

Response ID ANON-4WXN-B6CU-1

Submitted to **Supporting Disabled Children, Young People and their Families**

Submitted on **2018-09-05 15:47:58**

Title

1 Do you think the using the term resource in the title 'Supporting Disabled Children, Young People and their Families resource' is appropriate?

No

Guide

If other, please state::

How could the title be improved?

How could the title be improved? :

We suggest "A guide for disabled children and young people and their families: know your rights and know how to access care and support"

Format

2 Please select your preferred format*:

Website

If other, please state::

Our Vision for the Resource

3 Do you think the vision for the resource is appropriate?

Yes

If no, how could the vision statement be improved?

If no, how could the vision statement be improved? :

Together for Short Lives' submission to this consultation is informed by the views of our members in Scotland. Our members include children's palliative care services and professionals, including those within children's hospices, other voluntary sector services and NHS acute and community teams.

We believe that the guide could be more effective at conveying the range of services which are available to families of disabled children – and the extent to which families are able to seek assessments for them and have access to them. It is likely that families would be using this resource at potentially distressing times, possibly following a diagnosis, when they would be trying to understand what services would be available to them and what they would be entitled to.

While the family stories provide useful insight to the lives of disabled children and those who care for them, it is important that they better reflect the breadth of experiences that families may have. We are concerned that some of the information contained in the stories could create unrealistic expectations for some families. A specific example of this is the high eligibility threshold for Self-Directed Support, which is not conveyed in the resource.

The Big Picture: Understanding the Wider Impacts of Disability

4 Does the resource provide enough information for disabled children and young people who also identify with other protected characteristics, such as being LGBT or from an ethnic minority?

No

How could information about the wider impacts of disability in Scotland be strengthened?

How could information about the wider impacts of disability in Scotland be strengthened? :

We believe that children and young people with other protected characteristics would benefit from much more information about their rights and about the services which are available to them to achieve the outcomes they wish to. People who are LGBTQI - or who are in an ethnic minority - are likely to face multiple barriers and need dual supports.

Rights and Information Awareness

5 Does the content provided help you make choices about ways to communicate?

Yes

Does the content help you understand more about human rights and advocacy?

No

Please suggest any other ways in which content in this section could be enhanced.

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While the section on rights and advocacy is helpful, we feel that the information on communication is incomplete. Specifically, we feel that the focus on AAC and deafness, while important, makes the scope of the section too narrow. For example, we would like the guide to include more information on rights and support for young people with learning disabilities, who are non-verbal, or who find it difficult to participate.

Accessibility of Support

6 Please indicate whether the information within the resource about each of the following topics is sufficient?

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - National Policy Context:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Getting it Right for Every Child:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Health and social care:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Self-Directed Support:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Mental Health:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Support for the whole family:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Housing Options:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Financial Support:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Early Learning and Childcare/Education system:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Access to/links with local community:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Making accessible journeys/accessible travel and holidays:

Q6 Please indicate whether the information within the framework about each of the following topics is sufficient? - Safety and Justice:

What, if any, additional information should be included that is specifically designed for children and young people?

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Many of the children and young people Together for Short Lives and our members represent have multiple complex conditions. This means that their needs and abilities vary greatly. For this reason, finding one way of communicating the information in this resource that will suit everyone is extremely challenging. We believe that the format of the guide should be simpler to most effectively convey its messages to children and young people. For example, an 'I need help with housing/benefits/etc' format would help readers relate their experiences and needs with the most crucial sections of the resource and find a simple route to receiving the support they need.

What, if any, additional information should be included to help support the families/parents/guardians/carers of disabled children and young people?

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- More information on the rights of carers and links to resources specifically on this. This could include links to information about carers' grants and those organisations which represent and advocate for carers, with additional information on advocacy for carers as well as children.

- Information on care standards, as well as a link to resources on Healthcare Improvement Scotland and care inspectorate sites, would help carers stay informed of the performance and background of services they are considering.

- Many children with life-limiting conditions rely on bulky and heavy electrical equipment to keep them alive. Carers of children with these needs therefore need information on a number of services such as specialist transport and domestic energy supplies - as well as guidance on what government assistance is available to them.

Please suggest any other ways in which the information about support available to could be improved.

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In feedback received by Together for Short Lives, members asked to see the needs of children with life-limiting conditions reflected more holistically throughout the section, rather than contained within a short sub-section. The needs of children with life-limiting conditions are varied and often complex and so pose a different set of challenges to other children. Nevertheless, there are some changes that could be made that would also be helpful to other children with disabilities

and their families and carers.

Transitions

7 Does the resource provide sufficient information about improving transitions from child to adult services (e.g. education, health and social services)?

No

Please suggest any other ways in which the information about transitions could be improved.

Please suggest any other ways in which the information about transitions could be improved. :

We are concerned that the information in the guide concentrates on policy, rather than practicalities and services. This is particularly true of information for children with life-limiting conditions. For example, there is no mention of Anticipatory Care Planning (ACP), which provides a vital toolkit for people looking to build a plan around their expected needs.

Children with life-limiting conditions face a cliff-edge in their care when moving from children's to adult services. It can be a distressing time for them and their families and risks causing avoidable harm to their health and wellbeing.

General Questions

8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics?

Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics? - The rights of disabled children, young people and their families:

Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics? - National policies relating to disabled children, young people and their families:

Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics? - The support available to disabled children, young people and their families:

Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics? - Access to support for disabled children, young people and their families:

Please suggest any other ways in which the information on rights, policies, and/or access to support could be improved.

Please suggest any other ways in which the information on rights, policies, and/or access to support could be improved. :

We believe that the guide provides some very basic background information which does not yet meet the needs of disabled children and their families. For example, there is insight into rights and government policies, but little information on how to seek assessments from public agencies - or seek redress if families feel that they are not able to access the assessments, care and support that they feel they are entitled to.

We ask that the hyperlinks signposting further information link to more specific webpages, as opposed to just homepages of websites. Currently, the hyperlinks included leave readers needing to navigate further. These families may have round the clock caring responsibilities and have little time to spare to access this resource; as such, we ask the Scottish Government to make it as simple and as quick as possible for families to access the information they need.

Overall, we feel that the resource provides adequate basic information for a professional working in children's palliative care. We suggest that the Scottish Government produces supplementary resources – perhaps online – focusing on specific regional services.

Is there any other information that the content does not cover that you think should be included?

Is there any other information that the content does not cover that you think should be included? :

We believe that information about the children's palliative care that babies, children and young people with life-limiting and life-threatening conditions should be included in the guide.

Specifically, we believe that:

- The Strategic Framework for Action on Palliative and End of Life Care should always be referred to in full (page 22).
- There is a typo in the name of 'Children's Hospices Across Scotland' on page 22 and it would be helpful to also include the often-used acronym 'CHAS'.
- Children's Hospices Across Scotland could also be hyperlinked to allow readers to find further information.
- Together for Short Lives has a wealth of information, including a service directory and helpline for families of children with life-limiting condition. These are rich resources for families looking for guidance and support and should be included in this resource.
- There is inadequate information on how families can request a health assessment. It would also be helpful to include information on rights to assessments, information on care plans and routes to redress.

More generally, we believe that the guide could better inform readers about the third sector-provided palliative care and support which is available to children with life-limiting conditions. Currently, For example, there is no information about what parents and carers can do if their child requires nursing care in school. Many children with life-limiting conditions have complex care needs; how these are facilitated in an education setting are a significant concern of their families.

Do you have any other comments?

Do you have any other comments?:

In 2015, research funded by the Scottish Government and commissioned by Children's Hospices Across Scotland (CHAS) found that there are 15,404 babies, children and young people in Scotland with palliative care needs, much higher than previously thought. This is a significant number and it's essential that resources such as this reflect the specific needs of this group and the support available to them. The study also showed that two thirds of babies, children and young people who die each year in Scotland do so without access to specialist palliative support.

This resource is an opportunity to address the challenges that babies, children and young people with life-limiting conditions face in accessing support. In its current form, it is lacking the specific information this group requires.

Respond in British Sign Language (video)

Add the link to your video on Youtube or Vimeo here:

Add the link to your video on Youtube or Vimeo here: :

About you

What is your name?

Name:

Lyndon Ashmore

What is your email address?

Email:

lyndon.ashmore@togetherforshortlives.org.uk

Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Together for Short Lives

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.: