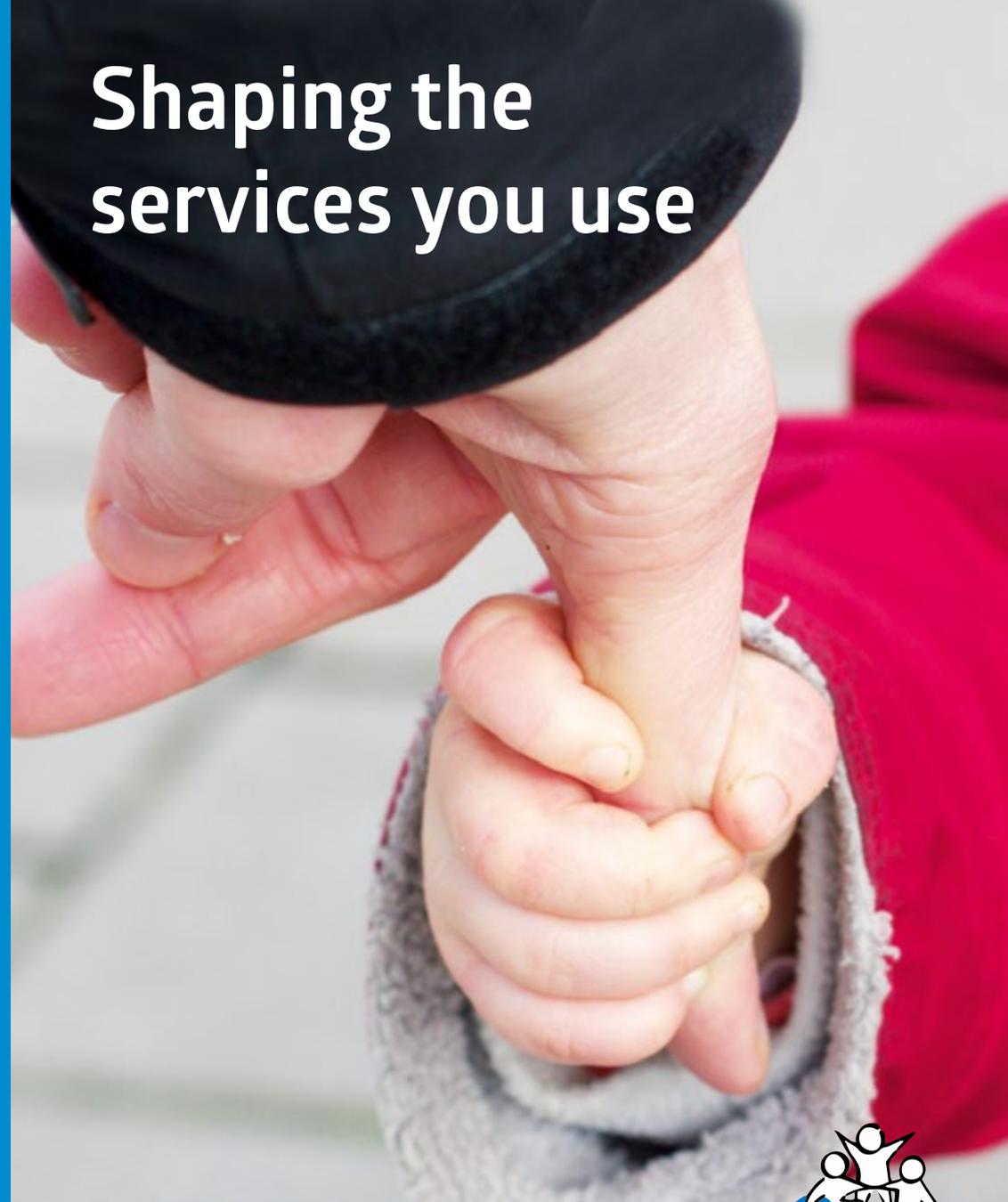


Shaping the services you use



fSDC would like to thank Action for Sick Children Scotland for their help in producing this guide.

for Scotland's Disabled Children
from good intentions to better lives

COVER IMAGE CREDIT: flickr.com/stephanski



**A guide to
parent participation**

for Scotland's Disabled Children
from good intentions to better lives

Shaping the services you use

NOTE: In this guide "parent" means parents and carers

Throughout their lives disabled children may need help from a range of services - health, education, social care or social work. As a parent you know your child best. It is important you know how you can help shape these services to meet their needs.

There are now many ways that national and local government, health boards, local authorities and other organisations try to involve service users in the planning and development of the law, guidance and services.

This booklet explains some of the ways you, as a parent, can get involved.

This is often called **Parent Participation**.

It's important services and families listen to the views of children and young people when planning support or services. There are lots of ways to do this. To find out more have a look at the Scottish Commissioner for Children and Young People's 7 Golden Rules of Participation: www.sccyp.org.uk



What is parent participation?

Parent participation is parents being involved and influencing decisions about the planning or delivery of services for their children.

Parent participation is:

Pro-active – it is about making sure services meet children's needs and can change or improve when they need to

Not about complaining about a particular service

Not just a good idea - it is often a legal requirement.



Why is parent participation important?

Parents can provide information about what their children need.

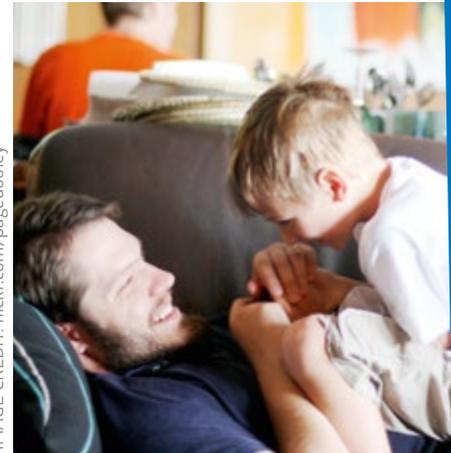
Parents know when services are not working and can make suggestions about how to improve them.

Parents are often first to notice what different services are needed.

Involving parents can:

- save time and money
- help families understand how and why decisions about services are made
- improve families' experience of using services
- build trust between parents and professionals
- ensure that the views of children are heard and listened to.

IMAGE CREDIT: flickr.com/pagedooley



Better services means better outcomes for families.

Participation ladder

There are a lot of ways services can involve you.

Step 4 Acting together

You are involved in on-going decisions about service developments.

EXAMPLE You are a parent representative on a committee reviewing the effectiveness of local children's services.

Step 3 Deciding together

You have an opportunity to take part in decision-making about service developments.

EXAMPLE You attend meetings about a new service and contribute to the design of the provision.

Step 2 Consultation

You are asked your views on service developments.

EXAMPLE You provide your views about a new service via an online survey.

Step 1 Information

You are provided with information about service developments.

EXAMPLE You sign up to a mailing list of a local service provider.



IMAGE CREDIT: flickr.com/nostri-imag



IMAGE CREDIT: NHS Health Scotland

Getting involved can be daunting!

Not all participation involves attending regular meetings. You may be able to send your views online, by post or email.

Social media (such as facebook) is also being used by organisations to collect parents' views.

There are lots of organisations that can help you. They can support you to share your views, attend a meeting or fill in a consultation form.

NOTE Look out for more details about these organisations throughout this guide.

Shaping the services you use

Legislation, policy and guidance

National consultations

The Scottish Government routinely publishes public consultations on new legislation, policy and guidance. Any interested person or organisation can respond to a public consultation.

Find out about current consultations and how to respond on the 'Getting Involved' page of the Scottish Parliament website.
www.scottish.parliament.uk/75.aspx



Local consultations

Local authorities and health boards usually offer local people the chance to comment on how legislation and policy will be implemented locally. Have a look at the "Have your say" or "Get involved" section of your local authority and health board website to find out more.

Organisations that can help

for Scotland's Disabled Children

fSDC are an alliance of disability and children's organisations who campaign to make sure that the needs of disabled children and their families are considered in new laws and local and national government activity.



To find out more about fSDC visit
www.fsd.org.uk

Shaping the services you use

Local planning

Getting it Right for Every Child

Getting it Right for Every Child (GIRFEC) is the set of principles that professionals who support children and families work to.

GIRFEC is about making sure that the needs of the child are the top priority, that the child and their family are involved in decision-making and that professionals from different organisations work together to meet children's needs. GIRFEC is important because more and more local services are now provided by partnerships of agencies.

Community Planning Partnerships

Each local area must, by law, have its own Community Planning Partnerships (CPPs) to help agencies work together to plan services and provide local people with an opportunity to be involved in the process.

Some CPPs have subgroups dealing with particular issues such as health, learning or disability services. Your local authority website will have information on CPPs and subgroups.

Shaping the services you use: Education

Parent Forums

Every parent whose child attends a local authority school is automatically a member of that school's Parent Forum.

As a member of the Parent Forum you have the right to:

- Information about your child's education
- Information about what the school is doing
- Have your views represented through the school's Parent Council

The National Parent Forum of Scotland represents all parent forums and parent councils.
www.parentforumsScotland.org



Parent Councils

The Parent Council is a group formed to represent the Parent Forum's views and work closely with the school. It normally includes parent representatives from each year group and school staff. To find out about joining or raising an issue at a parent council meeting ask your school for the name of your parent representative.

Parent Teacher Association

Some schools have a Parent Teacher Association for organising events, fundraising or dealing with one particular issue such as additional support needs. They offer a chance for parents to get involved with school life. Speak to your school to find out more.



The Scottish Parent Teacher Council provides information and advice to make parental involvement in Scottish schools as good as it can be. www.sptc.info

School inspections

Local authority schools are regularly inspected by Education Scotland. Collecting parents' views is an important part of an inspection. You may be asked to give your views when your school is being inspected.

Learning plans

If your child is disabled they may need additional support with their learning. Schools should involve you when deciding whether your child has additional support needs and planning their support.

Schools should provide you with information about your child's needs as well as ask you and take account of your views in decisions about your child's support.

Your child may have a support plan, such as an Individualised Educational Programme, Additional Support Plan or Co-ordinated Support Plan. You should be involved in creating and reviewing their plan.

Speak to your school if you have any questions about your child's additional support needs or getting more involved in planning their support.



Enquire is the Scottish advice service for additional support for learning. Call Enquire on 0845 123 2303 or visit www.enquire.org.uk for more information

How you can get involved

Attend planning meetings

Comment on your child's learning plan

Provide training to school staff about your child's disability

Give the school information about your child and their needs

Start your own parent group

Local authorities

Some local authorities have Additional Support for Learning Forums that include parent representatives. To find out if there is one in your area contact Enquire.

Most local authorities have Parental Involvement Strategies. Contact your local authority to find out more.



For more information look at the Parent as Partners toolkit on Parentzone www.educationscotland.gov.uk/parentzone

Shaping the services you use: Health

Patient Focus and Public Involvement

NHS Boards involve patients and the public in developing local health services through an approach called Patient Focus and Public Involvement (PFPI).

You can get involved by becoming a member of a Public Partnership Forum. These are networks of patients, carers or community organisations that are interested in the development and design of local health services. Anybody who lives or works in a local area can be a member.



The Scottish Health Council website has lots of information about Patient Focus and Public Involvement including a leaflet about Public Partnership Forums and contacts for local groups. www.scottishhealthcouncil.org.uk

Hospitals

If your child is in hospital regularly you can get involved in patient groups or in the case of children's hospitals the Family Council or Committee

Local health services

Individual health services may have their own way of involving their users. For example a local GP practice may ask for feedback on clinic times.

To find out about local patient involvement have a look at the 'Involving you' 'Your NHS' or 'Get involved' section of your health board website.

Child's Plans

Your child may have a Child's Plan or a Care Plan. As a parent you should be involved in creating and reviewing your child's plan. You should have an opportunity to provide information about their needs and comment on the final plan.

Organisations that can help

Action for Sick Children Scotland (ASCS) campaigns to raise awareness of the healthcare needs, rights and responsibilities of sick children, young people and their families. One of their key roles is to empower parents to influence the planning and delivery of services.

They have built up a network of parents who are interested in participating. They support families to share their views in lots of ways including:

Responding to public consultations

Taking part in surveys or research

Providing comments on publications and policies

Being part of a Scottish Government or other agency committee

Speaking at conferences or events



To find out more about ASCS work see www.ascscotland.org.uk

Shaping the services you use:

Social care and social work services

Care Inspectorate

Every social care or social work service in Scotland must be registered with the Care Inspectorate. The Care Inspectorate inspects services for quality and to make sure they meet users needs. As part of an inspection, services have to show that they listen to and involve their users.

You can get involved during an inspection by talking to inspectors when they visit and providing your experience of using the service.



Visit the 'Get involved' section of the Care Inspectorate website for more information
www.scswis.com

Children with disabilities teams

Most local authorities have a team or worker for children with disabilities. They may offer ways to share your views such as filling in a questionnaire or attending a user group.

Local authorities

Local authorities must, by law, look after the interests of children in need including disabled children. Legislation about the assessment and planning of support for children and families stresses the importance of involving and listening to parents' views.

Some local authorities have User Involvement Strategies. Visit their website to find out more.

Child's Plan

Your child may have a Child's Plan or a Care Plan and as a parent you should be involved in putting together and reviewing the plan. You should have an opportunity to provide your views about your child's needs and comment on the final copy.

Self Directed Support

Self-Directed Support (SDS) allows people who use social care services to choose how support is provided to them. It gives users and their carers control over the individual budget spent on their support.

As a parent you could be given control over the budget for your child's support.

If you want to know more ask about SDS at the next review of your child's care plan.



Visit the Self Directed Support Scotland website for more information
www.selfdirectedsupportscotland.org.uk

Shaping the services you use: Other ways to get involved

If you feel strongly about an issue related to service provision that you don't feel is being addressed through the routes mentioned in this guide there are other ways to highlight the issue:

Local campaign or petition

Parents, as part of a parent support organisation or individually, can gather the support of other parents in a local area to influence changes to local service provision. This might include writing to a local education or health committee or collecting parent signatures to request discussion about change.

Engaging with local councillors or MSPs

Parents can write to their local councillor or MSP about any issues they feel strongly about. Details of local councillors can be found on local authority websites. Contact details for MSPs can be found on the Scottish Government website.



Find out how to petition the Scottish Parliament on the 'Getting Involved' page of their website www.scottish.parliament.uk/gettinginvolved/petitions/index.aspx

Shaping the services you use: If you do participate what can you expect?

You should be:

- provided with clear and easy to understand information about what is expected of you
- be given time to prepare for meetings or consultations
- given feedback on what will happen after you have shared your views
- offered expenses to cover any costs related to your participation.

What makes parent participation work well?

- Services have a genuine interest in listening to parents' experiences
- Parents are asked what the best way to participate is
- Parents from different parts of the community are represented
- The views of mothers, fathers as well as carers are sought
- Parents who don't live with their children are given a chance to take part
- Services make it easy for parents to get involved and think about this when they are arranging times and venues of meetings
- Parents who can't attend meetings are offered alternative ways to be involved
- Parents are told what will happen next and further ways to be involved
- Parents are given feedback on what happens as a result of their involvement