

**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

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If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

The Scottish Government would like your

permission to publish your consultation

response. Please indicate your publishing

preference:

[x]  Publish response with name

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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

**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):

We suggest more empowering language is used in the title, such as ‘Know your rights: Supporting Disabled Children, Young People and their Families.’

**Q1b How could the title be improved?**

**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):

Should also be available in British Sign Language.

**\*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 ❑ Go to Q3a

Don’t know ❑ Go to Q3a

**Q3a How could the vision statement be improved?**

**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 ❑ Go to Q4a

 Don’t know ❑

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

**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 ❑

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

Yes ❑ Go to Q5b

 No ❑ Go to Q5b

 Don’t know ❑

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

**Inclusive communication:**

Referencing the BSL national plan does not provide adequate sign-posting for parents who want to explore communication options for their deaf baby. 90% of deaf babies are born to hearing parents with little or no experience of deafness. We view the family as the most important influence on deaf children and they need clear, balanced and accessible information in order to make informed choices on communication options for their child.

There are currently no standards in place in terms of early years support for deaf children and their families after a child is identified as being deaf. This lack of information about what parents should expect from early years settings and what services are available for them and their deaf child post-identification results in a lack of empowerment for parents to successfully engage with services and leaves them with little or no informed choice. Parents should be provided with information to consider:

Whether the childcare setting deaf friendly, welcoming and inclusive

If the setting be able to develop the child’s language and communication skills

If the staff will learn skills to support their child, such as deaf awareness training and sign language skills

Additionally, specialist services usually only provide support for deaf children in Local Authority and Private Childcare Partnership scheme nurseries. If a child is attending a private nursery, they may not receive specialist support, or they may only receive this at home.

We view the family as the most important influence on deaf children and they need clear, balanced and accessible information in order to make informed choices. Well-resourced, inclusive communities, effective mainstream service and supported families are critical to achieving primary prevention for deaf children. This will require investment of resources and the involvement of families in the planning and development of services as well as staff training to achieve culture change and deaf awareness.

We recommend referencing the National Deaf Children’s Society under ‘more information’ as the leading charity in childhood deafness. We are currently developing a resource for families of newly-diagnosed deaf babies and children and the professionals that support them around language and communication options. We also have a number of resources and tools for practitioners. Our Early Years project, Everyone Together, team and Child and Family Support Officers are also available to work locally to support practitioners to make their settings inclusive to deaf children. We would welcome the opportunity to share these resources and our expertise widely.

**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.

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| **Q6 Please indicate whether the information within the about each of the following topics is sufficient?** |
|  | **Yes**  | **No**  | **Don’t know**  |
| **National Policy Context** | ✓ |  |  |
| **Getting it Right for Every Child**  | ✓ |  |  |
| **Health and social care** | ✓ |  |  |
| **Self-Directed Support** |  |  |  |
| **Mental Health** |  | ✓ |  |
| **Support for the whole family** | ✓ |  |  |
| **Housing Options** |  |  |  |
| **Financial Support** |  | ✓ |  |
| **Early Learning and Childcare/Education system**  |  | ✓  |  |
| **Access to/links with local community**  |  |  |  |
| **Making accessible journeys/accessible travel and holidays** |  |  |  |
| **Safety and Justice** |  |  |  |

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

**Mental Health**

We have concerns over how well the needs of disabled children and young people are addressed within mainstream Children and Adolescent Mental Health Services.

Getting it right for every child means ensuring every child and young person has the supports they need to flourish physically and mentally. Ensuring the services that support young people are equipped to address their unique needs is critical. Many disabled children and young people are at increased risk of experiencing mental ill health, but for various reasons mainstream services may be inadequate to meet their unique needs.

Deafness itself does not cause mental health problems however the communication barriers and language delays that deaf children and young people may experience increases how likely they are to be affected by mental ill health. According to NHS statistics, 40% of deaf children and young people will experience mental ill health compared with 25% of hearing children (NHS, 2004). In addition, at the recent Deaf Learners Conference, bullying and social isolation was identified by deaf young people as one of their top challenges.

There is currently no specialist mental health service for deaf children in Scotland despite such services being well established in other parts of the UK. Access to mainstream health services has been found to be challenging for deaf children and young people and their families and the knowledge, skills and experience of staff there is unlikely to match that which a specialist service could offer.

By exploring how current Child and Adolescent Mental Health Services meet the needs of disabled children and young people, the Scottish Government can commit to building a mental health workforce with the right skills and expertise to meet every young person’s needs, including those who are disabled.

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

**Financial support**

More detail in this section is recommended. PIP is vital for families of deaf children. It can help with purchasing of equipment, communication support and transport costs to and from appointments. Cuts to benefits or tightening of eligibility criteria could leave many families unable to pay for the extra support their children need, leaving their children vulnerable to isolation, bullying, low levels of achievement and unemployment/poverty in later life. Deaf children already have significantly poorer life outcomes than their hearing peers.

The provision of accessible information and advice is critical to ensure families of disabled children and young people understand the benefits they are entitled to and the process they must follow to make the necessary applications. The complexities that can arise from the application process often means that families require support to complete these forms.

Our Child and Family Support Officers support deaf young people and their families across Scotland to complete these applications, guiding them through the process and supporting during appeals when required. Without support of this kind, many families would be unaware of funding available or would be unable to complete applications successfully.

Issues with Personal Independence Payments process include:

* From the very outset deaf young people are denied full access to the claim process because they are expected to use the telephone to request an application form.
* Completing the application form can be a confusing and daunting experience which can impact upon the chances of successfully getting the benefit.
* Whilst in the process deaf young people report that staff lack deaf awareness. In some cases communication support is not provided at assessments despite it being requested and agreed to.
* Many deaf young people are being told they are not eligible for the benefit but upon appeal, or in some cases legal action, it is deemed that the original decision to deny the benefit was incorrect.

**Education**

Around 87% of deaf learners are educated in mainstream settings, around 5% are in mainstream schools with attached Hearing Impairment resource provisions and another 7% are within special schools (CRIDE 2017). The support in each of these settings varies considerably, with the majority of deaf learners in mainstream settings relying on peripatetic Teachers of the Deaf or other specialist staff who visit mainstream schools to support their learning.

However when it comes to choosing the most appropriate provision, the reality of the situation is that not every local authority has these options and placing requests are not always successful.

In many cases, parents will consider a placing request to resource provision only once they feel that their child is not progressing, or where there is a difference of opinion from the parents and the professionals on what support and progress their child is accessing.

Support and information for parents and carers will be critical to them taking up an active and engaged role in their child’s education. In the case of parents of deaf children, they require targeted specialist support to understand how their child learns, the approaches that work best for deaf children, and the challenges and barriers that exist for their deaf child in learning environments. We would welcome the opportunity to work in partnership to achieve this.

The absence of any national standards or expectations around delivering peripatetic service can also lead to local disparity. We recommend refreshing the [Count Us In: achieving success for deaf pupils guide](http://lx.iriss.org.uk/sites/default/files/resources/asfdp.pdf) (produced in partnership between NDCS and HMIE in 2007). This could help provide a relevant, consistent, framework which would support Education Scotland to achieve the assessment of teaching standards. We recommend that this framework would also establish expectations around self-evaluation and peer review among peripatetic services to help assess teaching standards.

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

**Workforce**

Having the right workforce across education, health and social care is essential to achieving equal access to key areas of life for disabled children and young people. Ensuring the workforce has an effective set of skills, knowledge and experience and is fit for the purpose of supporting the access of disabled children and young people is vital and should be addressed within the resource.

**Anti-bullying**

Bullying is a key issue for many disabled children and young people and connects to the social stigma that continues to be attached to disability. Bullying has consistently been raised as a key issue by deaf pupils attending our Deaf Learners Conferences. Their experiences include being treated differently and being excluded to pupils being directly targeted and made fun of because of their deafness.

As one profoundly deaf young person recently told NDCS:

*“I went to a mainstream primary and secondary school, and loved it right up to fourth year. But then I was bullied and felt really excluded, and down on myself. I told my mum, and she was able to get me a place at a specialist unit for deaf children in a nearby area, and although there was more travelling, I enjoyed it better, the teachers were lovely, I made new deaf friends, and got my head down to get my highers. If I hadn’t moved school, I would have probably just left school altogether*.”

Stigma and discrimination continues to exist and impacts on disabled young people’s life outcomes. It is a fundamental barrier in promoting their equal access and should be referenced within the document with appropriate sign-posting to organisations, such as Respectme.

**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.**

Research commissioned by NDCS from the University of Edinburgh found that although deaf young people are entitled to transitional planning under the Education (Additional Support for Learning) (Scotland) Act, very few who took part in the research recorded having received this kind of planning. As such the challenge of supporting smooth transitions for disabled young people, and making rights real under article 29, is about ensuring both children’s and adult services are actively playing their role to promote positive post school outcomes.

There have also been significant shifts in the specialist workforce who play a key role in implementing Additional Support for Learning. Recently this has become an increasing priority for the Educational Institute of Scotland who have recognised the impact on teachers and schools that struggle to meet the needs of disabled learners due to a lack of appropriate skills and expertise in this area. A workforce planning exercise around ASL may be a helpful way to determine the existing roles and provision, any gaps or challenges that exist and consider how to future-proof this important workforce.

**8. GENERAL QUESTIONS**

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| **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?**

**END OF CONSULTATION**