

## **About the RCPCH**

The Royal College of Paediatrics and Child Health (RCPCH) is responsible for training and examining paediatricians. The College has over 18,000 members in the UK and internationally and sets standards for professional and postgraduate education. We work to transform child health through knowledge, research and expertise, to improve the health and wellbeing of infants, children and young people across the world.

## **RCPCH response to 'Supporting Disabled Children, Young People and their Families'**

### **Comments**

#### **RCPCH response to the Scottish Government's consultation on 'Supporting Disabled Children, Young People and their Families resource'**

#### **Title**

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

Yes

#### **Format**

**Please select your preferred format\***

\*excluding necessary accessible formats such as Easy Read

#### **Website**

### **Our Vision for the Resource**

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.

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

Yes

### **The Big Picture: Understanding the Wider Impacts of Disability**

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?**

No

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

- Although the document reasonably explains that it cannot delineate information tailored for the wide variety of individual disabilities, it then goes on to highlight those families affected by hearing impairment who employ British Sign Language. Whilst this is an important group, this tailored information would be best brought up as a case example.
- In general, a few more case studies of young people with disabilities and other protected characteristic(s) with issues they need to solve could be helpful.
- By contrast we commend the document for its primary reference to the importance of communications and how it highlights CALL based at the University of Edinburgh.

**Rights and Information Awareness**

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.

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

Don't know

- There are options but they could be extended. The [NHS Accessible Information Standard](#) goes into more detail that might be of use to check against, such as noting communication needs may require flexibility in timing of support i.e. double appointments within health services. So how to communicate plus some logistics around making it work could enhance this section.
- This question is best answered by children, young people and their families. RCPCH fully supports a focus on communication as suggested. The [2017 State of Child Health Scotland](#) recommends the "The Scottish Government should include the views of children and young people in the patient surveys of GP services and inpatient settings. The Scottish Government should also extend the surveys to cover outpatient and community settings and include the views of children and young people". RCPCH also asked, "NHS Scotland should ensure better transitions from child to adult services, involving children and young people in planning the transfer" and "Health Boards should ensure that clinical teams looking after children and young people with known medical conditions make maximum use of communication tools to support improved communication with and clarity around ongoing management."

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

Yes

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

RCPCH support the principles of taking a children's rights approach to all policy, which should ensure:

- Children's best interests are always central
- The voice of the child is at the centre
- Children's views are taken into account and given due weight

- A holistic approach which looks at the whole child and not just their status e.g. a disabled child

## Accessibility of Support

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.

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

	Yes	No	Don't know
<b>National Policy Context</b>	National Policy Context Yes <input type="radio"/>	National Policy Context No <input type="radio"/>	National Policy Context Don't know <input checked="" type="radio"/>
	<ul style="list-style-type: none"> <li>• Is the guidance for CYP? CYP are unlikely to be reading any guidance like this in a non-easy ready format Parents / support workers or extended families will. If it's aimed a professionals / parents &amp; carers then it reads well, is comprehensive in this section, with good links. However, the links that go out to scot.gov are not accessible for families short on time supporting disabled CYP. A landing page that is in the same look, feel and language tone as this resource may be needed for health, parenting and education links on page16.</li> </ul>		
<b>Mental Health</b>	Mental Health Yes <input type="radio"/>	Mental Health No <input checked="" type="radio"/>	Mental Health Don't know <input type="radio"/>
	<ul style="list-style-type: none"> <li>• We think this needs a case study and should offer more support. <a href="#">MindEd</a> from Families could be included here.</li> </ul>		
<b>Support for the whole family</b>	Support for the whole family Yes <input type="radio"/>	Support for the whole family No <input checked="" type="radio"/>	Support for the whole family Don't know <input type="radio"/>
	<ul style="list-style-type: none"> <li>• We suggest <a href="#">Contact for families with disabled children</a> could be added here.</li> </ul>		

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

- We commend the document for highlighting bullying, which is so destructive of children and young people's wellbeing, and think the document would be enhanced by information in a web link to how to stay safe on social media.
- We suggest including guidance or support links relating to sexual health and positive relationships (love and friendship advice, such as [Mencap](#)), advice and guidance on where to go for on child sexual exploitation issues /grooming of young people with disabilities such as [Underprotected, Overprotected - Child Sexual Exploitation and Young People with Learning Disabilities](#)(particularly a vulnerable group for falling into situations such as those under the PREVENT agenda focusing on radicalisation so would also suggest [NSPCC Protecting Children from Radicalisation](#) and [Prevent Duty Guidance](#)).

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

- Could the voluntary sector, including those which are disability/condition specific, be incorporated and if they are national, can they simply be given as a default when one looks at local services so that families get a comprehensive view of what is out there? When we have looked at available local services using the Royal Hospital for Sick Children's Edinburgh post code, very little came up, whereas we know there to be a lot more.
- Is there a sustainable plan in place to keep these important web links to local services current and live?
- The document appears to be primarily making reference to other government papers but no "evidence" as such, just testimonials. There are some high quality evidence based guidelines, which it might be useful to link to. There is a risk that when a document is understandably aiming to be generic in discussion of disability, it can become bland and non-specific and there is an impression that a family could be looking through the document and still be unclear about how they could take action to make things better. However it is excellent that the document is brave enough to advance the view that the disadvantages for children and young people with a disability can be considerably increased in the presence of material disadvantage and the presence of adverse childhood experiences. Also to point out that this works in the other direction, that parents contending with these disadvantages are more likely to be affected by disability in their family.

### **Transitions**

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.

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

**No**

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

It is well-reported that transition arrangements are often poor for children, with only half of all children receiving support from a lead professional to ensure a smooth transfer. [RCPCH Facing the Future: Standards for children with ongoing health needs](#), including those with a disability, recommend that service planners ensure there is a designated person within the child health service who is responsible for ensuring that developmentally appropriate transitional care is provided and coordinated by both child and adult services. This must be reflected in the person's job description as a recognised role and responsibilities should include:

- Sharing and updating transition policies
- Ensuring all professionals within the team are planning for transition with their patients
- Coordination of transition with other specialties (in child and adult services) for young people with complex and multisystem conditions
- Ensuring national guidance is followed and audited
- Holding regular meetings with adult services

More information is available in [RCPCH Facing the Future: Standards for children with ongoing health needs](#).

The children and young people's engagement team at RCPCH have been running engagement sessions across schools, youth centres and hospitals to find out what young people think and feel about transition. Clinic Chats take place in hospital waiting rooms, where patients aged 11-25 and families are asked questions about their hopes, wishes and experience of services. Roadshows or project days take place in schools, youth centres and condition specific charity events, where young people and families share their views through workshops and activities. They stated the following elements as being central to creating a good transition process:

- Having individual needs recognised, discussed and catered for in transition, with young people friendly terms
- Looking at all transition holistically, to include social, emotional, educational, geographical, employment, relationships and physical health ensuring it will follow the needs with each individual, helping us to stay within adults health services (retention)
- Important that they [adults' services] have an ability to make social connections and have a long standing relationship so we have continuity of care
- Having a multidisciplinary team is important – with the children's services worker, young adolescent worker and adult services worker all meeting regularly with the young person to prepare for transition
- Signposting knowledge for local services will help improve outcomes
- Young people with a long term conditions need support with their mental health – there is a lack of help for young adults in adult services following transition out of CAMHS but who are not "in crisis" yet for AMHS.
- We suggest including a link to the [Disability Matters employment guide](#) (I can We Can and Work and Employment sections).
- The Healthcare Quality improvement Partnership have just published [Addressing child to adult transition in national clinical audit – A guide](#), which offers guidance on child to adult transition and its relevance to national clinical audits.

## General Questions

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

**Neutral for all topics.**

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

- We appreciate that the document is designed to highlight what services are there, not to identify gaps in services, but as the overarching documents mission, is to discuss resources and rights for families affected by disability, we would recommend an opportunity for ongoing feedback after the consultation period so that the document could be updated as gaps are identified and filled.
- We felt the document was very helpful in the way that it emphasised rights and responsibilities and legislation out there for all children and young people, because of the importance of remembering that a basic threshold is that children and young people with a disability are entitled to this level and

access to these services. Because of the importance to families to getting timely help when they are worried about their child's development or whether they might be expressing a disability, I would recommend that the document highlights the innovative universal child health review approach of this government administration.

- I think the document should also be "brave" enough to talk about thresholds for services. It makes reference to professional assessments that then decide what a family might be entitled to, but we know that this can be a postcode lottery and I think the document should include ways for families to find out about their local and national thresholds and therefore be able to challenge them if they seem unhelpful.
- It is excellent that the document heavily relies on the emphasis of function as the critical outcome for a disabled child or young person when their bodily function/impairments render them unable to function due to poor environmental fit. However there is no link to what types of environmental measures are specified in the legislature so that families understand their rights if they encounter a difficulty in their everyday life and to whom should they report it.
- There is also no mention of the presumption of mainstream education and why? This could well make sense to families when they know that this is a UN stated right for children, that they can receive their education in a mainstream setting, but we know that there is a wide variability in the type of support that similar children might receive across different localities for all sorts of different reasons and this might include a view on employing specialist education staff to go into mainstream schools or not. Where in this document could a family look to see what standards there are and who they can look to, to discuss this to take things forward?

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

- The document makes reference to the excellent work "Keys to Life". However this work primarily looked at adults, because they could be identified by linkage with DWP information. There is no similar way of assessing how many children across Scotland have a disability and no clear vision as to how this could be achieved without a nationally updated Special Needs System. I think it would be helpful if the document explained to families what information is kept on children and young people and how it is shared across agencies. Families affected by disability often highlight the stress of having to repeat their story across many different settings, and I think it would be helpful for them to understand how the legislation deals with this. Here again some reference to universal child health reviews and information that is kept on children in school through the pupil census and some of the universal and targeted health service datasets could be usefully cross-referenced to for the interested family.

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

- As we referred to earlier in this document, the real challenge of a paper of this nature is keeping it up to date, especially as, not only does legislation change but services relying on voluntary sector are prone to open and close at the vagaries of funding. However it is commendable that the needs of families affected by disability have attracted the commitment of this document.
- The government should be putting its efforts into the successful implementation of existing policies including the new Carers Act and promoting services that can be accessed in local areas including the services that Carers Centres can offer to families rather than producing a glossy publication that few carers will have the time to read.
- The government should also be promoting existing online resources such as <https://contact.org.uk/scotland> and <https://www.enable.org.uk/>

**For further information about any aspect of this consultation response, please contact Professor Steve Turner, Officer for Scotland at: [s.w.turner@abdn.ac.uk](mailto:s.w.turner@abdn.ac.uk)**