

I Want the Same As You: Developing effective independent information and support services for children and young people accessing Self-directed Support

The Social Care (Self-directed Support) Scotland Act 2013 came into force in 2014. Self-directed Support enables adults and children and young people to choose how their social care support is provided, and gives them as much control as they want of their individual budget.

A summary of key messages from consultations with parents, carers, children and young people, and Children in Scotland's final recommendations made to the Scottish Government

Introduction

Children in Scotland was funded by the Scottish Government to make recommendations for the future delivery of independent information and support on Self-directed Support. From 2013 to 2015 we consulted with children, young people, parents and families in order to shape these recommendations on what kinds of information and support needs to be available in order for young people and their families to effectively use Self-directed Support.

Children in Scotland carried out consultation sessions gathering the views of 44 young people across five different local authority areas. The young people we consulted with had a wide range of additional support needs and there was a mixture of mainstream and special school attendees.

Our Participation and Engagement Officer worked closely with school and youth group

staff to tailor each consultation specifically to the needs of the young people in the groups, in order to ensure that any barriers to participation were mitigated and that every young person was able to participate as much as they wanted to.

Children in Scotland also surveyed more than 260 parent carers and family members as part of the Parent Participation Project with for Scotland's Disabled Children (fSDC). This survey included five questions on Self-directed Support which looked at respondents' preferences for receiving information and support. We also held focus groups in nine different local authority areas, meeting more than 50 parents and family members to talk about Self-directed Support.

What we found out: key messages

We asked: "If you wanted to find out more about Self-directed Support, who would you ask?"

Parents want information from professionals
The majority of parents clearly indicated that they would prefer to get relevant, informed support and advice from any and all of the professionals who work with their children.

Parents want peer examples
Parents also want to hear directly from other parents and families who have already gone through the Self-directed Support process. They want to know what to expect to feel more prepared and to learn more about what can be done with Self-directed Support.

Young people turn to parents

Most of the young people we engaged with would turn to their parents as a first point of contact for getting advice and information on Self-directed Support.

Young people have trusted adults

In addition to their parents, young people showed a strong preference for trusted adults, professionals that are already in their lives, as providers of support and information.

Young people want peer examples

Young people told us that they want to hear from other young people who are already going through the Self-directed Support process. They felt that having real life examples of what Self-directed Support could be used for would make it easier to understand.

Lack of awareness

A key message that came out frequently through our consultations was that there is a distinct lack of awareness among both parents and young people around Self-directed Support. Parents and young people had many questions and were unsure about who could provide them with answers.

We asked: "What aspects of Self-directed Support would you want to receive information on?"

Young people want to know how Self-directed Support will help them

Young people wanted to know about money and potential budgets: how much would they be entitled to and what kind of options would be

available locally for them to spend this budget on. Young people also told us they want to know about how Self-directed Support could help them to be independent, how it could help them with post-school life and through their transition to adulthood.

Parents want locally specific information

Parents and carers want information that clearly explains the way in which Self-directed Support is being implemented in their local authority. Parents would welcome transparent information on local rules and regulations regarding assessment and eligibility criteria. Parents also told us that they want information on what services and supports would be available for their children in their local area.

We asked: “How would you like to get information on Self-directed Support?”

Young people need accessible information

Young people told us that any information and support they receive must be accessible, in terms of content and availability, and meet their communication and support needs.

Young people want to be able to access information online in a variety of formats

Young people expressed a clear preference for accessing information online, through phones, tablets and personal computers. Young people want to access information in a variety of formats, including video and audio, through social media and through general web searches.

Parents want to be able to access information online

Parents want to be able to access information on Self-directed Support online. Having information online means that parents can access it in a place and at a time that’s convenient for them.

Parents like to get information from other parents

Parents felt that other parents were often the most trustworthy source of information and wanted more ways to share experiences and connect with other parents who were going through Self-directed Support.

Parents want to get information from one central source

Parents said they want a one-stop shop that could support, advise, signpost to other agencies, and provide information, covering anything that related to the health and wellbeing of their child.

Parents want timely access to information

Parents want to be given information by the team around their child as early as possible, whether that be at the start of their child’s life or from the point of diagnosis of a condition, disability or additional support need.

Our recommendations to the Scottish Government

1. Creating a National Hub

- A National Hub should be developed as a central point where children, young people,

parents and carers, and professionals can access expert information around Self-directed Support.

- The National Hub should also be able to signpost users to contacts in local areas who can provide information and support.

2. Building on existing information and support services

- The National Hub should have a role in supporting and building on information and support services that are already available both nationally and locally.
- The National Hub should be able to provide resources and guidance around Self-directed Support to these services.

3. Developing local information and support services

- Each local area should have an information resource that builds on an existing resource e.g. Carers Centre.
- These local services should explore what works best for young people in their area in terms of online information so that they can meet their needs and preferences.
- Local Self-directed Support information, specifically designed for parents and carers, should be available online in clear and accessible formats.
- There should be a clear and simple process for children, young people and their families to

raise any concerns they might have around this information and support.

4. Producing information resources

- A publication similar to the Enquire ‘Parents’ guide to additional support for learning’ should be developed for the Self-directed Support legislation.
- Local information should also be available and should include: practical, step by step guidance; details of what Self-Directed Support can be used for; local contact information; and real experiences and examples from children, young people and families who have already accessed Self-Directed Support.
- Information for children and young people on Self-directed Support should be age appropriate and appeal to their interests and preferences. It should also recognise and mitigate any barriers to accessing information that young people may experience e.g. by using symbols commonly used in inclusive education.
- Parents and carers should have access to appropriate resources and materials that can be used to support conversations with their child about Self-directed Support.

5. Supporting professionals working with children and young people and their families

- Key professionals (e.g. teachers, youth workers, social workers) need to be suitably informed so they can discuss the basics of Self-directed Support with children, young people and their families.

- These professionals also need to be able to signpost children, young people and their families to other professionals and organisations who have more specific and detailed local information.

6. Involving children and young people

- Children and young people should be involved in the creation and ongoing development of any information and support services and resources for Self-directed Support at both national and local levels.
- This involvement should follow sound principles and practices for participation and engagement.

7. Involving parents and carers

- Parents and carers should be involved in the creation and ongoing development of any information and support services and resources for Self-directed Support at both national and local levels.
- This involvement should follow sound principles and practices for participation and engagement.

8. Learning model approach

- The provision of information and support should be informed by a learning model approach, a continuous process of review and evaluation, which builds on experience.

- Examples of best practice around the provision of information and support should be shared across local authority areas and at a national level.

9. Provision of advocacy

- There should be a national and local assessment of what advocacy provision is available for children and young people who access Self-directed Support and if it meets need.
- This could identify how access to independent advocacy and other forms of impartial support could be developed so that all eligible children and young people have access to independent advocacy.

10. Self-directed Support as an integral part of the framework for Children’s Services

- Self-directed Support for children and young people is an element of integrated and coordinated health and social care support for children and young people, directly linking to the GIRFEC framework with the key roles of Named Person and Lead Professional supporting its delivery.
- All national and local guidance must be explicit in this regard.