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

RESPONDENT INFORMATION FORM

Please Note this form **must** be completed and returned with your response.

To find out how we handle your personal data, please see our privacy policy:
https://beta.gov.scot/privacy/

Are you responding as an individual or an organisation?

☐ Individual

☐ X Organisation

Full name or organisation's name

Rebecca Scarlett, Lead Scotland

Phone number 0131 228 9441

Address

Room B05, Edinburgh Napier University Merchiston Campus, 14 Colinton Road, Edinburgh,

Postcode: EH10 4DT

Email: rscarlett@lead.org.uk

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

☐X Publish response with name

☐ Publish response only (without name)

☐ Do not publish response

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 If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.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

☐X Yes

☐ No

Lead Scotland is a charity that enables disabled adults and carers to access inclusive learning opportunities. At a local level, we do this by providing direct support to learners through flexible person-centred learning opportunities and individualised guidance and support to help them plan their learning journeys. At a national level, we provide information and advice on the full range of post-school learning and training opportunities, as well as influencing and informing policy development.

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	❑X Go to 1a
Don't know	❑

Q1a Please select your preferred term:

Handbook	❑
Guide	❑ X
Introduction	❑
Other (please write):	

Q1b How could the title be improved?
'A Guide to getting support for Disabled Children, Young People and their Families'
'Resource' may be less familiar language for some people

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	**X**❑
PDF	❑
Mobile App	❑
Hard Copy	❑

Other (please write): It's important to make the resource available in various formats as different versions will suit different needs. An accessible website would be the most widely accessible, however you should make the information available to download for people that want or need it. The resource does not currently follow accessible information guidelines in relation to the colour of the text against the background, the non-linked contents page and unclear hyperlinks, such as 'here' and 'website', which is not suitable for people using screen readers. Ask disabled people with a range of impairments to test the guide for accessibility, and we suggest using SAIF Scotland's guides to creating accessible electronic information and Dyslexia Scotland's guide to dyslexia friendly formats.

*excluding necessary accessible formats such as Easy Read

---

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	❑X Go to Q3a
Don't know	❑ Go to Q3a

Q3a How could the vision statement be improved?
Place more emphasis on practical information and advice and signposting for further support. Families have told us that practical information with clear steps on what to *actually* do, is more valuable than rhetoric about what *should* be happening. We appreciate the resource does not aim to be an exhaustive list of impairment specific information or a directory of local services, however it should clearly guide families on where to get help and what practical steps they can take.

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 ❑ Go to Q4a
No X❑ Go to Q4a
Don't know ❑

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

If the aim of this section is to provide information to disabled children and young people who identify with other protected characteristics, then the language needs to change to be more accessible for this age group. There should be less focus on rhetoric and entitlements and more on practical advice. Further signposting to national helplines and services would be helpful. Images/case studies that children and young people identify with would also be helpful.

In terms of the wider impacts of disability in Scotland, it would be useful to signpost to disabled people's organisations providing information, advice, services and an opportunity to engage in campaigning for change.

---

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	❏ Go to Q5a and Q5b
No	❏ Go to Q5a and Q5b
Don't know	X❏

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

Yes	X❏ Go to Q5b
No	❏ Go to Q5b
Don't know	❏

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

There was reference to a forum for young disabled people, so information about how to access/join this would be useful.

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 There is sufficient information here, however it would help to explain to families and children/young people exactly what is meant by		

	policies, frameworks, approaches etc, and how they can use all these policies to realise their rights and entitlements. The language needs to be more accessible and appropriate for the audience, too much jargon is being used.		
Getting it Right for Every Child	X As above – how can families make GIRFEC meaningful to them?		
Health and social care	X As above, the language needs to be more accessible and audience appropriate		
Self-Directed Support	X As above, more accessible language. Also, a lot of families we speak to don't know how to get in touch with social workers, and are not sure whether they're eligible to ask for an assessment. Lay out clear steps, who to call, where to access these details. Also there are details about making complaints about the NHS, but it would be useful to add information about what to do if families don't agree with social work assessments as well, as this is a common complaint we hear about on the helpline.		
Mental Health		X More practical information is needed here, e.g how do families get a CAMHS referral? Information about Mindfulness and how to access this would be useful. Signposting and referencing to digital tools that support young people's mental health would be useful, for	

		example as referenced on the [Aye Mind website](#).	
Support for the whole family		X Explain what a 'Carer's Assessment is' and the link needs to be fixed to that website. Not all siblings will consider themselves or be young carers, so some signposting to Sibling support groups/info would also be helpful.	
Housing Options	X		
Financial Support	X Yes, but again the language is not accessible or audience appropriate. Families may not know how governments and parliaments work and the difference between 'reserved' and 'devolved' or even what the term 'social security' means. More practical information would be useful, i.e. what is meant by 'working age' for DLA as families may not know this, and how do families go about getting a 'Family Financial Health Check Guarantee'? It would be useful to add in a link to [Turn2Us](#) for benefits advice, local services and grant searches.		
Early Learning and Childcare/Education system	X		
Access to/links with local community	X Would be useful to add information about where families can find out about play/activities/sports in their area rather than just referencing national strategies. Signpost to Euan's Guide and Disabled Go so families can search for accessible places in their area.		

Making accessible journeys/accessible travel and holidays	X Signpost to information about the National Entitlement Card/Young Scot card and explain the Blue Badge scheme.		
Safety and Justice	X Would be useful to add some more practical information here. In terms of justice, information and links about legal aid and Govan Law Centre would be good. Lead Scotland can also provide advice about the Equality Act in post-school learning via our national disabled students' helpline.		

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

In our opinion, none of the content is currently appropriate or seems to be aimed at children and young people. The language is not accessible and the information is high level. Consider how the information could be incorporated into a different format for children and young people using digital platforms incorporating multi media. Co-produce blogs, videos, animations and images with disabled children and young people – Enquire's 'Reach' website is an excellent model.

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

Already covered in earlier section. The language and information is also potentially too high level for families, there is a lot of jargon being used. More practical information and signposting is required to balance out the references to policies, frameworks, approaches and strategies, which could potentially feel alienating to families and cause disengagement.

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

As above

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   X❑ Go to Q7a
Don't know   ❑

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

Many parents refer to the transition from school into post-school learning and services as like, 'falling off the edge of a cliff', because there is very little in the way of information, support and provision after school. It is therefore unfortunate to see that less than one page of this resource has been dedicated to Further and Higher Education. Families looking for information and advice about the transition into FE or HE and about how support and funding works should have access to more information than is provided here. FE and HE needs to be a more visible aspiration for disabled young people. Too often, we hear, through our helpline, that teachers and sometimes families do not expect young disabled people to move on to college or university. The exclusion of more information about FE and HE in this resource perpetuates these lowered expectations and aspirations for our disabled young people.

While education at school level is a legal right afforded to all children and young people in Scotland, post-school education is not. It's important to make this clear distinction in the resource as the opening sentence in the FE and HE section could be misinterpreted. We often take calls from families asking whether their child has a right to a place at college or university. These calls often come in during the transition from school to post-school settings, when suitable places or the support and funding to take up the places have not been made available. While Opportunities for All is a commitment to offer all 16-19 year olds a place in post-school activity, it is not a guarantee and does not afford a legal right.

The Scottish Government fund our Disabled Students' Helpline and our Information & Advice service which provides a suite of online guides and factsheets, all related to disability and post-school learning. We provide information and advice to families, disabled young people and disabled adults about the options for post-school learning, the funding and support system to allow access to FE and HE, and the legal rights disabled learners have. It would therefore be prudent to include information about our helpline and links to our guides within the resource in this section.

It would also be useful to include information and a link to Partnership Matters, as this sets out the roles and responsibilities each different agency should have in supporting disabled students in FE and HE.

It would also be useful to link to the Child Poverty Action Group Scotland's website where they host multiple factsheets about the interaction of benefits and student income. More than a third of our calls relate to how welfare benefits are affected by the student funding system.

It would be helpful to state that each college and university have a team of staff dedicated to supporting disabled students, and families/young people should consider making an appointment with a disability advisor as early as possible to have a needs assessment and discuss appropriate support, prior to starting their course.

The 'measures' link included in the FE and HE page does not take families to any particular initiatives or information about widening access to FE and HE for disabled people. It would be relevant to include a link to the Scottish Parliament's 2016 enquiry into 'Disabilities and Universities'.

The link included for DSA takes families to a general Gov.scot student funding page, so it would useful to include this instead as a 'Student funding' page and then include a separate link to the specific SAAS DSA page here.

We are working alongside Contact to co-produce an extensive and practical Transitions resource website with parents, a project also funded by the Scottish Government. It would therefore also be very prudent to include information about the Contact resource and a link to the website when this is available.

While FE and HE should be an option and aspiration we have for all young disabled people, it is also vital we recognise the importance of Community Learning & Development (CLD) opportunities. CLD can act as a bridge into more formal learning and can offer a greater degree of flexibility than HE and FE in some cases. It is therefore really important we let families know how their young people can access opportunities and activities that don't fall into the FE, HE or employability categories. CLD teams within local authorities could be referenced, as well as advice about how to find out about local opportunities – for example through Local Area Coordinators. [Lead Scotland offer local CLD projects](#) specifically for disabled people and carers in areas across Scotland, including a project for young disabled people in Aberdeenshire.

In the employment section it would useful to explain what an Activity Agreement is and how to access one, and signpost families and young people to their local Youth Employment Activity Plan so they can search for appropriate services. It would be good to talk about Supported Employment, Supported Businesses and Social Firms to provide further information about specific provision to support disabled people into employment. Referencing [SUSE](#) (Scottish Union for Supported Employment) and linking to their website will allow families to search for local provision. A case study and information about Project Search would also be a great addition.

Some information about the role Skills Development Scotland play, a link to My World of Work and information about Access to Work would also be helpful. It would be good to remind families here about the ILF Transition Fund again and let them know this can be used to support young disabled people into work.

Some information about rights at work, Access to Work, Disability Confident Employers and ACAS, or signposting families somewhere they can get all this information would also be helpful.

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					
National policies relating to disabled children, young people and their families					
The support available to disabled children, young people and their families					
Access to support for disabled children, young people and their families					

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

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?

As the resource makes a statement about the Social Model of disability at the start, it would be great to continue using social model language throughout the whole resource in order to advance the use and understanding of this model. This means avoiding referring to 'people with disabilities' and instead talking about 'disabled people' or 'people with impairments'.

As previously stated, the language and tone used in the resource may not speak directly to families, children and young people. It may be too high level, using jargon and, in our opinion, it does not currently offer enough practical information and advice so that families know what steps they can take. The inclusion of policies, entitlements and strategies is important, but this information could be presented in a more accessible way so that people feel empowered, informed and confident to act.

END OF CONSULTATION