly believes that in order for staff to be enabled to do this appropriately there is a need to roll out training to social workers in deaf awareness. Where local authorities do not have a specialist worker skilled in working with deaf children and young people, NDCS Scotland recommends that local authorities invest in up skilling staff to fulfil this role.

NDCS Scotland agrees with the underpinning values of participation, dignity and involvement but believes that the Guidance could be further strengthened, particularly in relation to children, by inclusion of specific references to UNCRC (Articles 23; 24; 26) and UNCRPD (Articles 7; 28; 30).

NDCS Scotland recommends that it is made clear from the outset of this Guidance, the differences in the process of collaboration between adult and children's services. Around discussion of the values and principles within this section, it is important to highlight the intention for provision around self-directed support to feed into the GIRFEC model and Child's Plans and particularly the importance of all appropriate professionals being involved, beyond health and social services, to include those from education services.

NDCS Scotland welcomes the principle of Informed Choice underpinning care and support provision. We believe this value is essential to provide truly self-directed support in line with the positive personal outcomes of deaf children and young people. However, we would also like to highlight that at present deaf children, young people and their families do not have appropriate informed choice due to the inconsistency of service delivery across Scotland. Currently, families often have to choose between the services an authority has on offer, as opposed to what would benefit their child most. NDCS Scotland would urge the Scottish Government to recognise this issue and highlight how services can be made more consistent within the Guidance particularly by highlighting best practice from across

Scotland.

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)**

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

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

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| 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 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?

It is vital that deaf children are able to access social service support under the eligibility and assessment criteria. Research indicates that deaf children can be 60% more likely to experience problems with emotional wellbeing¹ and can be twice as likely to be victims of abuse².

NDCS Scotland would welcome the opportunity to work with the Scottish Government in relation to the assessment process for deaf children. Assessments for deaf children and young people should cover the following:

- Any requirements for specialist equipment
- Any requirements to facilitate communication within the child's family and leisure activities
- Consideration of any communication barriers that the child may be facing and whether this is impacting on his/her social inclusion and emotional wellbeing
- The impact of the child's deafness on the family Any child protection issues. Indeed, it should be noted that research indicates deaf children are more vulnerable to experience abuse³
- Any issues that the child may be facing in becoming independent.

¹ Department of Health and National Institute of Mental Health (2005). *Towards Equity and Access*.

² Sullivan and Knutson (2000).

³ Sullivan and Knutson (2000).

NDCS has produced guidance which outlines more detailed information on the key points that we would wish to be covered within an assessment of a deaf child. The '*Social care for deaf children and young people: A guide to assessment and child protection investigations for social care practitioners*' resource is attached to this response.

NDCS Scotland broadly supports use of the Exchange Model of Assessment and acknowledges its intention to take into account views from all appropriate stakeholders. However, we recognise that this may be perceived by supported children, young people and their families as overly complex. It is vital that the assessment process is communicated in an open and transparent way. It is essential that the supported person understands that their view, though it is taken into consideration alongside that of their carer, agency and assessor, is of utmost importance and should not be lost throughout the assessment process.

NDCS Scotland also recommends that the Guidance contain more explicit information regarding routes for redress where a service user is dissatisfied with the outcome of their assessment. Clear, accessible information should be made available to children, young people and their families about what to do if they are unhappy with the service they are receiving or the decisions that have been made about their service provision.

Similarly, NDCS Scotland feels that the Guidance should make more explicit mention of the consequences for local authorities who do not meet minimum standards for quality assessments. NDCS Scotland is aware of inconsistencies across Scotland with regards to social care provision for deaf children and, anecdotally, discrepancies in the assessment process is one reason for this. NDCS Scotland feels it is important that the Scottish Government take this opportunity to set out the consequences for local authorities who do not fully implement the model assessment process.

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)**

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

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

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| 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?

As previously mentioned, NDCS Scotland feels the Guidance should make explicit reference to the differences in Support Planning between children and adult services. We recommend including in this section a reference to the Child's Plan and the importance of local authorities using the GIRFEC model when engaging in Support Planning for children and young people.

NDCS Scotland agrees that Support Plans and Child's Plans should be communicated in accessible and creative ways to ensure the supported person is fully engaged and understands the content of their plan. For deaf children and young people and their families the use of alternative formats, in accordance to their requirements, is vital. This may include the use of British Sign Language and visual image.

NDCS Scotland also agrees that it is vital that Support Planning is shared promptly between those who will require this information to support service users. NDCS Scotland is aware of the many barriers which often prevent this information being shared within appropriate timescales and can result in delays to service delivery and support. NDCS Scotland believes it is important that these barriers are addressed in the Guidance and some more clarity is provided around what information is appropriate to share, with whom and when. The Guidance should also contain further information about how to overcome the technical and cultural barriers which make data sharing difficult across social care, health and education sectors.

NDCS Scotland welcomes the range of options available for self-directed support proposed in the Bill as the needs and support of each deaf child can differ greatly, as can the willingness of deaf children, young people and their parents to take full control of how to direct support.

The sliding scale of support is useful as it can be adapted to meet the needs of the individual child or family. Every deaf child will have different strengths and needs. The population of deaf children encompasses:

- ▶ Diverse language preferences, for example
 - British Sign Language (BSL)
 - Spoken English
 - Other spoken or signed languages (e.g. Sign Supported English)

- ▶ A range of communication strengths, for example
 - Better productive spoken language than receptive language skills
 - Better receptive skills than expressive skills
 - The ability to mix and match between visual and aural methods depending on who they are communicating with
- ▶ A range of communication and language needs, for example
 - Many deaf children do not have age-appropriate literacy skills
 - Some acoustic environments are more conducive than others to good communication
 - BSL may be used at home but not at school
- ▶ Users of a wide range of continually emerging technologies available for deaf - people and deaf children and young people with additional needs.
- ▶ Deafblind children and deaf children with additional needs.

Whilst this is just an overview of the different strengths and needs a deaf child or young person can have, it demonstrates why the tiered system could work well for this client group, as their needs and willingness to take full control of their support will differ greatly.

No matter what tier of self-directed support a deaf child or their family choose, it will be critical for service managers to ensure that whatever staff support this choice have the skills to work with deaf children and their families, particularly to ensure that the child's view is properly taken into consideration in the support provided.

NDCS Scotland agrees that the provision of accessible information and support is essential for deaf children, young people and their families. It is also essential that the range of communication and language needs of this group of individuals is taken into account before this information is disseminated. Particular caution should be taken to clarify the communication needs of parents and carers. Parents and carers for whom British Sign Language is their first or preferred language may find large amounts of English written materials unhelpful and may require an interpreter to understand this.

Lastly, the role of the third sector in providing this information and support is not clear within the Guidance and NDCS Scotland feels local authorities should be encouraged to work closely with the third sector in order to provide appropriate information and support to children, young people and their families.

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)**

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| Yes | No |
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**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 |
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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?

NDCS Scotland recommends that the Guidance explicitly highlights the importance of a flexible and responsive review process, particularly with regards to the needs of children and young people whose requirements may evolve and change quickly.

NDCS Scotland recommends that stronger Guidance is set out with regards to timescales for the review of support planning. While the Guidance suggests authorities should "aim" to conduct yearly reviews, NDCS Scotland questions whether children and young people may require further review, particularly with consideration of the impact their support may have on their educational outcomes.

NDCS Scotland also suggests the Scottish Government set out recommended best practice for dealing with requests for reviews that occur before the supported person's annual review is due. This should include target timescales for dealing with the initial request, conducting the review and implementing any changes to support planning.

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)**

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

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

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| 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?

NDCS Scotland firmly agrees that having access to choice on paper does not always equate to real access to support, which then improves a service user's personal outcomes. Active steps are essential to promote options and to ensure that real engagement has been achieved to determine what supported people need and want. It is vital that this process occurs in ways that are accessible to deaf children, young people and their families. NDCS Scotland recommends that these service users are involved and consulted in the design of methods to promote and engage with other service users.

With regards to the commissioning for self-directed support, while NDCS Scotland agrees that authorities should seek to learn and understand what people want, try different approaches and review, we have real concerns about the capacity of local authorities to deliver this for deaf children and their families. NDCS Scotland is aware of the inconsistency of service delivery across local authorities, in particular the patchy provision of social workers who have specialist skills in deafness and the very few who are skilled to work with deaf children and young people. Coupled with this patchy provision, NDCS Scotland is also aware of budget constraints and reductions affecting local authorities.

NDCS Scotland recommends that the Scottish Government strengthen provision within the Guidance around facilitating choice by including the recommendation that authorities undertake a review of their service to ensure there are clear plans, and capacity to appropriately commission, for self-directed support.

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)**

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

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

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| 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 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?

NDCS Scotland agrees that the NHS should work closely with local authorities to deliver a person-centred approach to service delivery and ensure that the information provided is accurate and maintained as up-to-date. Staff within the NHS should also play an important role in signposting patients to third sector and other organisations who can provide more ongoing information and support. We also believe that the NHS should work more closely with the local authorities in sharing information to help authorities plan for service provision, such as information on the numbers of deaf children and young people in the area.

Where joint work between social care and health is pursued, it is vital that the supported person is kept informed of important decisions which ultimately impact on the way their support will be delivered. These processes of transfer may be perceived as complex by supported people and their families and it is essential the processes are explained in an open, transparent and accessible way.

Where a joint approach has been taken to deliver services to a supported person, it is also vital that there are clear lines of leadership between social care, health and education with regards to undertaking monitoring and review. It is essential that throughout the joint working review, the needs of supported people are met appropriately and not lost through varying communication channels between services.

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)

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

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

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|--------------------------|-------------------------------------|--------------------------|--------------------------|
| 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 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?

NDCS Scotland welcomes provision for parents to be encouraged and supported to use self-directed support. We are hopeful that this will enable their children and young people to access the same kinds of opportunities and activities as their non-disabled peers. In addition, we can see that self-directed support should play a key role in sustaining and delivering the GIRFEC approach.

NDCS Scotland welcomes that the framework of choice and control will apply to children's social care and support in the same way that it applies to adults' support. But we would again sound the note of caution around ensuring that the services are in place to meet the choices of families of deaf children; an appropriately skilled team with specialist knowledge of childhood deafness is critical.

With regards to provisions regarding the Named Person within the GIRFEC model, **70% of parents of deaf children and 29% of deaf children** surveyed by NDCS in September 2012 **agreed that 'it's a good idea for every child and young people in Scotland to have one person to help them'**.⁴

However, NDCS is clear that this system can only work if: there is a common understanding of the role of that named person; that it is universally adopted and implemented in every area of Scotland; that there are no barriers to sharing information across agencies; and that the role of parents as lead partners in the decision making process is explicit. There are also potential challenges around pressure on the Named Person and their capacity to support children and young people, as well as clarity around how the roles of Named Person and Lead Professional differ. There are also ongoing issues with regards to redress where children, young people and their families are not satisfied with their Named Person and would like to change this Person for whatever reason. It is also essential that any Named Person or Lead Professional who has responsibility for deaf children and young people must be given appropriate deaf awareness training so they are aware of the individual's communication and development requirements.

As we have highlighted throughout this response, support for family and carers of deaf children and young people is vitally important. 90% of parents of deaf children have no previous history or knowledge of deafness, so it is critical that parents have access to specialist and unbiased information about the variety of communication methodologies and technology available to their child to inform their decision making. They also require information with regards to parenting and communicating with their deaf children, this is vital for both the wellbeing of the child and family. NDCS Scotland would like to ensure that all the information and advice that is offered is made available in a number of formats to ensure that BSL users have access to all the information available.

NDCS Scotland would like to see extra support and guidance offered to any young people aged 16-18 who choose to manage all the options available and ensure that they are able to cope with the high level of responsibility this requires. NDCS Scotland is aware that not all deaf children, young people or parents will feel confident enough to take full control over their support. In this case, staff must still find tools to consult with these individuals to develop the best level of support that suits their needs. We suggest that education services are best placed to deliver this, particularly with the curricular flexibility that the Curriculum for Excellence affords. NDCS Scotland would also recommend that the review period for

⁴ NDCS, 2012, Parents' consultation survey on Children and Young People's Bill

16-18 year olds is more frequent than is currently set for adults.

There are also situations where, even if a young person has taken full control of their support, they may require input from the local authority. If a young person does not manage their support budget well and runs out of financial resources to deliver the services they need, they may require the local authority to take over their service planning. This is particularly complex when we consider the duty of care a local authority still has over young people. NDCS Scotland would welcome further clarity in the Guidance with regards to this issue.

As has also been stressed throughout this response, with regards to consulting children and young people and having them contribute to their support planning, communication is essential. These opinions need to be actively sought and in the case of deaf children and young people authorities need to acknowledge that this process will require long lead times as well as input from specialist workers skilled in communicating with deaf children and young people. The importance of authorities engaging in this process, acknowledging capacity and time restraints, needs to be highlighted to encourage authorities to engage in this consultation consistently.

NDCS Scotland welcomes acknowledgement in the Guidance around the challenges of transition from children's support to adult support. However, NDCS Scotland suggests the Guidance is strengthened to include timescales of when transition planning should begin to reflect that this should happen as early as possible. It is possible that in order for a young person to take on Option 1 or 2 they will require support, as they will have had little experience of taking on this kind of independence and responsibility. Facilitating this transition should be done in an open way in consultation with the young person. In addition, review is extremely important in the early stages of a young person having made the transition to adult support. It may be that the young person realises they would like more or less independence, or is satisfied with the Support Planning in place. NDCS Scotland refers the Scottish Government to a number of resources we have established which highlight best practice in supporting deaf children and young people through transitions between children's and adult services. These include *A template for success: positive transition into further education, training and work for young deaf people in Scotland*⁵ and *Quality Standards: transitions from paediatric to adult audiology services*⁶

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"/> |

⁵ NDCS, 2013, http://www.ndcs.org.uk/about_us/campaign_with_us/scotland/campaign_news/a_template_for.html

⁶ Audiology services advisory group, forthcoming, contact NDCS for further information

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

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|--------------------------|-------------------------------------|--------------------------|--------------------------|
| 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 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?

NDCS Scotland agrees that supported decision-making and circles of support are extremely important for deaf children, young people and their families or carers. NDCS Scotland agrees that "reasonable steps" should be taken by professionals to enable the supported person to make relevant decisions with regards to their assessment, support planning and actual provision of support. However, NDCS Scotland recommends that the Guidance expand on what is meant by "reasonable steps" and that expectations are made very clear to authorities with regards to the importance of these steps being taken.

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)**

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

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

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| 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?

It is often the case that parents of deaf children and young people will require carers support to enable a number of support provisions such as respite, peer support or attendance at training opportunities, such as NDCS Scotland's Family Sign Language or Parenting a Deaf Child courses. Having the option to attend these kinds of events is invaluable, particularly for new parents.

As such, early intervention support for carers is essential and should be considered and

pursued in the assessment process. To ensure their own wellbeing and that of their deaf child, it is crucial that parents and carers understand their child's deafness and how they can support their child. It is also vital that services collaborate with the third sector to ensure that carers receive relevant and up to date information about the services that can support them and the person they are supporting.

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 type="checkbox"/> | <input checked="" 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?

NDCS Scotland has some concerns where, through a direct payment, service is provided by a voluntary or private sector organisation. While we welcome that this has been made possible, NDCS Scotland recommends that the Scottish Government include further detail in the Guidance regarding how authorities must work with these agencies to ensure all information and planning is shared. Similarly, further detail is welcome around how these agencies will remain involved in review and monitoring processes with regards to quality assuring service provision against the supported person's personal outcomes.

NDCS Scotland is concerned about the level of responsibility an individual must take as an employer and we feel the Scottish Government should ensure these individuals are properly supported to meet their subsequent responsibilities in this area. NDCS Scotland is particularly concerned about those deaf young people aged 16 to 18 years old, who will be entitled to take on Direct Payment but may not be fully prepared to manage these responsibilities. We would welcome further clarity around the responsibilities that will be placed on 16, 17 and 18 year olds and the review mechanisms that will be in place to ensure they are coping with these.

NDCS Scotland does agree with the approach by the Scottish Government not to place restrictions on who may be employed by an individual as quite often family members who currently carry out this role may be the most suitable person for employment. However, we are also aware that deaf children and young people may be more vulnerable to experiences of abuse, and while the Scottish Government has taken steps to ensure a culture of child protection in service provision, it is important that this is equally reflected within the new system. It is vital that Personal Assistants have gone through appropriate disclosure processes.

NDCS Scotland wants to see a balanced practice of empowering people to manage support against potential risk to their assessed needs. NDCS Scotland believes that input from skilled care professionals and statutory guidance is needed to ensure that self-

directed support does not overrule legislation to protect people at risk from harm. NDCS Scotland agrees that equal access to all the self-directed support options must be given to everyone but this can only happen if we can ensure that the options they use do not contravene the local authority's ongoing duty of care.

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?

No additional 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?

NDCS Scotland would like to see every local authority in Scotland employ the services of, or invest in training existing staff to become, a specialist social worker for deaf children who has:

- An understanding of the complexity and variety of linguistic and psychological developmental challenges deaf children and young people might face An awareness of deaf cultural identity and its implications for deaf children and their families
- Experience of the range of developmental trajectories of deaf children and

young people

- An understanding and up to date knowledge of what technology and equipment exists and how to use it
- An ability to recognise and assess the strengths and needs of individual deaf children within their particular family and social environments.

This type of expert knowledge is key to ensure that all parents of deaf children are properly advised if they decide to use the self-directed support option for their child's support. As mentioned NDCS' *'Practitioners Guide: Social care for deaf children and young people'* provides detailed information about the mechanisms of providing specialist social care support for deaf children and their families.

This Guide recognises that the support needs, even of deaf children with similar levels of hearing loss, may be very different. It is essential that skilled staff are able to make these assessments. Below are some examples of factors that should be considered when assessing a deaf child:

- Whether the child requires any specialist equipment (e.g. a hearing impaired doorbell)
- Whether the family requires any support in order to communicate effectively with their deaf child. The family plays an important role in the child's development and it is essential that families are able to communicate effectively with their deaf child. An assessment should consider whether parents need any support in this respect, for example, whether they require access to sign language courses/ specialist parenting courses
- The deaf child's emotional wellbeing. As a result of being deaf in a hearing orientated society, deaf children and young people can be more vulnerable to problems with emotional wellbeing. Research suggests that deaf children are 60% more likely to experience mental health problems than other children⁷
- Whether the child is experiencing difficulties in accessing services and leisure provision
- Whether the child requires any particular support at transitional stages, as deaf children and young people can face particular challenges at these stages
- Vulnerability of the child and whether they are at risk

NDCS Scotland would also welcome further clarity on the timescales within which local authorities will be expected to implement the new system. NDCS Scotland is concerned that with service provision for deaf children and young people already being patchy, leaving timescales open to interpretation may mean that some authorities, and deaf children and young people, get left behind in the implementation of self-directed support. Similarly, NDCS Scotland would also welcome further information around how the Scottish Government will oversee the implementation of self-directed support and the sanctions that will be imposed on authorities who are deemed to be failing in their implementation of the new system.

⁷ Department of Health and National Institute of Mental Health (2005). *Towards Equity and Access*.

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.

NDCS Scotland welcomes provision in the Financial Memorandum for “workforce development” and “information and advice”. NDCS Scotland urges the Scottish Government to highlight to local authorities how investing relatively little into deaf awareness training and staff provision can make significant overall differences to their service provision and to service delivery for deaf children, young people and their families.

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.

No additional 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>

No additional 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)?

Summarising NDCS Scotland's views on this issue, we believe that all processes around calculation, payment and termination of direct payment should be done openly, transparently and by disseminating accessible information in accordance with the communication needs of deaf children, young people and their families. It is also clear that long lead times are needed to ensure children, young people and their families are supported to engage in these processes and feel they are being genuinely consulted with. This is particularly important for the 16 to 18 year old age group who, while they may wish to take on Direct Payment options, may be unprepared to manage the responsibilities that come with this.

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

NDCS Scotland does agree with the approach by the Scottish Government not to place restrictions on who may be employed by an individual as quite often family members who currently carry out this role may be the most suitable person for employment. However, NDCS Scotland is aware of issues around financial safeguarding of children and young people, and the concerns around those in receipt of Direct Payments and individual budgets who maybe be vulnerable to exploitation. NDCS Scotland would welcome further information on how the Scottish Government intends to ensure adequate safeguards are in place around this issue.

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?

No additional 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?

No additional comments

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.

No additional comments

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?

While NDCS Scotland welcomes deaf children, young people and their families having access to direct payments, we note that there are some circumstances where there should be restrictions placed on choice of support. We see this as linked to the level of risk posed to the supported person by their take up of direct payments, including concerns around the financial safeguarding of that individual. We expect that professional assessments will prioritise this consideration, particularly where a direct payment is being taken up by a 16, 17 or 18 year old.

It is essential this group has access to regular support and advocacy that the professional is confident the young person will use. In addition, oversight of the implementation of direct payments will be key, this must involve steps to financially regulate direct payments (e.g. through voucher schemes or bank account regulation) and consistent monitoring and review of how the supported person is meeting the personal outcomes intended by support planning and choice of support. In relation to deaf children and young people, it is essential that these steps are taken by professionals with a clear understanding of the needs and requirements of this group and that they have undertaken the appropriate specialist training to do so.

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?

No additional 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 additional comments

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 additional comments

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 additional comments