



5 September 2018

## **Supporting Disabled Children, Young People and their Families**

The National Parent Forum of Scotland (NPFS) welcomes the opportunity to provide the Scottish Government with comments on this resource.

NPFS is a volunteer led organisation. We work in partnership with national and local government, and other organisations involved in education and child wellbeing issues, to ensure that parents play a full and equal role in education. When parents are involved in their children's learning, it benefits children, families and schools: children do better.

As the consultation document was very long and unwieldy, we decided to hold an online focus group for parents who have children or young people with disabilities; potential users of the finished resource. We limited the group to fourteen families and our response is based on their discussion, and on the feedback from our network of volunteers.

### **Title**

The parents who participated in our focus group thought that the term 'resource' was appropriate. However, they suggested that the title could be improved by a rewording which places emphasis on the child rather than the disability, such as: *"Supporting children and young people with disabilities, and their families."*

*(Parent, NPFS Focus Group)*

### **Format**

Overall, the consensus was that Scottish Government should not limit the resource to one format. A website, kept sufficiently up to date, was a popular suggestion. Hard copies would also be required, as not all families have internet access and many prefer to use to a tangible resource.

It was recognised that an 'app' would be popular, particularly with young people but also for many families. Participants mentioned the benefits of avoiding the need to remember a web address (once it is downloaded) and that it can be easily accessed anywhere. However, it was also noted that many parents have insufficient storage for downloading many apps.

Parents were keen to know how the resource would be promoted. A booklet or accompanying leaflet / poster would be welcomed; parents said that information given out by professionals, such as teachers or health professionals, seems to have more authority than information they come across online.

### **Vision for the resource**

Overall, the families were uncertain that the vision for the document is correct. While parents accept that condition specific information is not necessarily appropriate, all

the parents agreed that the lack of information at a local level is very problematic. Parents need to know what they are entitled to and how they can access it locally. Active support is what is required, rather than just a communication of aims.

The families would like Scottish Government to work with local authorities to signpost local services consistently. Parents explained their frustration and upset when faced with a lack of information and contacts:

*“It would be great if each local council then used the national guidelines to provide a type of resources which is specific to their council.”*

*(Parent, NPFS Focus Group)*

Parents highlighted the Information, Advice and Support Services (IASS) network in England: a statutory service that provides information, advice and support to disabled children and young people and their parents. The Council for Disabled Children’s website explains the IAS service and, most notably, provides a link for each local authority and town. This was seen as exactly what would be helpful in Scotland: for a site to provide national information and links to consistent local information.

### **Case Studies**

The parents agreed that the broad pillars of the resource seemed appropriate, but there were mixed responses to the case studies. These were seen as “unrealistic” and “cheesy”.

Best practice can be a helpful concept for professionals but it may set up “unrealistic expectations” for parents:

*“I think families will visit this site when they need something and reading about how other people are getting a great service when you are getting nothing is a bit galling.”*

*(Parent, NPFS Focus Group)*

Parents suggested that case studies would be useful to explain processes rather than convey best practice. For example, a case study might be helpful in the advocacy section:

*“It would be useful to give some suggestions/examples as to when a child or parent might need/want to use an advocate.”*

*(Parent, NPFS Focus Group)*

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

We understand that this section aims to introduce people to complex issues, such as multiple discrimination, poverty and adverse childhood experiences (ACEs), but much of the information seems aimed at professionals rather than parents. It was felt that general information on how Scotland is working to mitigate the impact, and how these issues often disproportionately affect people with disabilities, was not very useful for parents.

*“It’s just really wordy and doesn’t say a whole lot of anything. The only use I can see for this is as a resource to get quotes from when you want to put in a formal complaint.”*

*“This doesn’t seem to be useful for parents as it seems full of extracts from policies or legislation without actually being specific to the hurdles and barriers families and children with disabilities face.”*

*"It feels like a lecture, and not a resource to help parents support children to experience equality."*

*"I don't need them to tell me what it is, I want them to be clear about practice expectations around this area. I'd be hoping for examples, explaining the rights children have to 'reasonable adjustments' in order to access school activities."*

*(Parents, NPFS Focus Group)*

Parents did not feel there was enough focus on the specific supports for those who identify with more than one protected characteristic. For example, those who have English as an additional language (EAL):

*"...and if we can't read it in English imagine if you're trying to find something in a minority language..."*

*(Parent, NPFS Focus Group)*

Two specific sections drew further comment:

Parents strongly advised that Scottish Government should remember who the intended audience is for this resource. To begin the 'Child Poverty' section with 'poverty is both a cause and a consequence of disability' is an unhelpful and upsetting statement. More generally, parents felt this section:

*"...communicates that the only reason that they wish to help and support families of disabled children is because we fall into a pigeon hole within the poverty bracket. This reduces my child to a statistic and I'm sure that is not the purpose of this document - it needs to communicate support and assistance and not targets and policies."*

*(Parent, NPFS Focus Group)*

Parents were pleased to see Scottish Government giving recognition to adverse childhood experiences (ACEs) but, if this is not properly explained, it could cause worry for parents or be read as "blaming" parents. To be told their child is at risk of health and other problems if they have a high ACE score due to disability, poverty or other issues is worrying and concerning for parents

*"I think mentioning it in an offhand way is more likely to do that than either explaining it properly or just omitting it."*

*(Parent, NPFS Focus Group)*

This section needs more work. Professionals in some areas are only just receiving training on ACEs; this training needs to be fully implemented before parents are given information.

### **Rights and Information Awareness**

Parents agreed that the information reads well and is laid out clearly. However, they did not think that it is what most parents of disabled children are really looking for and felt that it was better suited to a political manifesto than a website for families.

*"I'm not sure it really TELLS parents anything though..."*

*(Parent, NPFS Focus Group)*

### **Communication**

Parents appreciated the value of this section but, as only two types of communication were looked at in any detail, felt it needed a lot of development to be useful. Parents and carers need to know "how they can be helped," as well as what their rights are for requesting help, where they should they go to request help, and the mechanisms they need to go through.

*"I think it's important that parents find something to identify with here. So something for deaf people, something for people who use AAC, something for parents of kids with LD who communicate non verbally, for parents of kids who use Makaton, for parents of kids with social communication disorders who can speak but not adequately communicate their needs and wishes."*

*(Parent, NPFS Focus Group)*

Again, parts of this section (e.g. inclusive communication) appear to be aimed at professionals. It is also important to be mindful of adult literacy levels, as not all reading ages of parents is high.

### **Advocacy**

The inclusion of this section was seen as useful, but the content requires some development to meet parents' needs. It could be strengthened greatly by covering: that parents/carers have the right to advocacy too and how they would access it; different types of advocacy; specialist advocacy.

Overall, parents felt it would be better to explain the process of how parents and young people can access the service, possibly with some suggestions/examples as to when a child or parent may need/want to use an advocate.

### **Accessibility of Support**

Parents thought it was correct that a core aim of the resource is to provide information on the support available to the families of disabled children and young people. Our focus group mainly discussed the two sections within our remit (Education and Early Years) but many of the comments are applicable in a wider sense.

### **Education**

Parents felt this section did not provide any of the information they needed, other than the signpost to the Enquire service. They think it should include a greater amount of helpful information, such as the rights of parents in choosing placements, the different types of planning processes for children with Additional Support for Learning (ASL) and the appeal process. Parents felt that if the section was to be so brief, then it should just direct straight to Enquire.

*"I don't feel this section is very helpful, as a parent who at the moment is trying to arrange the correct support in school for my daughter."*

*(Parent, NPFS Focus Group)*

*"Parents need guidance and support. They need clear information about the process of diagnosis and what this means for the future. Parents can be told their child will be meeting with a support teacher or educational psychologist to be assessed, but they don't really know what that means going forward."*

*(NPFS Rep.)*

*"Also no mention of presumption of mainstream. All it states is the law assumes mainstreaming but not in a way a parent could comprehend easily."*

*(NPFS Rep.)*

## **Early Learning and Childcare**

Feedback from parents included:

*“There is also no explanation about different providers - childminders, LA nursery, third sector nurseries. Some areas do still have specialist provision I think?”*

*“I agree this needs to say how to secure the support, what that support may be and what to do if the school are resistant.”*

*“I think this will be useful information but only if it is backed up on the ground.”*

*“I also know that locally only certain facilities are “approved” for taking ASL supported placements so you can’t choose your provision. Which is really important knowledge. Again, I know of someone going through it now who is having to CHANGE provision now the ASL is identified.”*

*“We had a home-visiting preschool teacher for about 7 months before nursery started. If this service is still available, it would be well worth mentioning. She sorted out our nursery placement and support for nursery.”*

*(Parents, NPFS Focus Group)*

## **Support plans**

Feedback from parents included:

*“More detail on support plans would be good. For example, the format for care or support plans, child plan for school and how they should be written and who should be included in writing them. I have found that even within schools in the same local authority they have their own format and it isn’t clear and not very detailed, the info the school can give.”*

*“What I have always said is that once a diagnosis is given, or even during the diagnostic process, information should be given to each family with contacts of people and organisations that we can call on for help and support. Where I come from, this doesn’t seem to exist. I have had to make dozens of phone calls to get my own help for my son.”*

*“My daughter was diagnosed and then nothing - just left to it for support for diagnosis and for support in school. At times it is very overwhelming.”*

*(Parents, NPFS Focus Group)*

## **Transitions**

Parents had mixed views on these sections. They felt this part had the most information and was broken down into relevant sections. However, as with other parts of the resource, some felt:

*“...it doesn’t contain much of practical reference.”*

*“...it doesn’t seem to give parents a clear guide on the actual process of when, how and who should be responsible for transitions. I feel parents would prefer information in a step by step approach to the process for each type of transition with relevant links to other sources or legislation.”*

*(Parents, NPFS Focus Group)*

They also felt there was key information missing, such as:

*"I also know that there are legal timescales in terms of when transitions should start for children leaving school etc but didn't find this information in here."  
(Parent, NPFS Focus Group)*

*"It lacks a clear direction and there is nothing within the document to make the transition process more transparent. Due to their complex situation, young people with severe additional complex needs find leaving school particularly difficult."  
(NPFS Rep.)*

*"It contains a lot of policy information but no clear information about how you access a transition, who is responsible, etc."*

*"More information is needed. Communication with parents is often poor during transition events and there's not enough support. You're not told anything and when you raise a concern a brick wall comes down."  
(Parents, NPFS Focus Group)*

There were positive comments on the employability sections:

*"I think the employability bit is the most useful as it actually contains links to websites where you can find out about specific schemes."*

*"The further education section is helpful for people wishing to access this area especially, as well as the employability section, it was informative and easy to understand."*

*"Transitions are really poor in our area and things like college etc are mostly not an option at all. I was interested to read colleges have a duty to disabled students because ours pretty much just says no."  
(Parents, NPFS Focus Group)*

### **Other Comments**

The inclusion of children's rights was welcomed.

Parents would appreciate the definitions section being expanded and the provision of a complete glossary of terms that parents might encounter. For example, it would be useful to have explanations of professional roles, such as the function and responsibilities of Additional Support Managers.

Lastly, the NPFS would welcome the opportunity to contribute to the work on this resource as it progresses. The parents in our focus group have also offered to consult on the final formats (e.g. a website).

Kind regards,

*Joanna Murphy.*

Joanna Murphy, Chair, National Parent Forum of Scotland