Scottish Government
Riaghaltas na h-Alba
gov.scot

Supporting Disabled Children, Young People and their Families

Analysis of Consultation Responses
Summary Report
April 2019

year of young people
bliadhna na h-òigridh
2018

Analysis of Consultation Responses: Supporting Disabled Children, Young People and their Families Resource

Summary Report by Mark Diffley Consultancy and Research

April 2019

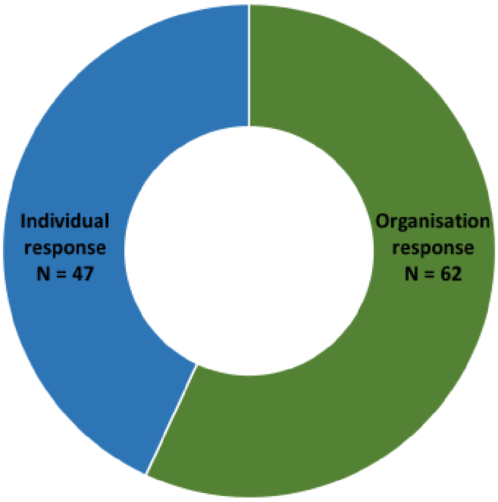
Contents

Introduction

The Children and Families Directorate at the Scottish Government has worked closely with a number of individuals and organisations including ninety policy areas within Government, disabled children and young people, their families and practitioners, and various third sector organisations, to develop a resource document to support disabled children, young people and their families. The resource is intended to coordinate and drive improvements in the experiences of disabled children and young people by providing clear, accessible information on national policies, entitlements, rights and support. The resource is centred on three key areas: rights and information; accessibility of support; and transitions to adult life. A key impetus for the resource has been evidence gathered from a survey commissioned by the Scottish Government in 2016 which explored the views of families with disabled children - the survey found that there was widespread support for a centralised resource which signposts the support available, and the policy and legislative framework underpinning support for disabled children and their families.

A consultation was issued to review the full content of the resource and ensure it meets the information needs of disabled children, young people and their families. The consultation was issued on the 5th of June 2018 and closed on the 5th of September 2018, a total of 110 responses were received. One duplicate response was received and was removed from the dataset, leaving a total of 109 responses for analysis. The profile of respondents is shown in Figure 1.1.

Figure 1.1. Profile of respondents - split between organisation and individual level responses



The remainder of this report presents a high level indicative summary of the responses to the consultation.

Views on the resource

Overall perception of the resource

Two overarching themes emerged in the research regarding the Supporting Disabled Children, Young People and their Families Resource.

First, there was discussion about the provision of local services which inhibited the efficacy of the Resource document – **there was the view that limited or underfunded services mean that the support available for disabled children, young people and their families is not being delivered**, this was particularly felt in rural areas. Considering this point it was felt that the resource document, in and of itself, could have limited impact. Related to this point was a recognition of a lack of signposting of local services to enable groups to identify and make use of the support available. To this effect, responsdents commonly mentioned that including information on local services would make the resource document far more useful for families in terms of identifying the support services that are available to them in their area.

One suggestion made in this regard, was that a website or forum along the lines of "TripAdvisor", could be established to allow people to rate the local services they use, leave feedback, and spread awareness and advice. Respondents mentioned that such a platform would help focus attention on the local services that are failing so that improvements could be made, and provide practical guidance on how to navigate local support services.

While the main finding is outwith the scope of the consultation which is focused on resource content, participants took the opportunity to share their experiences of service provision.

Second, there was a view that **the resource document was better suited to professionals rather than disabled children, young people and their families**. Respondents cited the focus on best-practice case studies over real or practical case studies as an example of this point, as well as the view that the resource document contained more jargon than children could be expected to make sense of, and a tendency towards excessive wordiness.

There was a perception, particularly among individual respondents, that the resource document felt like a policy overview for the Scottish Government rather than something created to help equip members of the public with useful information. Attention was seen to have been given to describing how things should be in theory, rather than how they were in practice. Guidance would often describe services that are in fact unavailable in many areas or are affected by long waiting lists. A very common request was for a greater emphasis on providing practical guidance that can be referenced easily by children and families when they need it.

Views on the title, format and vision of the resource

There were **mixed views on using the term "resource" in the title of the document**: a similar proportion felt that using the term "resource" in the title was appropriate as those who felt that it was not.

Table 1.1. Do you think the using the term resource in the title 'Supporting Disabled Children, Young People and their Families resource' is appropriate?

	Individual (N)	Organisation (N)	Total (N)
Yes	26	23	49
No	17	26	43
Don't know	4	6	10
Not answered	0	7	7

Among a small number of respondents there was a view that the term "resource" could be misinterpreted as offering funding or practical support, rather than just information and guidance.

Moreover, a minority of respondents indicated a preference for the term "resource" to be put at the start of the title instead of at the end.

Among those who disagreed with the use of the term "resource" in the title, there was **a preference for using the term "guide" as an alternative,** particularly among organisational respondents.

Table 1.2. Please select your preferred term for the title of the document

	Individual (N)	Organisation (N)	Total (N)
Guide	12	22	34
Handbook	1	3	4
Introduction	2	1	3
Other	4	5	9
Not answered	18	31	49

Of those who gave other suggestions for the title of the document, there was mention of "toolkit", or "hub" in place of resource.

To a lesser extent, there was discussion of specific details related to the title of the document. There was a view that the term "additional support needs" should be used in place of "disabled". Moreover, there was a view that "carers" should also be referenced alongside "disabled children, young people and their families".

There was also discussion of the use of the language "supporting" in the title, as this may imply that the document in itself is intended as the support available to disabled children, young people and their families.

> “There was broad consensus at all consultation events that the name didn’t accurately reflect what the resource sought to deliver. They felt that the term ‘supporting’ makes people think of support packages or funded services, which could be misleading. More appropriate terms were identified as: ‘national guidance’ or ‘toolbox’, ‘infokit’, ‘rights handbook’”
>
> (Organisation response from ARC Scotland - Scottish Transitions Forum)

In terms of improvements to the title of the document, there was a view that there should be greater clarity on who the document’s intended audience is, and what they are supposed to get from it. This would involve setting expectations that the document directs the reader to sources of information, rather than containing all the necessary information itself.

Reflecting this view, it was felt that the document should clarify that the scope is national policies/initiatives rather than local services that groups could directly access.

Respondents also expressed the view that Plain English, and memorability/intelligibility for disabled children should be prioritised.

In terms of the preferred format for the document, **there was a preference for it to be available on a website, with half of respondents (51%) selecting this format option**.

Table 1.3 Please select your preferred format for the document

	Individual (N)	Organisation (N)	Total (N)
Website	27	29	56
Mobile App	7	5	12
PDF	7	1	8
Hard Copy	5	2	7
Other	1	15	16
Not Answered	0	10	10

Despite the website format emerging as the preferred format, there was a recognition that this was not suitable for people who do not have internet access. Thus, there was a view that the document should be provided in multiple formats. It was felt that there should also be provision for British Sign Language, minority languages and Braille.

Reflecting on the resource in broad terms, **overall, most (67%) felt that the vision for the resource was appropriate.**

Table 1.4. Do you think the vision for the Resource is appropriate?

	Individual (N)	Organisation (N)	Total (N)
Yes	34	39	73
No	7	9	16
Don't Know	6	4	10
Not Answered	0	10	10

Among those who disagreed that the vision was appropriate, this was related to two key points:

1) The resource was seen to have limited information on local services, in particular advocacy and support services.
2) The resource was seen to be focused on government policies and positions to the detriment of providing practical guidance to children and families.

Respondents offered a range of suggestions to improve the vision for the resource, this included, committing to continuously updating and promoting the document, so that it stays relevant and useful past first publication; providing greater clarity on the document's aims, content, and target audience; making it shorter, using simpler language, and/or improving accessibility/inclusivity. It was also felt that case studies should be realistic and relatable (ideally recent real-life) examples should be used in place of best practice examples.

Views on the information and content of the resource

Views on the information and content of the resource differed by the various topics covered in the document.

Around a third (34%) felt that the resource contained enough information for disabled children and young people who also identify with other protected characteristics, a similar proportion did not know (29%), and 25% felt it did not have enough information on the topic.

Table 1.5. 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?

	Individual (N)	Organisation (N)	Total (N)
Yes	17	20	37
No	10	17	27
Don't Know	19	13	32
Not Answered	1	12	13

In terms of how information about the wider impacts of disability could be strengthened in the resource, there were a range of suggestions, some of which have been discussed in the overall perceptions section regarding local services and ensuring the resource is pitched to children and families.

Reflecting the mixed quantitative findings, there was the view that the resource document should contain more information for children and young people with other protected characteristics. There was also the suggestion that the resource should contain a function to interact with the content of the document, and provide feedback on the support that is being provided to young people and their families on the ground to enable the resource can be continuously improved.

As the document is also intended for families, it was felt that attention should be given to the impact disability has on the entire family, both in terms of emotional and social impacts.

A majority (55%) agreed that the content of the resource enabled them to make choices about the ways to communicate information about supporting disabled children, young people and their families

Table 1.6. Does the content provided help you make choices about ways to communicate?

	Individual (N)	Organisation (N)	Total (N)
Yes	32	28	60
No	11	9	20
Don't Know	4	12	16
Not Answered	0	13	13

The consultation invited views on specific aspects of the resource content, **most (70%) felt that the resource gave them more information on human rights and advocacy.**

Table 1.7. Does the content help you understand more about human rights and advocacy?

	Individual (N)	Organisation (N)	Total (N)
Yes	37	39	76
No	5	5	10
Don't Know	5	4	9
Not Answered	0	14	14

In terms of how this section could be enhanced there were a number of points raised by respondents:

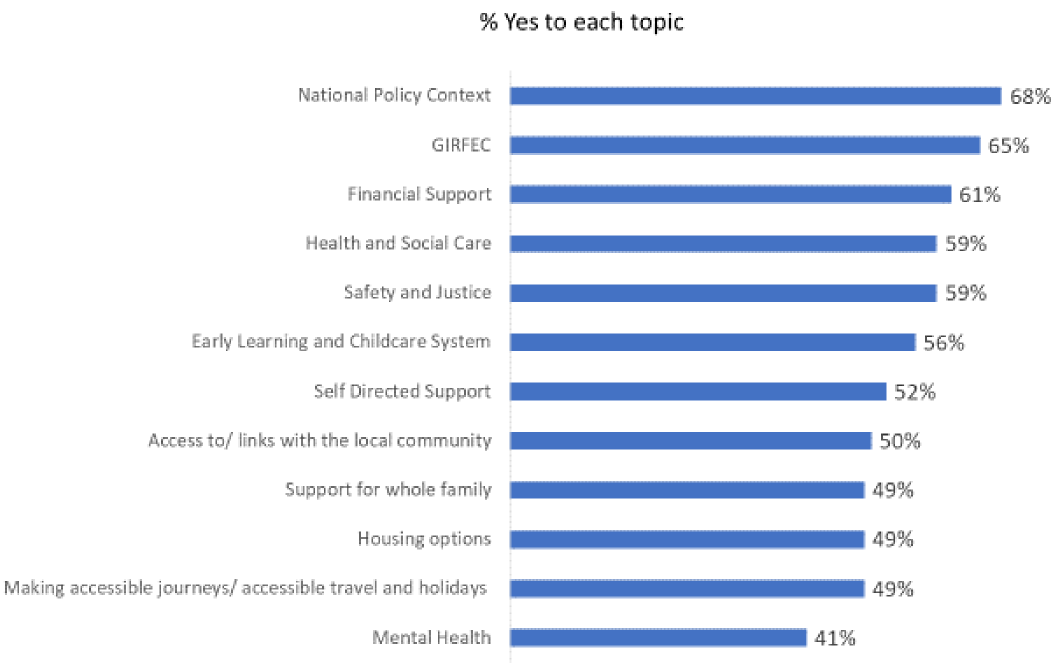
- the document could provide more information about advocacy, how it works, and where to find it at a local level
- the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) should be the central focus of this section of the resource
- information in this section could be simplified, particularly to make it accessible for those with cognitive/literacy difficulties.

Further to this, respondents were invited to consider whether there was sufficient information on a range of different topics.

Overall, **a majority felt that there was sufficient information in the resource on the national policy context and policies such as Getting it Right for Every Child (GIRFEC).**

A lower proportion (41%) felt there was sufficient information on Mental Health.

Figure 1.2. Please indicate whether the information within the framework about each of the following topics is sufficient?



In terms of additional information that could be provided specifically for children and young people, there was a **widespread view that the language and accessibility of the resource could be improved.**

> “Language would benefit from being simpler and clearer, and further use of images. A general accessible document for children and how they can exercise their rights would also be beneficial.”
>
> (Organisation response from the Health and Social Care Alliance – The Alliance)

It was felt that **information on mental health should be enhanced** particularly as the issue is seen to be worsening and there are specific concerns around bullying and exclusion among disabled children.

A lesser mentioned view was that there should be additional information on the availability of various forms of transport (bus, rail etc), and on social media use.

In terms of support for parents, and families, there was a view particularly among individual respondents that **information on financial support could be strengthened**, in particular it was felt that this section should outline the eligibility criteria for the support that is available.

> “I feel it would be really helpful to have some tables that summarised what benefits/grants are available in preschool years , school , and leaving school. It would be helpful to include whether things were freely available or means tested.”
>
> (Individual response)

It was also felt that there should be further support provision for those in a caring role, in terms of respite care, and carer’s rights to self directed support.

Views on information concerning transitions from child to adult services were mixed, 40% felt that there was sufficient information on the topic, while a third (33%) felt that it was not sufficient.

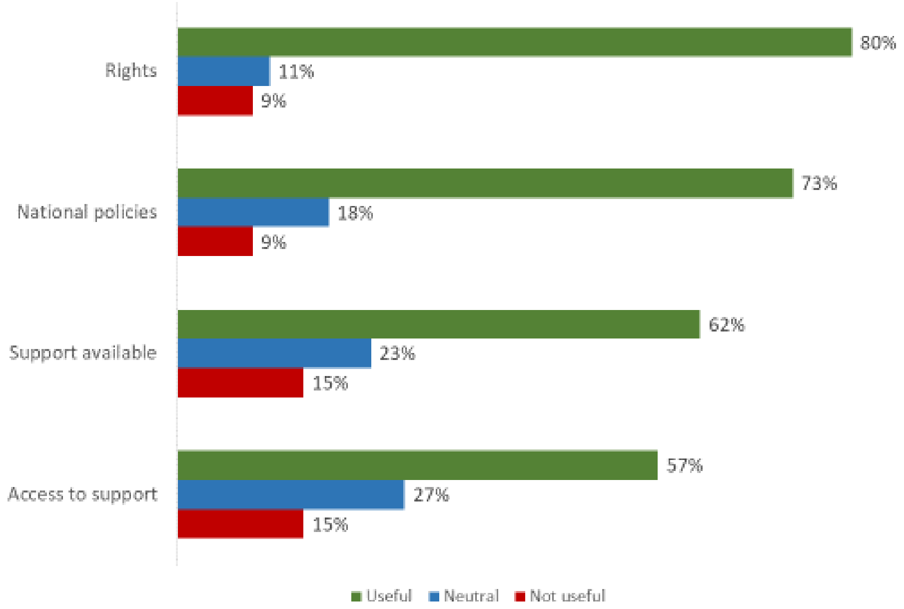
Table 1.8. Does the resource provide sufficient information about improving transitions from child to adult services (e.g. education, health and social services)?

	Individual (N)	Organisation (N)	Total (N)
Yes	18	26	44
No	17	19	36
Don't Know	8	4	12
Not Answered	4	13	17

In terms of how this section could be improved, it was felt that this could **cover earlier transitions, as early as birth, not just transitions from child to adult life**. Moreover, there was a view that there could be more information on transition pathways, and who is responsible for transitions, and the timescales around this. More specifically, it was felt that there could be more information on opportunities in adult life, covering more information about further and higher education. It was also felt that employment and volunteering should be separated into two different sections, as presenting them together may send the wrong message to children and families, it was also felt that information in this area could go deeper as this will have a tangible impact on outcomes for young people.

Reflecting the foregoing findings, respondents were more likely to think that information on rights and national policies in the resource was more useful than information on access to support.

Figure 1.3. Please indicate how you would rate the usefulness of the information within the resource about each of the following topics?



Conclusions

In summary, the resource is seen to be valuable as a central document that consolidates the range of policies covering disabled children, young people and their families – indeed, 67% think that the vision for the resource is appropriate.

However, it is felt that there are areas where the information content of the resource could be improved, this is in relation to the provision of local services, particularly in relation to advocacy and support, information on mental health for disabled children and young people, and information on the support available to families, parents and carers of disabled children.

There are also key messages in terms of the impact of the resource, as discussed in the overall perceptions section, there is a view that local services should be improved to deliver the national policies and aims detailed in the resource document. Moreover, the language of the document should be reviewed in terms of accessibility for children and families , in addition to simplifying the language it was felt that case studies should cover real-life examples rather than best practice .

Scottish Government
Riaghaltas na h-Alba
gov.scot

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew’s House
Edinburgh
EH1 3DG

ISBN: 978-1-78781-672-5

Published by The Scottish Government, April 2019

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS557370 (04/19)