

Consultation on the Supporting Disabled Children, Young People and their Families Resource



Scottish Government
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RESPONDENT INFORMATION FORM

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Are you responding as an individual or an organisation?

Individual

Organisation

Full name or organisation's name

Scottish Independent Advocacy Alliance

Phone number

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Address

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Postcode

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Email

enquiry@siaa.org.uk

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

- Publish response with name
 Publish response only (without name)
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Information for organisations:

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

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

No

CONSULTATION QUESTIONS

This document contains brief explanations of the content included in the Draft Framework. Please refer to the full *Consultation Document*, available for download separately, to answer in more detail.

1. Title

Q1 Do you think the using the term Resource in the title ‘*Supporting Disabled Children, Young People and their Families Resource* is appropriate?

Yes

Go to 1b

No

Go to 1a

Don't know

Q1a Please select your preferred term:

Handbook

Guide

Introduction

Other (please write):

Q1b How could the title be improved?

The title could be altered to make clear what the resource is offering and to whom it is aimed.

2. Format

The format of this resource will be primarily digital, so that it is responsive to the real world, and changes as improvements are made.

The resource will be underpinned by a commitment to communicate the content in ways that are inclusive (easy to understand) and accessible (for example in Easy Read).

It is also important for children and young people to access as much of this information as they wish, therefore a version aimed specifically at them will be considered.

Q2 Please select your preferred format*:

- Website
- PDF
- Mobile App
- Hard Copy
- Other (please write):

***excluding necessary accessible formats such as Easy Read**

In order to be accessible as possible the document should be available in a variety of formats. (BSL, Easy Read, alternative languages)

We would prefer the format to be website with an accompanying mobile app. However, there would still be a need for hard copies to be produced to ensure that families without internet access can still access the information.

We would support the idea of a version aimed specifically at children.

3. Our Vision for the Resource (page 3)

We aim to provide clear, accessible information on national policies, entitlements, rights and the different options for support available. The guides to policies will be interspersed with examples and real life case studies to showcase what best practice looks like.

Q3 Do you think the vision for the Resource is appropriate?

- Yes Go to Q4
- No Go to Q3a
- Don't know Go to Q3a

Q3a How could the vision statement be improved?

We believe the vision for the resource is largely appropriate and is aligned to third sector work to help children, young people, parents and carers be more aware and have a better understanding of their rights and how to access these. However, we wish to make some additional points.

The resource provides information on national policies, entitlements, rights and the different options of support available. However, there are various gaps between policy and practice and we would like to see the resource address what happens when policy does not happen in practice, for example, there are gaps in funding for independent advocacy for children and young people in various local authority areas across Scotland. We believe that as a result of this the resource could set false expectations for people who are entitled to certain support but in practice are unable to access it.

Additionally, in order for the vision to be met it is important that children, young people and families are aware of the resource. We would welcome a commitment to promote the resource widely and to update it frequently.

4. The Big Picture: Understanding the Wider Impacts of Disability (page 5)

This section aims to introduce people to complex issues such as multiple discrimination, poverty and adverse childhood experiences. It explores how Scotland is working to mitigate their impact in a general sense, but also recognises that these issues often disproportionately affect people with disabilities.

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?

- | | |
|------------|---|
| Yes | <input checked="" type="checkbox"/> Go to Q4a |
| No | <input type="checkbox"/> Go to Q4a |
| Don't know | <input type="checkbox"/> |

Q4a How could information about the wider impacts of disability in Scotland be strengthened?

We would agree with the Health and Social Care Alliance that an asset based approach should be taken. Existing services already working with disabled children and young people who also identify with protected characteristics, should be mapped to help extend reach, accessibility and choice.

We also believe the resource would be more locally beneficial if it was accompanied by a guide to local services, including advocacy organisations.

5. SECTION 1: Rights and Information Awareness (page 8)

This section focuses on broad topics such as Human Rights and the role of advocacy as an important mechanism for realising those rights. The section also looks at the different ways we communicate and addresses the specific information needs of disabled children, young people and their families by recognising key issues and concerns.

Q5 Does the content provided help you make choices about ways to communicate?

- | | |
|------------|---|
| Yes | <input checked="" type="checkbox"/> Go to Q5a and Q5b |
| No | <input type="checkbox"/> Go to Q5a and Q5b |
| Don't know | <input type="checkbox"/> |

Q5a Does the content help you understand more about human rights and advocacy?

- | | |
|------------|---|
| Yes | <input checked="" type="checkbox"/> Go to Q5b |
| No | <input type="checkbox"/> Go to Q5b |
| Don't know | <input type="checkbox"/> |

Q5b Please suggest any other ways in which content in this section could be enhanced.

Although we believe the information on human rights and advocacy is helpful we believe this information could be significantly improved.

We would like to see the heading on page 14 changed to 'Independent Advocacy' rather than 'Advocacy' and throughout this section we would like to see Independent Advocacy mentioned.

We also believe this is an area where policy and practice are different as the Advocacy Map highlights that there is a lack of funding for Independent Advocacy for children and young people across various local authority areas. In reality, children and young people do not have easy access to independent advocacy and in some local authority areas there is no provision at all as a result of a lack of funding.

We think it would be useful if, on this page, there was a clickable link which took users to the 'find an advocate' section of our website to help with signposting them to advocacy organisations so that people can find out what support may be available to them in their area.

This section should also expand on what a human rights based approach looks like. We think that it would be useful if instead of rights just being listed, more details were provided about how you can access each right with practical information and advice provided e.g. 'this is how you apply for X', 'contact X to find out about X' etc.

This section of the resource could also benefit from additional detail about what a Human Rights based approach involved – for example, explaining the PANEL principles.

6. SECTION 2: Accessibility of Support (page 16)

A core aim of the resource is to provide information on the support available to the families of disabled children and young people. This section is designed to be a starting point for the families of disabled children and young people to find out about the kinds of support available to them, to empower individuals and communities and to promote a fairer Scotland for all.

Q6 Please indicate whether the information within the about each of the following topics is sufficient?

| | Yes | No | Don't know |
|--|------------|-----------|-------------------|
| National Policy Context | X | | |
| Getting it Right for Every Child | X | | |
| Health and social care | X | | |
| Self-Directed Support | X | | |
| Mental Health | X | | |
| Support for the whole family | X | | |
| Housing Options | X | | |
| Financial Support | X | | |
| Early Learning and Childcare/Education system | X | | |
| Access to/links with local community | X | | |
| Making accessible journeys/accessible travel and holidays | X | | |
| Safety and Justice | X | | |

Q6a What, if any, additional information should be included that is specifically designed for children and young people?

This section could be more person-centred. Many of the case studies focus on the practitioners rather than the children and young people themselves. We would also like to see the resource available in different, age appropriate formats suitable to children of different ages.

Q6b What, if any, additional information should be included to help support the families/parents/guardians/carers of disabled children and young people?

We believe the resource should include references to carers and guardians rather than only to families. We believe this would encourage more carers and guardians to use the resource and to provide them with specific information and advice aimed at carers and guardians. This is particularly important with the Carers Act coming in this year.

Q6c Please suggest any other ways in which the information about support available to could be improved.

We believe that although the information about each of the various topics is useful. The tone and language used in this section is perhaps not that accessible to families who may have little prior policy knowledge.

Generally, answering the questions: 'How do I apply or get access to X' would be particularly useful along with FAQs in each section.

7. SECTION 3: Transitions (page 48)

Transition is the period when young people develop from children to young adults. It is not a single event, such as leaving school, but rather a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or those who care for the young person.

Q7 Does the framework provide sufficient information about improving transitions from child to adult services (e.g. education, health and social services)?

- Yes
- No Go to Q7a
- Don't know

Q7a Please suggest any other ways in which the information about transitions could be improved.

We believe that the information about transitions needs to begin at an earlier age with more information about transition from primary to secondary school. We also think it would be useful if there was a visible pathway which families and carers can see and be aware of the different options on the pathway. Transitions also need to be more centred around the children and young people – lots of decisions are made for children at school and we believe this resource could be a useful tool to help empower children and young people to make their own decisions and to feel listened to. We would like to see the resource used to help improve signposting to allow agencies to work better together for the young person.

8. GENERAL QUESTIONS

| Q8 Please indicate how you would rate the usefulness of the information within the resource about each of the following topics? | | | | | |
|--|--------------------|---------------|----------------|------------------------|--------------------------|
| | Very useful | Useful | Neutral | Not very useful | Not at all useful |
| The rights of disabled children, young people and their families | | X | | | |
| National policies relating to disabled children, young people and their families | | X | | | |
| The support available to disabled children, young people and their families | | X | | | |
| Access to support for disabled children, young people and their families | | X | | | |

Q8a Please suggest any other ways in which the information on rights, policies, and/or access to support could be improved.

We believe an important step could be to ensure professionals (e.g. teachers, doctors etc.) are informed of the information in the resource and that it is embedded in their training or CPDs.

Something else which could be useful would be to produce physical leaflets which summarise children and young peoples' rights. These could empower children and young people to know their rights and allow them to physically hand them over to professionals / services.

Q8b Is there any other information that the content does not cover that you think should be included?

Q8c Do you have any other comments?

Overall we think the resource could be more person-centred and user friendly.

We believe the case studies used should be more about the person and less about the practitioner as this would make them more relatable to children, young people and their families using the resource.

It would be beneficial if there was an accompanying pathway for people to use which outlined steps, human rights and entitlements.

We believe that this information resource should be a key aspect of training for professionals such as teachers, social workers, paediatricians etc.

Section of useful contacts

END OF CONSULTATION