

**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

Children’s Health Scotland

Phone number

0131 553 6553

Address

22 Laurie Street, Edinburgh EH6 7AB

EH6 7AB

Postcode

Email [enquiries@childrenshealthscotland.org](mailto:enquiries@childrenshealthscotland.org)

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If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.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

Publish response only (without 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 x❑ 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?**

Put the “vision” and intended target group on the front page as a sub-title

**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 x❑

Mobile App x❑

Hard Copy x❑

Other (please write):

Great care needs to be taken to make this as “readable” as possible, i.e. be BOBBY Approved, Plain English, AAA accessible standard

We agree that the resource needs to be flexible and an electronic version is easier to update. However, we must not forget a significant minority of people who would struggle to access the internet or use digital materials.

Contents of the resource must also be downloadable.

Please ensure that columns can easily be read by accessibility software

The Easy Read version is good, but could be improved further.

Relevant pictures and images would be good for all versions

Resource needs to be available in minority languages

**\*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?**

What is set out in the first paragraph under **Our Vision for the Resource** and quoted above is not a vison statement but rather a practical description of how you will do that and what the resource will look like from a practical point of view.

Suggested vision statement:

Our vision is a Scotland where disabled children, young people and their families have access to information which enables them to be active citizens, address barriers to participation, develop their personalities and live fulfilling lives.

After the vision statement, the intention should be made clear to publicise, promote and update the resource on a regular basis

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

This section aims to introduce people to complex issues suis 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 x❑ Go to Q4a

No ❑ Go to Q4a

Don’t know ❑

**Q4aHow could information about the wider impacts of disability in Scotland be strengthened?**

We welcome that the correlation between disability and poverty has been made. Caring for a disabled child can have significant financial implications for families.

We agree that everyone in Scotland should become “ACE aware” , but to mention disability in connection with ACEs could easily become stigmatising

Links within the text are useful but should be bulleted at the end of each section

Protected characteristics (page 5) and information about these could easily be strengthened through a cross-referenced Appendix reference section entitled Other Useful links

**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 x❑ Go to Q5a and Q5b

Don’t know ❑

Is this the right question? Most disabled children and their families do not have a choice about how they communicate. They want services toput in place the right communication support for them to access services effectively. It is up to public authorities to ensure they do not discriminate in the ways in which they provide the service. This is what children and parents need to know; this is their

* Right to be ‘listened to and taken seriously’
* ‘right to find out and share information’
* ‘a right to get information in the way I can understand’ and what to do if it is not available.

A lot of equality, diversity and rights based work and information has been provided and achieved by public authorities to ensure the rights of disabled children, young people and their families are upheld/claimed and can access services as required without discrimination. Equality Act 2010.

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

Yes ❑ Go to Q5b

No x❑ Go to Q5b

Don’t know ❑

You should add “children’s rights” every time you mention “human rights” while children’s rights are an obvious part of human rights, there are a number of important specific rights. As this resource is for children and young people, it is important to emphasise this.

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

This section should set the context for the whole document and be placed at the beginning. The resource would benefit from stating what the rights are and what a rights based approach is, and specifically set out the UNCRC in a succinct way.

If this section is about Rights, then Rights should come first and from that will flow the right to be involved in decision-making UNCRC Article 12 and the right to be informed UNCRC 17 – you have the right to have information in lots of ways so long as it is safe.

Page 8 – para 3 talks about a human rights-based approach and then from pages 8-12, there is no mention of Rights!!

Page by page comment:

Page 8, para 3-4 there appears to be no link between para 3 and 4 – it goes from talking about a rights-based approach to information about public services!

Page 8 – right hand side para 2 all of this should come after the UNCRC section and is an example of UNCRC 12 and 17.

Page 9, para 2 – we do not see how this relates to the document as a whole or para 1 specifically. If the audience is intended to be disabled children and families, then this is too specific and detailed.

Page 9 – right hand side, no mention has been made of Talking Mats or Board Maker. The reader could be referred to the Appendix of Useful Links where these should be included.

<https://www.talkingmats.com/product/talking-mats-taster/>

<https://www.google.co.uk/search?q=boardmaker+symbols&tbm=isch&tbo=u&source=univ&sa=X&ved=2ahUKEwiXgsHT0eLcAhVKAcAKHWnKAJ4QsAR6BAgGEAE&biw=1440&bih=899>

Page 10 and 11 – Two whole pages are devoted to those with visual and hearing loss or impairment which id risks excluding those who have communication difficulties resulting from other forms of disability e.g. Genetic syndromes or other cognitive impairment. It is vital that these sections and references are inclusive otherwise the risk is that the reader may think it is not for them.

Page 11, para 1 – while we understand the rationale behind the focus on the social definition of disability, we feel that medical information should also be highlighted here so that families with children who have long-term conditions, or a genetic syndrome can also access what they need. Contact have a medical directory with over a thousand conditions listed and therefore there is no need to give condition-specific information in this resource other than the overarching link to Contact who also provide a great deal of other information around all aspects of disability and welfare issues including Benefits. Again, it is important that this resource recognises the valid national one stop shops which obviates reinventing the wheel and will cut down on the amount of information and text in the resource itself.

<https://contact.org.uk/medical-information/>

Page 12 – to be consistent with the section title, these pages 12 -14 should come at the beginning of the Rights and Information section and precede section on Communications.

|  |
| --- |
| **5b continued**  It would be helpful if the UNCRC Article numbers were included where mention is made of the 4 general principles as follows:  Non-discrimination – Article 2  Best interests – Article 3  Survival and development – Article 6  Children’s views given due weight – Article12  It would also be helpful to include UNCRC 23 – disabled children’s rights and  UNCRC 31 – right to play  UNCRC 28 – right to Education  UNCRC 24 – right to access health services  UNCRC 17 – right to information  There is no mention of the Children and Young People (Scotland) Act 2014 and GIRFEC as the national model for upholding and promoting a child’s health and wellbeing along with the well-being indicators. This seems to be an omission.  We suggest linking to the Commissioner’s website and the UNCRC articles in picture format – there is a child and a young people’s version.  <https://www.cypcs.org.uk/rights/picture>  Page 13 –mention has been made of Together and the CYP Commissioner Scotland. We would recommend also including Children’s Health Scotland as the only 3rd sector organisation dedicated solely to the promotion of children and young people’s rights in health. The 10-point European Association for Children in Hospital (EACH) Charter is endorsed by the Scottish Government and used by health boards as a bench mark for children’s services.  EACH -<https://www.childrenshealthscotland.org/resource/each-charter-full/>  CHS has recently developed a digital e-Learning resource supporting practitioners in health and social care to further and pursue rights-based practice in their work.  To access the course(s) please follow  [*www.enetlearn.com/childhealthscot*](http://www.enetlearn.com/childhealthscot) |

**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?**  Consider changing the chapter heading “Accessibility of Support” to: “Support and Information” | | | |
|  | **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 separate these into ELC and Education |  |  |
| **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?**

Rights - There should be more promotion of children’s rights throughout and the CYPCS (Commissioner) Cartoons for both children and young people could be used. We anticipate that the plan will be for the resource to have illustrations, visual images and photographs to make it more children and young people-friendly with lots of interactive activities.

Some information could also be taken out. Each section talks about the Scottish Government’s intentions. This should be captured in the introduction on no more than one page and lift out the relevant documents/links and include them at the end of the page for further reading. By all means create a lead into each of the sections by stating the Scottish Government’s intention in one sentence and aligned to significant policy (children and young people’s Act (not mentioned) and GIRFEC).

Each section could have a summary page (for downloading and printing) . This page should start by saying: All children have the right to.....

and then use information that helps CYP and families to claim this right, in the knowledge that the Scottish Government’s position, policy and practice has been clearly stated at the beginning of the document

Education – Enquire has a website called REACH specially for children and young people <https://reach.scot/>

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

The resource would benefit from the comprehensive inclusion of help and information services. The document should focus on what is available to enable/support CYP and families to lead fulfilling active lives. Fulfilling their potential and what to do, who to speak to and how to get help/information/support easily to do this.

There is a great deal of detail here that families do not need to know and will be off-putting because it is too much to take in and not all necessary in this document. For example, there are 2-3 pages on the Children’s Hearings System when what families need is a few sentences explaining what it is and how to access it via a link.

Page 16 – The CYP (Scotland) Act 2014 should be mentioned here in Policy context as the vehicle for promoting CYP Rights and the UNCRC. This is followed with a whole page 17 on GIRFEC so it would make sense to set GIRFEC in its policy and legal context and mention how GIRFEC gives effect to the UNCRC rights. GIRFEC as a national approach is vital to supporting the health and wellbeing of children with disabilities.

|  |
| --- |
| **6b continued**  There is much mention of Autism throughout the document which runs counter to the assertion elsewhere that this resource will not deal with condition specific information  It would be good to include a case study that demonstrates how advocacy can be vital in supporting CYP to have their views heard and taken into consideration  Pages 18-19 – there is too much detail here and families who are interested and need to know about this can read it by going through the websites. It would be worth including a link to the EACH charter which addresses CYP’s rights in relation to their health and healthcare <https://www.each-for-sick-children.org/>  Page 20 SDS – for information on Self Directed Support please see this guide.  <https://contact.org.uk/advice-and-support/social-care/>  Page 21 - AHPs - <https://contact.org.uk/media/1158641/concerned_about_your_child.pdf>  Page 21 – it is good to see a reference to Sleep Scotland as this is often a major concern for families caring for a disabled child. We would also recommend the Contact Guide on the role of Allied Health Professionals who are often a life line for families. <https://contact.org.uk/media/1158641/concerned_about_your_child.pdf>  Page 22 – this section seems quite random with no order to what is in it and we move from SDS to Palliative Care and Allied Health Professionals to Complaints Procedures without much logic. Some of these would be better placed in the Support for the Whole Family section.  Page 22 – left hand side reference to Palliative Care – mention should be made here of the Scottish Children and Young People’s Palliative Care Network (SCYPPN) which is specifically Paediatric. There are ongoing plans for a NMCN for Palliative care to be called PELICAN – for more information please apply to Caroline Porter or Neal Healy at the SCYPPN via [Danielle.harley@chas.org.uk](mailto:Danielle.harley@chas.org.uk)  Page 22 – please add Contact’s Guide to social care services <https://contact.org.uk/advice-and-support/social-care/>  Page 23 – left hand side, para 1 – resource centre link does not work page does not exist.  Page 23 - None of these topics, which are not properly headed up, seem to relate to the Self-Directed Support section.  The section under -If I am not happy with my care - should also contain the NHS Inform link which has information for children and young people.  <https://www.nhsinform.scot/care-support-and-rights/health-rights/young-people/information-for-young-people-using-nhs-services>  as well as NHS Inform universal health rights and patients charter  <https://www.nhsinform.scot/care-support-and-rights/health-rights#feedback-and-complaints> |
| **6b continued**  Page 24 – Mental Health and Wellbeing–there is nothing specific on this page about how/where/who to get in touch if you are concerned about your child’s mental wellbeing. What does a family do who is concerned? Speak to their GP.  There should be information here about Mental Health and Emotional Well-being in schools, counselling, the Scottish Mental Health First Aid (SMHFA) programmes and organisations like SAMH.  Place to be - <https://www.place2be.org.uk/what-we-do/where-we-work/our-work-in-scotland/>  SAMH - <https://www.samh.org.uk/>  SMHFA - <http://www.smhfa.com/>  Given a possible absence of CAMHS provision for some families, we would recommend signposting to Hands on Scotland <http://www.handsonscotland.co.uk/>  Page 24 – Support for the Whole Family –there are support and guides on family life available via the Contact website on siblings, grandparents, relationships, your child’s behaviour, as well as family support groups for a range of conditions – both more common and rare.  Page 25 – the example given on this page in the box is another autism example whenit would be helpful to use another condition.  Page 25 – right hand side – we very much welcome the information relating to the CEN network and we are their 3rd sector partners and we strongly recommend including a link to **ALL** the national MCNs as disability can flow from one of a huge number of different conditions. Again, to devote nearly a whole page to one MCN when there are so many others is debatable and listing here what can be easily found by visiting their website.  However, while the 3rd and 4th paragraphs mention information and a booklet, there is no mention of the very important suite of e-Learning modules on a range of useful topics, one of which is transition.  Page 26 –under More Information, it would be helpful to include Contact’s medical directory information so that families can access information on any condition, rare or otherwise. <https://contact.org.uk/medical-information/>  Page 27 – We welcome the fact that you have included the Family Fund in this resource as a life line for families in terms of accessing resources and supports. There is also a varied case study (page 28) showing just how one child and their family have benefited from Family Fund support.  Page 29 – Housing – there is some very helpful information on this page to which could be added 2 other Scottish Government links::  SG - <https://beta.gov.scot/policies/housing-and-independent-living/>  SG – Scheme of Assistance <https://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/HSfS/SoA> |
| **6b continued**  However, it will also be important to include information on housing adaptations for families with disabled children. See this guide:<https://contact.org.uk/media/1174648/aids_adaptations_and_equipment.pdf>  Pages 30 and 31 – Financial Support  While this subject is of extreme importance in the lives of families affected by disability, this resource should not be the vehicle for carrying all the information relating to financial matters for families and should instead **signpost** to the relevant organisations.  Given the link made in The Big Picture (pages 5 and 6)between Poverty and ACEs and disability, we would suggest also including a link to the Child Poverty Action Group website where there is a specific section on Disabled Children and Young People with a very useful Benefits Checklist: <http://www.cpag.org.uk/scotland/factsheets>  in addition to Contact’s guide Money Matters and other Benefit related materials. See the following:  <https://contact.org.uk/media/1174614/money_matters.pdf>  Families should also know that they can have what is called a benefit check by calling the Contact Helpline 0808 808 3555 and asking. There are Scotland specific advisers based here whose job it is to advise families in Scotland. There are Financial Inclusion Services based at many hospitals  Page 31 – there is lot of information here on what the Scottish Government is doing but there are no obvious links on how to access any of this.  Page 33-35 Education – we suggest that 3 pages on Education is possibly too much and it would be better to signpost families to Enquire as the National Service for Additional Support for Learning.  We would also like to draw attention to 2 factsheets on the Enquire website which are very pertinent to disabled children and young people’s healthcare in education as follows:  <http://enquire.org.uk/20100622/wp-content/uploads/2016/04/when-a-child-cant-go-to-school.pdf>  <http://enquire.org.uk/3175/wp-content/uploads/2018/06/supporting-children-and-young-people-with-healthcare-needs-in-school.pdf>  Education Scotland(ES) <https://education.gov.scot/scottish-education-system/Support%20for%20all> and within the ES website Parent Zone <https://education.gov.scot/parentzone/additional-support> are 2 useful links which should be added to this section.  Page 36 – Community Life –We mentioned earlier that the UNCRC should be given greater prominence throughout the resource so that practitioners and families are encouraged to pursue and adopt a rights-based approach in all practice relating to children and young people. To this end it would be helpful to embed links to the relevant UNCRC Articles throughout the resource where appropriate for example here right hand side, paragraph 2, insert Article 31 – the right to play and recreation. This could be further enhanced by using the Commissioner’s cartoons (the Articles in pictures).  Throughout the entire resource, in addition to promoting  the Scottish Government’s projects and initiatives, it will be important to include other initiatives and projects available through 3rd sector and other voluntary organisations some of whom will be in receipt of funding from the Scottish Government.  **6b continued**  Page 40 – having facilities available throughout Scotland is of vital importance if disabled children and young people are to benefit fully from a truly accessible Scotland. We note there are now 172 on the website CPTs map and would suggest altering the resource to say; *there are now over 170 CPTs in Scotland.*  While we commend the work of PAMIS and the CPTs, these are not universally available throughout Scotland and where they are not, full information should be given in respect of other facilities for example the Radar toilet scheme. <https://nks.directenquiries.com/nks/page.aspx?pageid=10&tab=National+Key+Scheme&level=2>  There is more information here on how to participate in the scheme: <https://www.scotborders.gov.uk/info/20052/environmental_problems/585/public_toilets/3>  We welcome the inclusion of such interesting and innovative case studies on pages 41 and 42.  For a full list of all the Contact guides for families: <https://contact.org.uk/media/1203292/publications_list_july_2018.pdf>  Page 43 – we welcome the inclusion of pages detailing information on bullying and hate crimes. It is often not only the disabled young person who is a victim of bullying but also siblings and other family members who may be less obvious victims. In any section on Safety and Justice, it will be important to include organisations who support children and young people themselves for example Scottish Child Law Centre (SCLC) and CLAN Child Law.  Page 44 – What are Children’s Hearings? (page 44) apart from the fact that there is information here on SCRA which is not necessary for families at this point, there is also an inaccurate emphasis on offending; in paragraphs 2 and 3 a reference to offending comes first when it should be reversed and the phrase relating to care and protection placed first and in para 3 child safety, health and welfare should come first as the majority of referrals to the Reporter and Grounds are related to this and **not** offending. By doing this, the general public is given the wrong impression and again on page 45 right hand column, there is another reference to offending behaviour.  There is no specific explanation made in this section as to why in a resource on Disability, the Children’s Hearings System is mentioned in relation to offending when what would be more appropriate is to cite the higher number of children with disabilities in areas on the SIMD and that these disabled children may have to be “looked after” when their birth families are unable to cope and lack of parental care becomes a concern. |

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

**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 x❑

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

The layout on pages 49 and 50 are clear and a useful heading ‘more information’ used. This section would benefit from support and help information for parents and children as well as what the Government is doing. Terms such as ‘person centred’ could be explained and set in a box. This and other sections might benefit CYP and families with a “frequently asked questions” section.

A case study that demonstrates a positive intervention by advocacy services would be really helpful to reflect the growing independence and autonomy of young people

Also the following links would be very important and useful to families:

1. The NMCN CEN eLearning module on Transition available through the CEN website <https://www.cen.scot.nhs.uk/elearning-toolkit/>
2. Contact’s Transitions Project <https://contact.org.uk/scotland>
3. SIGNPOST in West Lothian have a Transitions course for parents and carers of young people about to go through Transition. Apply to SIGNPOST <http://signpost-online.co.uk/>
4. Enquire information on transition <http://enquire.org.uk/3175/wp-content/uploads/2017/11/education-and-additional-support-after-16-3.pdf>

Transition timescales - <http://enquire.org.uk/3175/wp-content/uploads/2017/11/transition-timescales-summary-of-duties-1.pdf>

**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.**

1. Rights could be much more prominent throughout the resource – particular emphasis should be given to children’s rights (UNCRC and EACH charter)– not just human rights. Rights should be named and demonstrated in all sections and a special mention should be given in regards to specific rights within the healthcare system.
2. The Children and Young People (Scotland) Act 2014 needs to be mentioned and GIRFEC as the National Practice Model. Without this, the rights-based approach is not set in context and leaves GIRFEC without an obvious policy background.
3. As mentioned before, the support shown as available is not comprehensive enough taking account of the very many 3rd sector and other options for support. All links need to be transparent and working. If a support is mentioned, it needs to be made very clear how to access it.
4. There is a lot of good information included but the document has lost its way a little. It’s very wordy, duplicates, some of the links are to English organisations so these need context, and there are better links and agencies not included..
5. The ‘voice’ and audience of the document changes, so need to check consistency, along with grammar in some places.
6. Example Structure:

Who is this guide for?

What are your rights?

Scottish Government aims, policy and practice overview (links in resource section)

Topics:

Who can help (Help, information, national organisations, links on how to find help locally, FAQ’s)

Resources (including Scottish Government info)

S.Gov contact.

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

We have added information which should be included in other sections of this document

Further additions should be:

Where to get aids and adaptations?

Housing section- Gypsy Traveller site information.

Translation and Interpretation as part of language support/communication

Legal advice as a stand-alone section

Accessible buildings (dentist used to come up a lot as not accessible for wheelchair users)

Local Authority support as well as NHS (Access panels)

**Q8c Do you have any other comments?**

**In summary and in no particular order:**

There is a great deal of theory and policy in this resource and when families lead incredibly busy lives with 24/7 caring responsibilities, they need a quick link on the topic of concern not lots of detail which can be off-putting. We understand the need to know what your rights are and the need for background information on policy, but this can be accessed by those who wish to outside the main source document.

We also understand the resource may be trying to do two things, set out the policy background and rights while at the same time provide options for support. It is important to keep the audience in mind and achieve the right balance between the two aims.

We recommend passing the finished resource to the Plain Language Commission (Clear English Standard) for scrutiny. This will assist in ensuring that it is accessible to the intended audience – disabled children, young people and families. We’d welcome age appropriate versions of the resource for children and young people.

There is too much emphasis on Scottish Government provision and projects and not enough on other sources of help.

The resource must be interactive so that families can navigate quickly and easily to sections of interest, so that if they enter key words and resource type, it will take them straight there. Consider making the resource “interactive” where users can follow a “pathway” to get to the relevant information and help they need.

While we welcome the definition on disability and the explanation for using the Social Model as outlined on page 4, we believe that there is insufficient mention made of disability relating from a health impairment, long term condition, genetic disorder/syndrome or injury and suggest that information about this should be included in the resource.

As has been suggested, there needs to be a list /appendix of useful links to non-condition-specific organisations and services cross-referenced into the text itself so that the reader can quickly access what they are looking for via a topic-based reference list. Examples would include Family Fund, Enquire, Contact, Children’s Health Scotland, and carers’ organisations or the umbrella body.

Children’s Health Scotland considers this to be an extremely valuable resource of vital importance in ensuring that disabled children,youngpeople and their familiesgrow up to be the best they can be, fully supported by all that is available in Scotland today to help them on their journey.

We look forward to beingable to promote this resource when it is completed and advocate for its promotion and dissemination all across Scotland.

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| **8c continued**  It should be couched in language that is accessible to families as being the primary audience; the resource will still be invaluable to practitioners and allow dialogue between disabled children, young people and their families, and those who work with them.  There needs to be a strong commitment to update this resource regularly and disseminate it among professionals in Health, Education and Social Care, third sector organisations, GPs and other healthcare professionals, teaching institutes (where all professionals are being trained) and, of course making it very accessible to families  The positive role of key workers needs to be highlighted more  There needs to be a section on legal advice and mediation services  All sections should have “clickable” and printable summaries as well as FAQs  Children’s Health Scotland considers this to be an extremely valuable resource of vital importance in ensuring that disabled children, young people and their families grow up to be the best they can be, fully supported by all that is available in Scotland today to help them on their journey.  We look forward to being able to promote this resource when it is completed and advocate for its promotion and dissemination all across Scotland. |

**END OF CONSULTATION**