

Supporting Disabled Children, Young People and their Families

Consultation Summary

Easy Read Version





What is this consultation about?

This consultation is about a public resource that should make things better for disabled children, young people, and their families in three areas:

- rights and information
- access to support
- changes in people's lives.

We have worked with disabled children and young people, their families, and professionals to design this resource. The consultation will help us make something that will be useful for people now and in the future.

What we want the resource to be

We want to give people clear, accessible information on:

- the law
- what they are entitled to
- their rights
- the different kinds of support they can get.

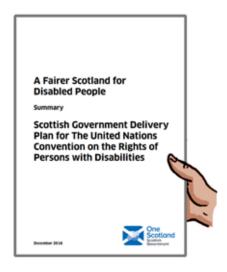


The resource will be mainly available online, so that it can be kept up to date easily. We will make the content available in ways that are easy to understand and accessible to people in any format they need, for example, in Easy Read.

It is also important for children and young people to access as much of this information as they want, so a version will be available specially for them.

After people have given us their views through the consultation the resource will be published in Winter 2018 or early 2019 as a website.

1. Background





In 2016 the Scottish Government set out a plan to make life better for disabled people in Scotland – this was called A Fairer Scotland for Disabled People.

Part of this plan was to make a special information resource for children and young people with a disability.

The resource is meant to give people all the information they need to understand the law and find all the help and support options that are available across Scotland.

It is a first step towards putting all this information in one place and making it available and accessible to all.

2. Disability and Equality



In planning the resource, we have used the Equality Act 2010's definition of disability – a physical or mental condition which has a serious and long-term impact on a person's ability to do ordinary day to day activities.

We have thought about the impact of past disability and ongoing medical conditions.

We have kept in mind that people are 'disabled' because some parts of society, like public transport, schools or services make it difficult for them to take part fully.



The Scottish Government has a duty to make equality a part of everything it does. We take into account things like age, disability, gender reassignment, marriage or civil partnership, being a Gypsy-Traveller, pregnancy or maternity, race, sex, sexual orientation, religion and belief.

We need to learn more about how these things affect children and young people with disability, and keep this in mind when we make decisions. Different kinds of discrimination are part of many disabled people's lives.

What do I do if I am feeling discriminated against?

Disabled children, young people and their families should never experience discrimination. This is true when they use public services like claiming benefits or taking the bus, community life like visits to the shops or leisure activities, in school and at work.

In Scotland, there is an independent Equality and Advisory Support Service who give advice on any type of discrimination. More information can be found in the SAFETY AND JUSTICE chapter.

Tackling child poverty is very important to the Scottish Government. Aiming resources at children living in poverty should also help children and young people with disabilities.

To help tackle the link between disability and poverty, the resource aims to make families more aware of the support they can get to lower the cost of caring for a disabled child. It is hoped this will help families to move out of poverty.

Another important aspect of disability refers to Adverse Childhood Experiences (ACEs). This means that stressful traumatic events in childhood can have an effect on normal brain development. This can cause problems with learning, behaviour and health later in life.



The latest Programme for Government also aims to make an action plan to stop or deal with ACEs across Scotland.

We need to hear more about the experiences of people living with disability who face more barriers because of poverty or bad childhood experiences.



With this consultation we want to get views and feedback from people affected so we can make a resource that gives them the support they need.

3. Rights and information

The Scottish Government wants to make sure that disabled children, young people and their families understand their rights and feel empowered to claim them, or to speak out if they feel those rights are being taken away from them.

The Scottish Government asked families of disabled children and young people about their information needs.



They told us they wanted clear, reliable, and accessible information, and families wanted a central resource that pointed them to the information and organisations they needed.

This consultation will help us to set up that resource.

Inclusive Communication

We need to let all young people communicate in whatever way they wish, with the same rights and opportunities as everyone else.



Inclusive communication means sharing information in a way that everybody can understand. It means everyone should get information and be able to express themselves in ways that meet their needs.

Service providers need to be aware that people understand and express themselves in many different ways.

What are some ways my child can communicate?



Augmentative and Alternative Communication (AAC) is a kind of inclusive communication that can help people when they have lost their voice or find speaking difficult.

There are a number of ways people can communicate without speaking, some involve technology but others do not. It may be helpful to see a Speech and Language Therapist. You can find out more about them from your local healthboard.

More information?

The website Now Hear Me helps people understand the many ways disabled children and young people might communicate.

Communication Matters are the UK-wide charity for AAC and have a number of helpful resources on their website.

Rights Awareness



Everyone has basic rights and freedoms so they can live with dignity, equality and fairness, and be all they can be, no matter who they are or where they come from.

This is true for children and young people as well as adults.

The Scottish Government has produced a Quick Reference Guide on Children's Rights and how the law protects them.

More information?

The website for the Children and Young People's Commissioner Scotland has lots of information for children and young people, their families and adults working with them on children's rights and where to get support. Learn more about the rights of children in the section on SAFETY AND JUSTICE.

Advocacy



To help make life better for children and young people, we need to listen properly to their views.

Advocacy is an important part of supporting a child. It helps them to say what they want and take part in important decisions about their lives.

Advocates do not make decisions for children, they support them to make their own choices.

The Scottish Government has published a guide to children's advocacy which can be used by family members and friends, as well as professionals and support agencies.

More information?

The Scottish Independent Advocacy Alliance (SIAA) is funded by Scottish Government. It aims to make sure that Independent Advocacy is available to any vulnerable person in Scotland.

4. Accessibility of support

The plan is not to include a list of every type of support available across Scotland in the resource. Instead, we think it will be more useful to give families the information they need to understand what they are entitled to and how to get the right support if they need it.

There are some kinds of support that all families are entitled to, whether the children and young people have disabilities or not.

Getting it Right for Every Child



Getting It Right For Every Child supports the wellbeing of our children and young people and their families or carers by offering the right help at the right time from the right people.

Most children and young people get all the help and support they need from their family and community, but sometimes they may need a bit of extra help.

A key aspect of the Getting it right for every child approach is to ensure that children and families can easily access information, advice and support. Many families say that when they need help they don't know who to go to.

Getting it right for every child ensures that there is someone who is responsible for helping families get the support they need if and when they need it.

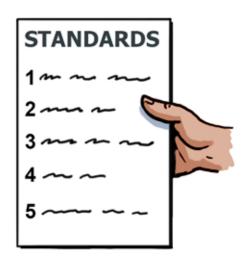
More information?

The Scottish Government website has a wide range of information about children and young people.

Health and Social Care Support

Health and Social Care Standards set out the sort of care people should get from health and social services. This is based on **five principles** – dignity and respect, compassion, inclusion, responsive care and support, and wellbeing.

Everyone who gets care from health and social services should be able to say these **five things**:



- I get good care and support that is right for me.
- I am involved in all decisions about my care and support.
- I trust the people who support and care for me.
- I trust the organisation I get care and support from.
- If I go to a service in a building, it is high quality.

It is up to the NHS and each Local Authority to make sure their Health and Social Care Support meets these standards.

What about my health and wellbeing?

The Digital Health and Care Strategy, (April 2018) aims to use digital technology to make health and social care services better. We want to give disabled people and their families better access to digital and online information. This will support people who want more control and choice over their health and wellbeing.

This will be helpful for people who may have difficulties accessing health services in other ways.

More Information?

The Health and Social Care ALLIANCE have more information about digital health on their website.

I want to understand more about my health:



In 2014, the Scottish Government published its first action plan, called Making it Easy to help more people understand information and issues about health. They also published an updated plan called Making it Easier, a health literacy action plan for Scotland for 2017-2025. It sets out the goal for Scotland to be a society where people have the confidence, knowledge, understanding and skills to stay in good health.

Self Directed Support

Self Directed Support is a way to give families more choice and control over any care they get from local social services.

There are four options for self-directed care. These include direct payment to pay for care yourself, payment to a provider of your choice (and you can direct how it is spent), the council can arrange a service for you, or you can choose a mix of all of these.

The Self Directed Support Directory, Search for Support, provides advice by local authority area.

Allied Health Professionals



Allied Health Professionals (AHPs) are professionals who work in different areas, including physiotherapy and occupational therapy, speech and language therapy, dietetics, podiatry, orthotics and prosthetics.



Ready to Act is a plan to help children, young people and their families have full involvement when making decisions about support from AHPs.

More Information?

The NHS Inform website and helpline has information on health, treatments, patient rights and long-term conditions. ALISS: (A Local Information System for Scotland) is also a useful directory.



The Scottish Government has a document called the Strategic Framework for Action on Palliative and End of Life Care. It aims to give better support to everyone in need of end of life care in Scotland by 2021. This includes a commitment to give better end of life care for people aged 0-25.

Social Services and Local Community Support



Local councils have a duty to look at a child or family's community care needs and then decide whether to arrange any services, taking the child and family's wishes into account.

Social work professionals will ask what is important to your child and family so that you can agree on what is best.

What if I'm not happy with the care I've been given?

If you need to make a complaint about an NHS service, there is a complaints procedure that you can follow.

Mental Health and Wellbeing

The principles in Getting it Right for Every Child (GIRFEC) make sure that the mental health and wellbeing of all children and young people are just as important as their physical health. The Mental Health Strategy backs this up.

Child and Adolescent Mental Health Service (CAMHS) teams assess and treat children and young people who have mental health, emotional or behavioural difficulties, including those with disabilities.

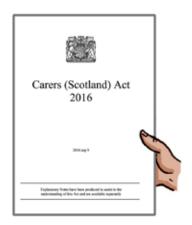


Breathing Space is a national mental health support and information service and helpline for Scotland.

Support is available for children and young people who have had someone they care about die. This is called bereavement support and it is available from a number of resources.

Support for the Whole Family

There are a number of resources available to families caring for a disabled child. This includes Care Information Scotland, which gives support from an early stage to help families cope with being carers. More practical and emotional support for carers can also be accessed through a carer's assessment, or from carers' centres.



Carer's rights and need for support are covered by the law. The Carers (Scotland) Act 2016 says that local authorities have to give carers information and advice and a support plan to suit their needs.

Young carers get special support and need a "young carer statement". Young Scot has a range of resources for young carers.

Carers who need to work flexibly are also supported by the Scottish Government's Family Friendly Working Scotland (FFWS) initiative, which includes Working Families, Fathers Network Scotland, and Parenting Across Scotland. This aims to give carers flexible options for long-term work.



Parents with learning difficulties are also supported by pregnancy and parenting resources – My Pregnancy My Choice, You and Your Baby, and You and Your Little Child.

More Information?

Scottish Autism give online support to families of individuals on the autism spectrum as well as an advice line and family support services.

The Family Fund is a UK based charity, supported by the Scottish Government which gives financial grants to families caring for disabled children and young people. The Family Fund's website has a section which points to other useful resources.

The Scottish Government are committed to providing short breaks to support carers and young carers through schemes including The Short Breaks Fund and Take a Break, supported by The Short Breaks Learning Exchange.

What support is available for parents of children with complex and exceptional healthcare needs?

The National Managed Clinical Network for Children with Exceptional Health Needs (CEN) has details about all the individuals and services who provide specialist care for children and young people with rare and/ or complex health needs. CEN points families to the best care. More information and a booklet is available through the CEN website.

Housing



We want disabled people in Scotland to live life to the full in homes built or adapted to enable them to be full and equal citizens. A Fairer Scotland; Our Disability Action Plan set out a number of plans for housing that will help this to happen.

What are we doing to provide more housing?

We are spending over £3 billion to make at least 50,000 affordable homes available by 2021. Most of these homes will be available through housing associations and councils and will meet people's varying needs.

The Scottish Government also has a number of schemes to help you buy a home if you can't afford the full cost. The Open Market Shared Equity scheme and the New Supply Shared Equity scheme can help people with a disability (including families with disabled children).

How are we helping disabled children, young people and their families to live safely and comfortably at home?



People with a disability should be able to have changes made to their homes if they need them. These changes are called adaptations.

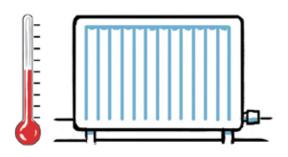
Home owners or private tenants who need an adaptation, should contact their local social work department. People who live in council or housing association housing should contact their landlord.

Care and Repair give independent advice and assistance to help homeowners repair, improve or adapt their homes so that they can live in comfort and safety in their own community.

Where can I go for advice or help?

The Scottish Government funds an organisation called Housing Options Scotland; they give personalised, person-centred advice and support to people with disabilities and their families.

I need help heating my home



The Scottish Government has a number of schemes to help households who may need help heating their home. To apply for any of these schemes contact Home Energy Scotland on 0808 808 2282 for free, impartial advice. Applicants can request a call back by completing the form on the Home Energy Scotland website.

More Information?

For independent information on your housing rights in Scotland, visit Shelter Scotland's website.



Financial Support

The new Social Security (Scotland) Bill 2017, means that Scotland is now in charge of some types of social security support and benefits including Disability Living Allowance (DLA), Personal Independence Payments (PIP), Attendance Allowance, Severe Disablement Allowance and Industrial Injuries Disablement Benefit.



Disability Living Allowance for children is a benefit for children under 16 years of age who have mobility impairment and/or need extra care and attention. It can also lead to other types of support such as Motabilty, Blue Badge, Housing Benefits, Carer's Allowance, Child Tax and Universal Credits.

PIP is like DLA and is for people of working age who need help with the extra costs caused by long-term ill health or disability.

Families, particularly those on low or single incomes, may be able to get national benefits and tax credits. They may also be able to get help with council tax, housing, and health costs from their local authority.

Local Council Benefits Offices and Citizens Advice Scotland both offer information about benefits.

What support is available for Carers?

Carer's Allowance gives financial support to someone caring for another person for at least 35 hours per week. The Scottish Government will raise the allowance rate to the same level as Jobseekers allowance from summer 2018.

From autumn 2019, young adults with serious caring responsibilities who don't get carer's allowance will be able to get a payment of £300 each year.

What support is available in a child's early years?

Other kinds of support include the Best Start Grant (due to launch in summer 2019), which gives support during the early stages of development, and a trial Childcare Deposit Guarantee Scheme to help parents and carers with childcare costs.

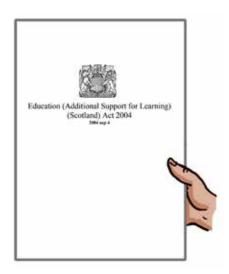


I need help with finances

The Family Financial Health Check Guarantee will be introduced by the Scottish Government in 2018, giving information about which benefits people can get as well as help with managing money. The Family Fund can also give grants for buying a wide range of items.

Early Learning and Childcare

Free early learning and childcare is available to some families from as early as two years of age. You can find out how to claim online. The amount of childcare people can recieve is being expanded. This must meet the needs of all children, including children who are disabled and/or have additional support needs.



The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) says that children's additional support needs should be identified so that schools can begin planning support for them before the child starts Primary school.

In some cases the family health visitor will tell the local authority about any additional needs. Additional support may also come from occupational or physiotherapy or speech and language specialists. The Scottish Government will also create a new £2 million Inclusion Fund which will give one-off funding for specialist training or equipment to staff who support disabled children and those with additional support needs.

More information?

The Scottish Family Information Service provides free, impartial information on early learning and childcare for all families.

Education

The Curriculum for Excellence aims to help all young people in Scotland reach their full potential and become "successful learners, confident individuals, responsible citizens and effective contributors".



How are we supporting learning for all?

The Equality Act 2010 says that schools have to tackle disability discrimination, and the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) says that education authorities have to meet the additional support needs of pupils including those with disability.

Schools have to make reasonable adjustments for disabled pupils and make help and services available, like support staff and communication tools. They also have to make and publish accessibility plans.

Mainstream education is usually given in local primary or secondary schools. The law says that young people should be educated in these schools unless this would not suit the child's ability, hold back the learning of other pupils, or cost too much money.

Special Schools are for pupils with additional support needs. Individual pupils might get their education in a mix of mainstream and special schools.



For parents who are unhappy with their child's school placement, information about education rights and responsibilities is available on the Enquire website, including a Parent's Guide and Factsheet.

The Additional Support for Learning legislation expects specific provision to be in place to support young people when leaving high school. More information is available in the transitions section of this resource.

There is a new children's service called: 'My Rights My Say', which will help children get advice and support at every stage of the education process.

It is made up of four parts:

- advice and information
- an advocacy service to support children to use their rights
- a service that can listen to children's views and make sure they are heard
- legal help for children who are appealing to the Additional Support Needs Tribunal.

Further information can be found here for parents and carers or here for children and young people.



Community Life

The UN Convention on the Rights of the Child says that every child has the right to relax, play and take part in cultural and artistic activities. These experiences are important for developing social and emotional skills in later life. We know that many of our disabled children and young people have problems accessing these activities.

The National Play Strategy says that play helps people to be confident, to learn, and to develop social skills. To make play more accessible for children and young people with a disability, the Scottish Government has carried out a Review of Inclusive Play in Scotland.

More Information?

The Bookbug programme has some helpful resources about play and reading for children with additional support needs.

How are we helping communities?

CashBack for Communities is a Scottish scheme that takes money recovered from crime and spends it on free activities and programmes across Scotland. The main aim is to help young people and those from disadvantaged communities. These are the communities most likely to be hardest hit by crime and anti-social behaviour.



How are we making Sport more inclusive?

The Fairer Scotland Disability Action Plan and the Curriculum for Excellence say it is important to remove barriers for disabled children and young people who want to take part in sports activities.

Scottish Disability Sport has a UK Disability Inclusion Training Course that supports coaches, teachers and leisure service providers to include people with disability in physical activity and sport. They also have a useful website that gives information about a wide range of sports clubs and facilities.



What about Theatre and the Arts?

Time to Shine is Scotland's arts strategy for children and young people aged 0-25. Its aim is to make young people's lives better through arts and creativity.



Inclusive Places

The national tourism organisation VisitScotland is working to make sure that visitor and tourism facilities are more inclusive, and has set up a new tool for businesses, to help them provide clear information on how their venue and services can be accessed.

The Scottish Government have also committed to make physical and online access better for Scotland's historic places by 2019.

Disabled children and young people often have difficulties in accessing the transport network. We are working to improve this: Scotland's first Accessible Travel Framework was introduced in 2016.



Why do we need Changing Places Toilets?

Without fully accessible toilet facilities many disabled children and young people can be excluded from everyday activities.

Ordinary "accessible toilets" in places like shopping centres and train or bus stations do not always have the space or equipment needed by people with more complex disabilities. Changing Places Toilets (CPTs) can help to fix this problem. Thanks to the work of Promoting a more inclusive society (PAMIS), a charity for people with complex needs, there are now more than 150 CPTs in Scotland. They also have a mobile CPT. This enables disabled children and young people to go to events that were not accessible to them before.

The Sense Scotland Touchbase Network are making inclusive community spaces which meet the needs of people with communication support needs. These are welcoming and safe places in a local community setting, with additional services which include early years support, family support and advice for young people going from school to adult life.

One Giant Leap is a youth group run by Touchbase Glasgow which gives social and educational opportunities to young disabled school leavers.

Safety and Justice

We know that children and young people with disabilities experience discrimination, bullying, and sometimes violence, because some people see them as different.



What if I'm worried about bullying?

The Scottish Government takes bullying very seriously. Bullying of any kind including bullying because of disability is unacceptable and must be stopped quickly, whenever it happens.

The Scottish Government funds respectme, Scotland's anti-bullying service. They have a helpful resource for parents and carers about bullying, as well as a webpage specifically for children and young people.

The Scottish Government recently updated its anti-bullying guide for everyone working with children and young people: Respect for All: The National Approach to Anti-bullying for Scotland's Children and Young People.

More Information?

You can visit respect*me*'s website for more information or call them on 0844 800 8600.

What is Hate Crime and how do I report it?



We know that hate crime is wrong and against the law – we all have the right to live our lives free from harassment and without fear.

A hate crime is any crime committed against a person or group because of things like their age, race, religion, or disability. The Equality Act 2010 calls these 'protected characteristics'.

Hate crime does not have to involve physical assault or injury. It can include having personal property stolen or vandalised, or abusive remarks.

Why is Third Party Reporting important?



We know that victims or witnesses of hate crime may not feel comfortable reporting issues directly to the police. They may be happier to report matters to someone they know.

Because of this, Police Scotland is working with organisations that can work as Third Party Reporting Centres across Scotland. Centre staff can support a victim or witness in making a report to the police, or can make a report for them.

To find your nearest centre, search Third Party Reporting Centre or follow the link to Hate Crime Reporting Form.

Keep Safe is a national partnership with I Am Me Scotland and Police Scotland. It sets up places where anyone who is feeling lost, scared and vulnerable or has been a victim of crime can get help. Keep Safe is working with British Transport Police and Police Scotland to expand the scheme across the public transport network.

What are Children's Hearings?

The Children's Hearings System is the care and justice system for Scotland's children and young people up until the age of 16 (or in certain cases, up to the age of 18). Children and young people who have problems in their lives may be asked to go to a meeting called a 'children's hearing'.

Children and young people might need a hearing because something in their life is causing concern. This is usually because there are serious worries about the child's safety, health and welfare. They are referred to the Children's Reporter, who decides whether they need to have a hearing.

How are we making Children's Hearings more accessible?



The Scottish Children's Reporter's Association (SCRA) are working to make sure the information they provide is accessible.

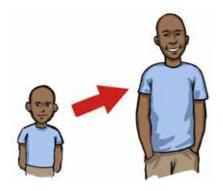
To receive this service from SCRA, you can ask them directly or your social worker can contact them for you. Their website also has an accessibility tool, which allows content to be translated or read aloud. It also has resources which are available in a range of formats, such as Easy Read, as well as resources for children, young people or parents and carers with a learning disability.

The 2016 Better Hearings Report outlined a number of ways in which Children's Hearings could be better. Work has begun to make sure hearings centres have all the facilities needed so that SCRA can provide the right supports to children, young people and their families.

More information?

The Scottish Child Law Centre and Community Law Advice Network give free legal advice and information.

5. Transitions



During the change from childhood to becoming an adult, young people take more control of their own lives and have to get used to different experiences, responsibilities, places and routines. We call these changes 'transitions'. They can also affect families and carers.

Scottish Government policies that deal with transitions include The Doran Review (The Right Help at the Right Time in The Right Place), The Children and Young People (Scotland) Act 2014, Self-Directed Support and Welfare System Reform, Developing the Young Workforce (Scotland's Youth Employment Strategy) and Opportunities for All (Supporting all young people to participate in post -16 learning, training or work).

The Health and Social Care Alliance, known as the ALLIANCE, produced a report which looks at the transition experiences of disabled young people and their families.

Principles of Good Transitions

Young people with a disability often need support in many different areas of their lives.



The Principles of Good Transitions set out the professional support needed by children with additional support needs between the ages of 14 to 25 years who are making the transition into young adult life.

The Principles of Good Transitions were made by ARC Scotland.

Coordinated Transitions Support

Feedback from young people and parents tells us that transitions support needs to be more joined up, with a single point of contact.

Transition planning and support needs to be well organised at a local level, particularly for those with learning disabilities or complex needs.

The Scottish Government has set up a Transition Fund, run by the Independent Living Fund, to give young people aged 16 to 21 a grant to help them make the transition from childhood to young adulthood.

Adult health and social care



We should put the wishes of children and young people and their families at the heart of the decisions that are made about their health and social care. This makes things better for young people in transition.



Getting it Right for Every Child (GIRFEC) puts the child's wellbeing at the centre of all decisions and should also be applied to transitions.

The needs and roles of the family are likely to change as the young person they care for grows up – they are the people most likely to provide guidance and support during transitions. They should get the information they need to make important decisions about things like self-directed support. They should get this information in an accessible format.

Further and higher education



If young people choose to go into further education it is important that they get the support they need both in college and during transition.

A number of things are being done to give more disabled young people access to further and higher education by people like the Scottish Funding Council.

The Equality Act 2010 says that colleges and universities have to meet the needs of disabled people.

Disabled students in higher education can apply to the Student Awards Agency Scotland for a Disabled Student Allowance (DSA), to cover extra costs caused by disability or learning difficulty.

Employment and volunteering

Every disabled young person who can and wants to work should have the opportunity to find a good job which suits their skills.

The Scottish Government's Fairer Scotland for Disabled People Action Plan aims to make more opportunities for disabled people of all ages to join the workforce.

Developing the Young Workforce: Scotland's Youth Employment Strategy aims to have as many young disabled people in employment as the rest of the population by 2021. The Equalities Action Plan for Modern Apprenticeships (MA) also includes employment targets for young disabled people.



The Community Jobs Scotland Programme (CJS) gives support and job training to unemployed young people to help them find work. This programme is run by the Scottish Council for Voluntary Organisations (SCVO) with funding from the Scottish Government.

The Workplace Equality Fund will help to reduce employment inequalities and discrimination, including barriers for disabled people.

We know that that being in work is good for a person's health and wellbeing, boosting confidence and helping them to be more independent. Some schools for learners with additional support needs are working with employers to help young people with their careers.

As these services develop we need to talk with disabled children and young people and their families, and listen to their ideas.

6. Concluding statement



In 2016, the Scottish Government funded Contact to ask families with disabled children and young people across Scotland about their information needs. They said they wanted a single resource that pointed to all the information and organisations they need.

To give these families what they asked for, we began to develop this information resource with help from a wide range of partners.



We asked families about the kind of information they would most like to access. This resource points to existing sources of information about these topics. We would like to know if we have covered all of the information that is important to you.



We know that access to clear and reliable information empowers families. Information needs to be shared properly and in ways which are accessible for everyone.

This resource aims to give information as inclusively as possible and give families more choice and control over the care and support that they need and are entitled to.



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