



Supporting Disabled Children, Young People and their Families



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This consultation focuses on the content and format of a public resource that will look to coordinate and drive improvement of the experiences of disabled children, young people, and their families across three pillars: rights and information, accessibility of support, and transitions.



Underpinned by a **rights-based approach**, we have worked with disabled children and young people, their families and practitioners, as well as third sector partners to design this resource. The consultation will be crucial for us to provide something that is both practical and useful but also ambitious and forward-looking.

OUR VISION FOR THE RESOURCE

We aim to provide clear, accessible information on national policies, entitlements, rights and the different options for support available. The guides to policies, legislation and service provision will be interspersed with examples and real life case studies to showcase best practice.

In order to capture the complex nature of disability and the diverse range of people across Scotland who have a disability, this resource will not attempt to be an exhaustive list of condition-specific information or a directory of local services. We also recognise that transitions occur at different times for different people, so we have not applied a specific age limit and hope that it will act as an additional layer of support, both for families navigating the complexities of raising a disabled child and for young people looking forward to the next stages of their lives.

The format of this resource will be primarily digital, so that it is responsive to the real world, and updates can be made as necessary. The resource will be underpinned by a commitment to communicate the content in ways that are inclusive (easy to understand) and accessible, for example, in Easy Read. It is also important for children and young people to access as much of this information as they wish, therefore a version created specifically for them will be made available.

This consultation document uses some words or phrases which might be unfamiliar, and others which have specific legal meanings. Below is a short explanation of some of the most important terms.

In the Equality Act 2010 a disability means a physical or a mental condition which has a substantial and long-term impact on a person's ability to do ordinary day-to-day activities.

Conditions like HIV, cancer or multiple sclerosis, which can become more severe over time, are also covered, even if the person might currently be able to carry out normal day to day activities. Children and adults are protected as soon as they are diagnosed. The Equality Act also covers those who had a disability in the past.

The Social Model of disability views disability as the relationship between the individual and society. It creates a distinction between 'impairment', which refers to the functional limitations that a person faces due to a physical, sensory or cognitive impairment and 'disability', which refers to the barriers an individual may face in their daily life because society places a disadvantage upon them based on their impairment. This means that it sees the barriers created by society as the cause of disadvantage and exclusion, rather than the impairment itself. Based on this, the aim is to remove the barriers that isolate, exclude and so disable the individual.

Legally, additional support for learning and disability often overlap but are not defined as the same thing. An additional support need can arise for any reason and be short or long term. Additional support may be required to overcome needs arising from a learning environment; health or disability; family circumstances or social and emotional factors. For example, a bereavement in the family or a short period of illness is as much an additional support need as more long term needs such as cerebral palsy or autism. Looked After Children and Young People are also deemed to have additional support needs until they are assessed otherwise.

Families: The consultation document will refer to families rather than "parent" or "carer" as these terms may not capture the various caring relationships a child or young person might experience during their lifetime.

Support: The term support captures the "services" which are provided by a wide range of public bodies as well as the resources and opportunities available to assist disabled children, young people and their families via the third sector and other partners.

Rights-based Approach: This is an approach to creating policy and legislation which holds human rights at its core. It supports equality and inclusion. Using a rights-based approach empowers people to know and claim their rights and increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations.

Co-production means working with people to shape the services they use in order to better meet their needs.

Duty: A 'duty' is an action that someone must carry out, either legally (because it is the law) or morally (because it is the right thing to do). In this resource, we have mentioned that organisations, such as the Scottish Government or local authorities, have 'duties' placed on them by legislation. This means that the legislation requires that they must act in a certain way or complete certain actions. There are many different actions that these organisations are required to carry out and so the type of duty will vary in each piece of legislation.

There is no place in Scotland for any form of prejudice or discrimination. Equality is about creating a fairer society where everyone can participate and has the opportunity to fulfil their potential. We believe that no child or young person should be denied opportunities.

The *Equality Act 2010* places a duty upon the Scottish Government to integrate an equality perspective into the everyday work of government. Scotland will be the first nation of the United Kingdom to commence the socio-economic duty section of the *Equality Act*. This duty will require public bodies to seek to reduce inequalities caused by socioeconomic disadvantage. The new duty should have a positive impact for disabled children, young people and their families, who experience both higher poverty rates and greater social inequality than non-disabled people.

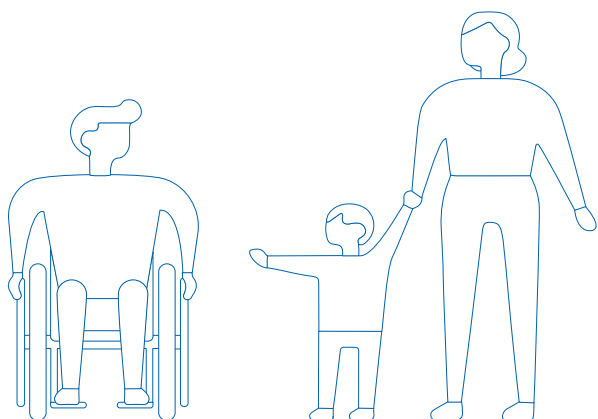
MULTIPLE DISCRIMINATION

If we are to achieve our aim of full equality and human rights for disabled people in Scotland, then we must take account of all disabled people, including children and young people. We also have to understand how other characteristics such as age, sex, race, religion, sexual orientation, transgender identity or being a Gypsy Traveller can impact on a disabled person's experiences and use this understanding to shape our actions.

It is important to recognise that people often experience disadvantage because of a combination of protected characteristics. As research by organisations such as the Equality Network indicates, this is not simply something encountered by a "minority of a minority". Multiple discrimination is a part of many disabled people's lives, and directly impacts on how they experience and respond to their disability.

What do I do if I am feeling discriminated against?

Disabled children, young people and their families should never expect to experience discrimination. This applies to interactions with public services such as claiming benefits or taking the bus, community life such as 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 in this resource can be found in the SAFETY AND JUSTICE Section.



CHILD POVERTY AND DISABILITY

Tackling child poverty is a key priority for the Scottish Government and statistics show that poverty is both a cause and a consequence of disability.

A broad range of actions have already been taken to try to address inequalities in our society: including free school meals for all P1-P3 children; expanding the funded provision of early learning and childcare; an improvement programme to address neglect and enhance wellbeing; and investing to mitigate UK Government welfare reform and support low income families.

The *Child Poverty (Scotland) Act 2017* underpins all Government action, and holds Scottish Ministers to account for their efforts in tackling poverty. The first Child Poverty Delivery Plan was published in March 2018, and will seek to take a cross-Government approach to reducing child poverty.

This resource supports the Poverty Delivery Plan by helping families to be more aware of FINANCIAL SUPPORT available to them to assist with the financial implications of caring for a disabled child. Similarly, the Delivery Plan specifically identifies disability as a key area for the Scottish Government to continue to target support measures. Only through such coordination will we effectively remove those barriers which prevent families from moving out of poverty.

Where can I find out more about poverty and inequality in Scotland?

The Scottish Government has established a [Poverty and Inequality Commission](#). The Commission will provide independent advice and scrutiny on Government targets and Delivery Plan, as well as wider economic inequalities, and openly hold Scottish Ministers to account on their progress.

TRAUMA: ADVERSE CHILDHOOD EXPERIENCES

Adverse Childhood Experiences (ACEs) refer to stressful events occurring in childhood including: being the victim of abuse or neglect, or growing-up in a household in which there are adults experiencing alcohol and drug use problems, mental health conditions, domestic violence or criminal behaviour resulting in imprisonment.

Why is it important to understand and confront ACEs?

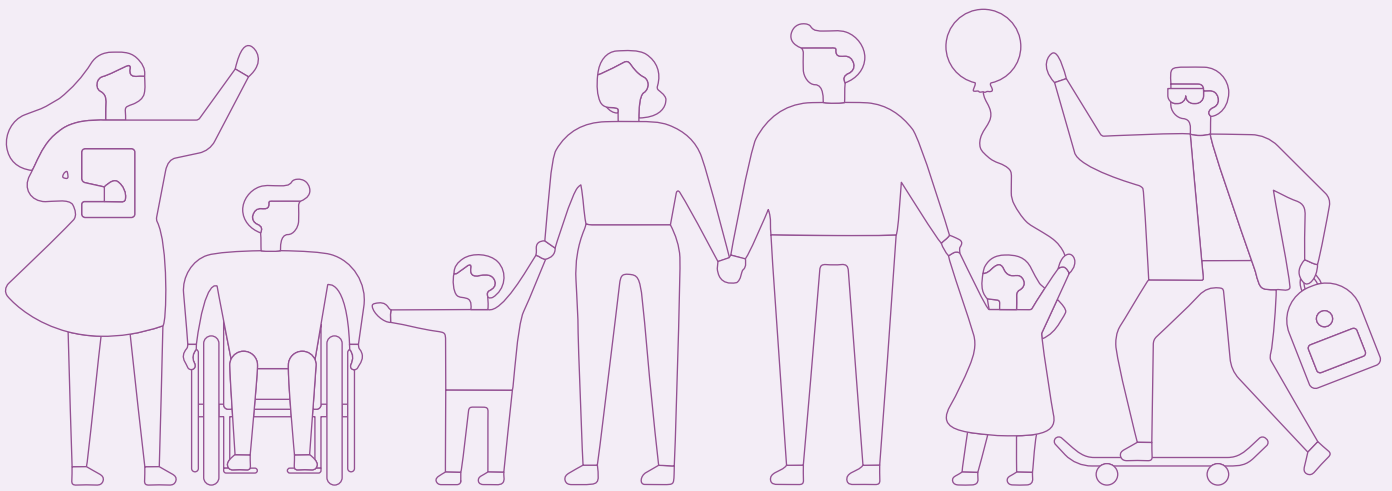
Traumatic childhood events can create harmful levels of stress which impact healthy brain development – resulting in long-term effects on learning, behaviour and health.

There are a wide range of policies and practices implemented in Scotland to prevent adversity in childhood and mitigate impact. However, there are calls for a greater focus on ACEs across all policies and services. Approaches that are focused on ‘understanding and nurturing’ are advocated, recognising that robust neighbourhoods, systems and services are needed to best support children.

Learning on ACEs is increasingly informing the development of national policy to [help people affected by trauma](#). We acknowledge that more work must be done to gather evidence of the experiences of people living with disabilities who may also face barriers due to their socio-economic status or their childhood experiences.

More information? A [Scottish ACE Hub](#) has been established, co-ordinated by NHS Health Scotland, to develop and inform implementation of an action plan to contribute to preventing and responding to ACEs across Scotland.

1. Rights and Information



The Scottish Government is committed to respecting, protecting and implementing human rights for everyone in Scotland and to embedding equality, dignity and respect in everything it does.

This means ensuring disabled children and young people understand their rights, and feel empowered to claim them, or to speak up when they feel those rights are not being upheld.

We take a **human rights based approach** to policy which means ensuring that the standards and the principles of human rights are integrated into our policymaking as well as the day to day operations of support that disabled people access.

Where do I access general information about public services?

[Mygov.scot](http://mygov.scot) is the Scottish Government website which provides information about Scotland's public services for all citizens. As outlined in the Scottish Government's Digital Strategy, mygov.scot will be the single entry point for all services.

Information about laws, policies and the most up to date actions from the Scottish Government can be found on the website, Gov.scot.

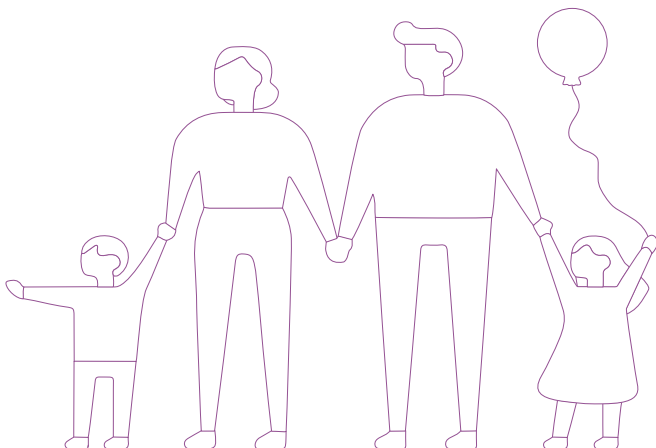
INCLUSIVE COMMUNICATION

Developing channels for meaningful communication and self-expression is vital for a child or young person's development and wellbeing. We need to create environments and opportunities that allow all young people to express their intent to communicate in whatever way they wish and are able.

Everyone communicates differently. Communication is a fundamental human right and is defined as giving and receiving information. It can be any gesture, behaviour, sound or act. Many young people do not communicate using written, spoken or sign language, but they are still communicating. It is important to ensure these young people can access the same rights and opportunities as others.

When we think about how the public sector communicates with people, three key points help us to identify and remove communication barriers:

- Inclusive communication means sharing information in a way that everybody can understand. The same information may need to be communicated in a variety of ways as everyone has different communication needs.
- For people who use services, it means getting information and expressing themselves in ways that meet their needs.
- For service providers, it means recognising that people understand and express themselves in diverse ways.



The Scottish Government has worked with partners to develop the [Inclusive Communication Hub](#) which is full of resources aimed to improve inclusive communication across Scotland. Communication, Access, Literacy and Learning (CALL) Scotland also have a number of helpful resources on their [website](#).

In March 2018, the *National Health Service (Scotland) Act 1978* was updated by part 4 of the *Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016*. This [update](#), known as a 'commencement', introduced a duty to provide communication equipment and support in using that equipment.

What are some ways my child can communicate?

Augmentative and alternative communication (AAC) is a form of inclusive communication. It is a term used to describe the range of options that can help people when they have lost their voice, or find speaking difficult, and covers any type of communication that supplements written or verbal communication. There are a number of ways people can communicate without speaking, some involve technology but others do not. It may be beneficial to see a Speech and Language Therapist. You can find out more about them via 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.

Case Study, Everyone Together

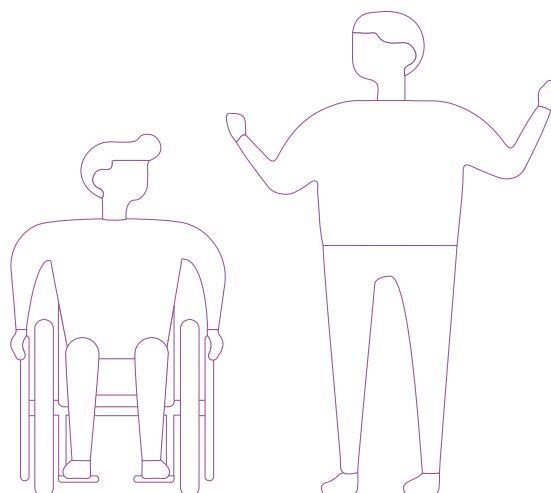
Delivered by the [National Deaf Children's Society](#), within the context of GIRFEC, Everyone Together is a national project supporting families of deaf children aged 0-8 years in Scotland. It is offering free training to Health Visitors across Scotland, helping them in their work with families of deaf children.

Each element of the training reinforces a key message: that families must be supported to develop their child's language and communication skills.

Everyone Together was invited to deliver Supporting Families of Deaf Children to a team of Health Visitors. This training was co-delivered by the Everyone Together Team and the local National Deaf Children's Society Children and Family Support Officer, who provides support to families within that area. The Children and Family Support Officer had

previously been made aware of a young deaf child living in the area who was struggling to acquire language as a result of their family not fully understanding the implications of their child's deafness.

The family's Health Visitor approached the Children and Family Support Officer immediately following training to request support for the family. Through improved information-sharing as a result of training, the Health Visitor and Children and Family Support Officer are now working together to provide targeted support, with the aim of helping the family to better understand their child's deafness and take positive steps towards improving their child's access to language and communication. The Children and Family Support Officer has also been invited to be part of the Child's Plan, ensuring that consistent advice and support is offered in relation to childhood deafness.



We recognise that many people who are D/deaf, blind or who have a sensory impairment do not identify themselves as disabled. This resource uses the social definition of disability which assumes that people are not 'disabled' because of their identity but because aspects of society, like public transport, schools or services often make it difficult for them to participate fully and that they face barriers in their everyday life because of this.

How are we reducing barriers in Communication?

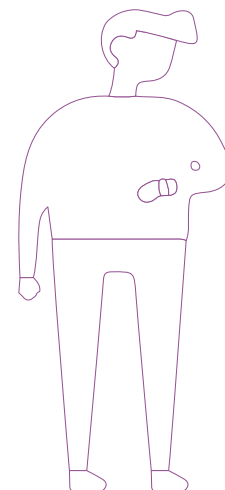
The Scottish Government is committed to improving the services, support and care available to people who have sight loss, deafness and dual sensory loss. Our long-term strategy, [See Hear](#), commits to ensuring that children, young people and adults have the same access to opportunities and public services as everyone else, including health care, social care, employment, education, and leisure. The strategy was jointly endorsed by the Convention of Scottish Local Authorities (COSLA) and is being implemented through local partnerships of statutory and third sector organisations. Local See Hear leads are in place to identify priority areas and drive forward the delivery of the Strategy at a local level.

The [British Sign Language \(BSL\) National Plan 2017-2023](#) means that D/deaf and Deafblind BSL users will be fully involved in daily and public life in Scotland, as active, healthy citizens and will be able to make informed choices about every aspect of their lives. The Getting it Right for Every Child approach is fully embedded, with a D/deaf or Deafblind child and their family offered the right information and support at the right time to engage with BSL.

What other support is available?

The Scottish Government has commissioned and funded [contactScotland-BSL](#). This is the UK's first publicly funded online BSL video relay service, which enables Deaf BSL users to contact public and voluntary services, and for these services to contact them. A number of organisations in Scotland have already signed up to use the service, including NHS Scotland, Citizen's Advice Scotland and The Scottish Children's Reporter's Administration. To use this service, you can access it via their [website](#) or download their [app](#).

More Information? [The Scottish Council on Visual Impairment \(SCOVI\)](#), and [the Scottish Council on Deafness \(SCOD\)](#) provide information on voluntary organisations which provide advice and support to people with sight loss and deafness in Scotland.



RIGHTS AWARENESS

What are human rights?

Human rights are the basic rights and freedoms to which we are all entitled in order to live with dignity, equality and fairness, and to develop and reach our potential.

Everyone has these Rights, no matter their circumstances.

Nobody can take these rights away from us and they are there to ensure we are protected and treated fairly throughout our lives, regardless of our background.

The Scottish Government participates in UK reporting to the United Nations and the Council of Europe on its international human rights treaty obligations. This ensures that Scotland's distinctive approach is communicated on a global stage and allows our progress on implementation to be continually monitored.

There are [nine core international human rights treaties](#) including the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child:

UN Convention on the Rights of Persons with Disabilities:

Disabled people should be able to enjoy their human rights on an equal basis with non-disabled people.

Disabled people continue, in practice, to face a wide range of barriers. The Convention sets out the measures governments are expected to take to remove them and to ensure that the rights of disabled people are respected. **Find out more** about what we are doing to remove barriers in Scotland.

Our commitment to the principles of this Convention are set out in the Fairer Scotland for Disabled People Delivery Plan. We also develop easily accessible resources such as this **Easy Read** version of the Conventions.

UN Convention on the Rights of the Child (UNCRC):

Sets out the overarching standards for supporting children. All of its rights are underpinned by four general principles: non-discrimination; best interests of the child as a primary consideration; the right to life, survival and development; and the right to have children's views given due weight.

The UNCRC also provides children and young people with a series of individual rights, such as the right to a name and nationality, the right to education, the right to health, the right to play and recreation, and the right to an adequate standard of living – alongside additional rights for specific groups, such as disabled children.

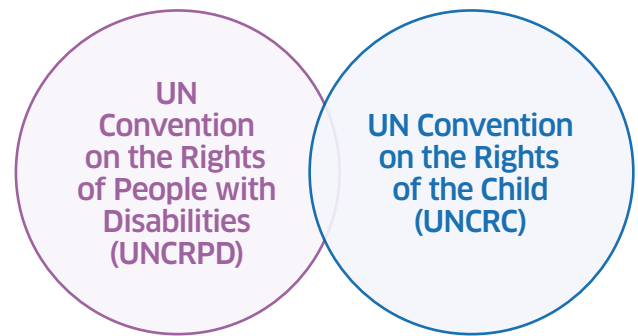
Ministers must listen to the views of children and young people, promote and raise awareness of their rights, and report to the Scottish Parliament every three years on relevant progress. View the **Easy Read UNCRC**.

These conventions help to protect the rights of disabled children and young people. The Scottish Government has produced a [Quick Reference Guide](#) on the Rights of Children and how we legislate to protect them.

How are we supporting the rights of disabled children in Scotland?

The Scottish Government is working hard to realise human rights for adults and children in Scotland, but we recognise that there is much still to do. The Programme for Government published in September 2017 – [A Nation With Ambition: The Government's Programme for Scotland 2017-18](#) includes many new commitments that will advance human rights in Scotland – and will be inclusive of disabled children and young people. For example, the Scottish Government has committed to undertaking an audit to explore the most effective and practical way to further embed the principles of the UNCRC into legislation, policy and practice. There will also be a three year programme to raise awareness of children's rights among parents, families, communities and public agencies – and crucially, among children and young people themselves. In order to deliver this, we plan to work closely with children, young people and third sector organisations.

In line with Article 12 of the UNCRC we want children and young people's voices to be heard and respected. It is important to us that all children and young people, including disabled children and young people, influence national and local policy including public services and the decisions that are made which affect their lives.



As part of the development of this resource, a Young Disabled People's Forum has been established to provide an inclusive space for young people with a disability to come together regularly and engage with the issues that interest and affect them and feed into policy making.

There are a number of national organisations committed to ensuring that human and children's rights are upheld. For example, the [Scottish Human Rights Commission](#) is an independent public body that promotes and protects human rights for everyone. [Together \(Scottish Alliance for Children's Rights\)](#) is a group of Scottish children's charities that works to improve the awareness, understanding and implementation of the United Nations Convention on the Rights of the Child (UNCRC).

More information? The [website](#) for the Children and Young People's Commissioner Scotland provides lots of information for children and young people, their families and adults working with them on children's rights, as well as where to get support.

ADVOCACY

The Scottish Government is committed to promoting and supporting the rights of all children in Scotland to improve their outcomes. Article 12 of the UNCRC makes very clear that every child has the right to say what they think in all matters affecting them, and to have their views taken seriously. Advocacy helps to make that right a reality for those children and young people who, for whatever reason, would not otherwise be able or allowed to share their views about something. Genuinely listening to young people and including their voice in decision making should help achieve this. Advocacy is a crucial part of supporting a child to express their own needs and views and to make informed decisions on matters which influence their lives.

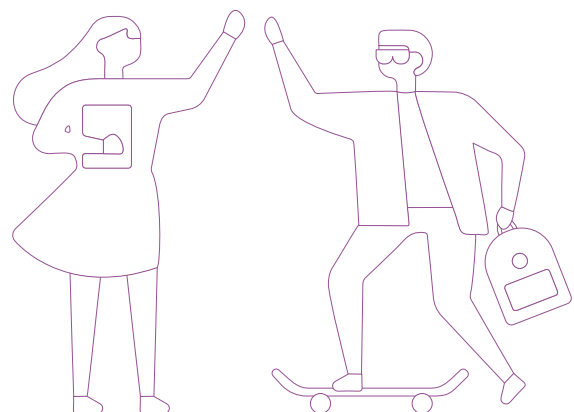
Advocates do not make choices for children. Instead, they support children and young people to make their own choices.

There are independent organisations which promote advocacy for children and young people's rights. The Children and Young People's Commissioner is a person, whose job is to help children and young people understand their rights and to make sure those rights are respected. The office of the Children and Young People's Commissioner has a useful [website](#) with lots of [resources](#) for young people.

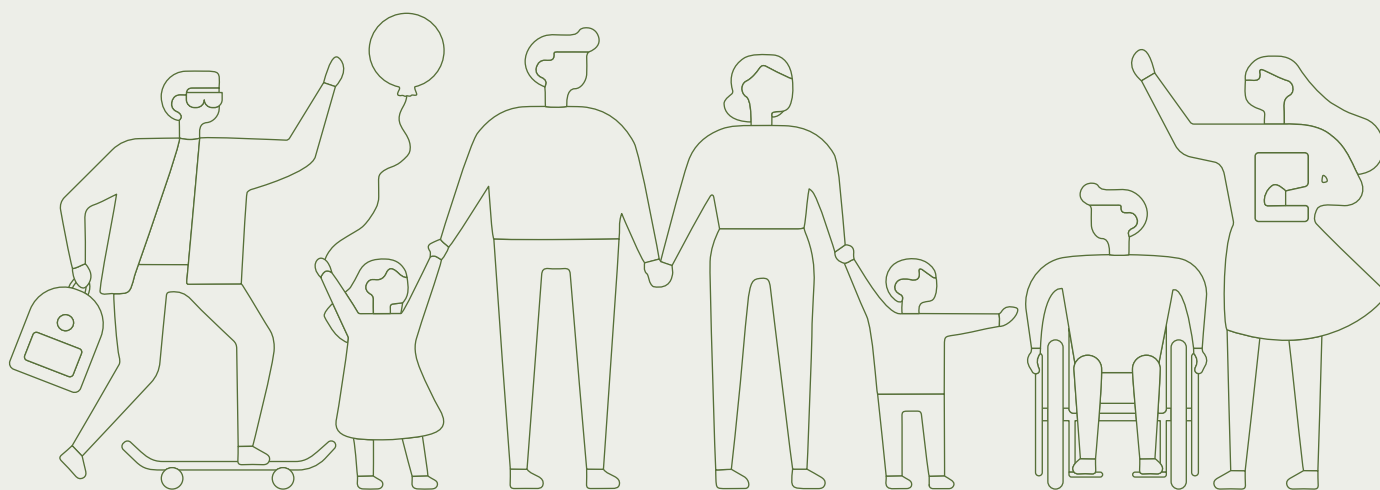
The Scottish Government has published a [guide to children's advocacy](#) which can be used by family members, friends, teachers, support workers and others who may at times advocate for a child. Support services should be mindful that parents themselves may have a need for advocacy in order to express their wishes in relation to decisions affecting their children.

It is vital that the needs of children and young people are given due consideration by local health boards and that national policy reflects a focus on improving the life chances of all of Scotland's children. Child Health Commissioners aim to ensure that, both locally and nationally, the interests of children and young people are supported and safeguarded.

More information? The [Scottish Independent Advocacy Alliance \(SIAA\)](#) is funded by Scottish Government. It has the overall aim of ensuring that Independent Advocacy is available to any vulnerable person in Scotland. Learn more about the rights of children in the section on SAFETY AND JUSTICE.



2. Accessibility of Support



The information provided in the *Supporting Disabled Children, Young People and their Families Resource* is not intended to be an exhaustive directory of every type of support available in the 32 local authorities across Scotland. Rather, we aim to provide the national view of policies from which families may start to better understand their entitlements and how to access the right support at the right time.

POLICY CONTEXT

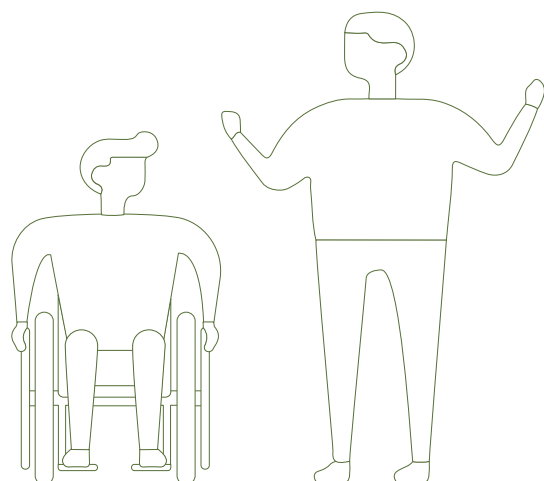
Disabled children and young people have access to the standard support and entitlements that apply to all families, as well as the additional support they require. There are many national policies that apply to families regardless of their additional support requirements, however it would be impossible to capture within this resource the myriad of policies relating to [health](#), [parenting](#) and [education](#) to which families are already signposted by other agencies such as the NHS and schools.

The Scottish Government has also previously developed national policies for people with learning disabilities and for individuals with Autism which remain relevant to the children, young people and families who might also benefit from this resource. The *Supporting Disabled Children, Young People and their Families Resource* aims to include all children and young people with the widest possible definition of disability.

The Scottish Government published an implementation framework for the delivery of [Scotland Learning Disability Strategy – The Keys to Life](#). The strategy recognises the value of building on the assets of individuals and communities and outlines the vision for children, adults and older adults who have learning disabilities. The Keys to Life Strategy also has a [website](#) that you can visit for more information.

The [Scottish Strategy for Autism](#) is based on a vision that autistic children, young people and adults in Scotland are respected, accepted and valued by their communities and have confidence in services to treat them fairly, so that they are able to have meaningful lives.

Following a national dialogue and consultation with autistic people, their families and carers, the Outcomes Approach will be refreshed, which will reflect the priorities to take forward up to 2021. For more information, you can visit the Scottish Strategy for Autism's [website](#).



GETTING IT RIGHT FOR EVERY CHILD

[Getting It Right For Every Child](#) is the national approach in Scotland to improve outcomes and support the wellbeing of our children and young people by offering the right help at the right time from the right people. The approach is underpinned by the United Nations Convention on the Rights of the Child. It is a way of working that empowers children, young people and parents by recognising and promoting their rights. This means putting their expressed needs at the heart of service development and delivery.

Getting it right for every child builds on the experience of most families: that children benefit from a network of support to promote and support their [wellbeing](#). This network starts with the family who can then call on the universal services of health and education for support as they want it. Many will also draw support from their local community through neighbours and friends, community clubs or activities, or faith groups.

Most children and young people get all the help and support they need from their family and community, but sometimes, perhaps unexpectedly, they may need a bit of extra help. Getting it right for every child ensures they are able to access this additional support easily and without stigma.

A number of disabled children and young people need more specialist support to address particularly significant, complex or multiple needs. Such needs will be identified and considered by practitioners, often from various services, working in partnership with children, young people and families using the [National Practice Model](#). This provides a consistent approach to planning support which can lead to the offer of a [Child's Plan](#). This is a single planning framework that all services may use to build solutions with children and their families to coordinate specialist teams or support from multiple services.

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.

The Getting it right for every child approach 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 maintains a wide range of information about the issues relating to [children and young people](#).

HEALTH AND SOCIAL CARE AND SUPPORT

The Scottish Government is committed to providing disabled children and young people the best possible quality of care and the [Health and Social Care Standards](#) set out what we should expect when using health, social care or social work services in Scotland. The Standards are underpinned by five principles; dignity and respect, compassion, be included, responsive care and support and wellbeing.

The Standards are based on five outcomes:

- **I experience high quality care and support that is right for me.**
- **I am fully involved in all decisions about my care and support.**
- **I have confidence in the people who support and care for me.**
- **I have confidence in the organisation providing my care and support.**
- **I experience a high quality environment if the organisation provides the premises.**

Who are these Standards for?

The Standards are for everyone. We are all entitled to the same high quality care and support. The Standards can be applied to a diverse range of services from daycare for children, to hospitals, to care homes. The Standards do not replace or remove the need to comply with legislation which sets out requirements for the provision of services. The Standards should be used to complement the relevant legislation and best practice that support health and care services to ensure high quality care and continuous improvement.

Example:

Principle: Dignity and respect

Outcome: I experience high quality care and support that is right for me

Standard: I am accepted and valued whatever my needs, ability, gender, age, faith, mental health status, race, background or sexual orientation.

Who ensures services meet the right standards?

There is a regulator called the Care Inspectorate which checks on a number of care services such as in-home support or child-minding. More information can be found on the [Care Inspectorate](#) and [Healthcare Improvement Scotland](#) websites while the [Care Information Scotland](#) website is designed specifically for those considering all their options.

What does the integration of health and social care mean for my local options?

The way we plan and deliver health and social care services in Scotland has changed. In 2016, we legislated to bring together health and social care in to a single, integrated system, with [Integration Authorities](#) now responsible for £8.5 billion of funding for local services, which was previously managed separately by NHS Boards and Local Authorities.

Integration is the most significant change to health and social care services in Scotland since the creation of the NHS. With a greater emphasis on joining up services and focusing on early intervention and prevention, integration aims to improve care and support for people who use services, their carers and their families.

There are 31 Integration Authorities across Scotland working with their local communities and providers of care to ensure care is responsive to people's needs. You can find out the name of the Chief Officer of the Integration Authority in your local area, as well as whether or not they are also responsible for children's services, and view key documents and reports [here](#).

The [Public Bodies \(Joint Working\) \(Scotland\) Act 2014](#) sets the framework for integrating adult health and social care, to ensure a consistent provision of quality, sustainable care services for the increasing numbers of people in Scotland who need joined-up support and care, particularly people with multiple, complex, long-term conditions. In some cases children's health and social care services have also been delegated to integration authorities. In areas

where this has taken place it would be the duty of the local Integration Authority to assess need and provide appropriate health and social care support.

Where the duty for providing health and social care support has not been delegated to the Integration Authority, the Local Authority will remain responsible for assessing needs for community care based on their own set of criteria. It is therefore important for families to have local contacts who can help them understand their local arrangements and what support is available.

Following an assessment, there are various individuals who can help guide families of children with disabilities through the health system. For many people it will be their specialist team, family doctor or Health Visitor.

The [Universal Health Visiting Pathway in Scotland \(October 2015\)](#) presents a core home visiting programme to be offered to all families by health visitors as a minimum standard. This consists of 11 home visits to all families, three of which include a formal review of the family and the child's health by the health visitor (at 13-15 months, 27-30 months and prior to starting school). It covers the antenatal to pre-school period and provides an opportunity for health visitors, children and their parents to build a strong relationship so that health visitors can appropriately support families, including acting as a gateway to other services.

The Scottish Government has invested to increase the health visitor workforce by an additional 500 by the end of 2018. This will ensure that NHS Scotland has the right levels of staff to provide visits and reviews for children so that they can have the best possible start in life.

What about my health and wellbeing? The Scottish Government is working on a [Digital Health and Care Strategy](#), which is due to be published in Spring 2018. Making better use of digital data and technology is key to improving the quality, efficiency and resilience of health and social care services. It can also help to give people greater control in managing their own health and wellbeing.

Supporting people and their families and carers to look after their own health and wellbeing can help to prevent hospital admissions and promote better health outcomes. Improving access to digital information and online support and services can help to facilitate this. It is hoped that this service will be particularly beneficial for people who may struggle to access health services in the traditional way, for example; those with communication needs or people who find it difficult to travel.

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, Scotland published its first health literacy action plan, called '[Making it Easy](#)'. It set out the ambition for Scotland to be a health literate society that enables people to have the confidence, knowledge, understanding and skills to maintain good health.

In July 2017, a [progress report](#) reflected on what had been achieved to date and based on this, a new action plan: '[Making it Easier, a health literacy action plan for Scotland for 2017-2025](#)' was published in November 2017.

This new plan broadens the ambition of the work to embed it in sectors beyond health and social care. It introduces the concept of 'common skills of connectors' – how many people in many parts of the system have roles to play in ensuring understanding when passing on information. These common skills can be widely promoted across sectors, situations and contexts to build more skilled workforces, organisations that are more responsive to the people's needs, and a more health literate society.

More Information? More detail about Scotland's health literacy work can be found [here](#).

What about self-directed support?

Self-directed support describes the mainstream approach by which social care is provided to eligible people of any age. It aims to give families more choice and control over their support, and is grounded in the human rights principles of autonomy, self-determination, dignity and respect.

Who is eligible for social care?

The first step is to arrange a meeting with a social worker to talk about what support is available to you. Social workers use local criteria for who can get support and decide whether a child or young person and their family are eligible for social care.

Local Authorities have a duty to offer anyone eligible for social care four options about how their support is delivered:

1. Direct payment, to pay for the support yourself;
2. The council can give the money to a provider/ organisation of your choice and you can direct how it's spent;
3. The council can arrange a service for you;
4. You can choose a mixture of these previous three options for different parts of your social care support..

By giving families greater choice and control over care support, this self-directed approach is designed to ensure that what matters to the child is central to every decision made.

More Information? To search for advice by local authority area, visit the Self-Directed Support directory [Search for Support](#).

Case Study

Fraser has muscular dystrophy and uses a wheelchair. His parents cared for him on their own without any extended family support. Through Self-directed Support the family have hired personal assistants. This has changed Fraser's life giving him security and an independence that has allowed him to have experiences that would not have been possible before. Through a centre he attends, he met Paul, a peer who has the same condition and is also in receipt of SDS funding. The boys asked to combine their resources and have a weekend away. The boys had a fantastic weekend away in Amsterdam, without SDS this would not have been possible. Fraser can now enjoy socialising like everyone else, going out to cafes as he has his PA to assist him. Fraser's mum says there will still always be good and bad days, but SDS has transformed their lives and they are over the moon with the outcomes for Fraser.

Changes in approach to social care are an on-going process: To support this change the Scottish Government has provided assistance to help local authorities and partner organisations. They have published the Self-directed Support Strategy Implementation Plan 2016-2018 in collaboration with the Convention of Scottish Local Authorities (which is the representative body for local authorities), [Self Directed Support Scotland](#), [Social Work Scotland](#), and a number of other important organisations. The strategy seeks to prioritise choice for children, young people and their families and improve quality of life.

What is the role of the Allied Health Professionals?

Allied health professionals (AHPs) provide treatment and help rehabilitate children who are ill, have disabilities or additional needs, to live life as fully as possible. They work across a wide range of different settings including the community, people's homes and schools, as well as hospitals. They often work in the independent sector and for charities. Twelve diverse professions are listed under the AHP umbrella: [podiatrists](#); [occupational therapists](#); [physiotherapists](#); [speech and language therapists](#); [orthoptists](#); [dieticians](#); [paramedics](#); [diagnostic and therapeutic radiographers](#); [prosthetists](#) and [orthotists](#); [drama therapists](#); [music therapists](#); and [art therapists](#).

Pharmacists also play a key role in the NHS.

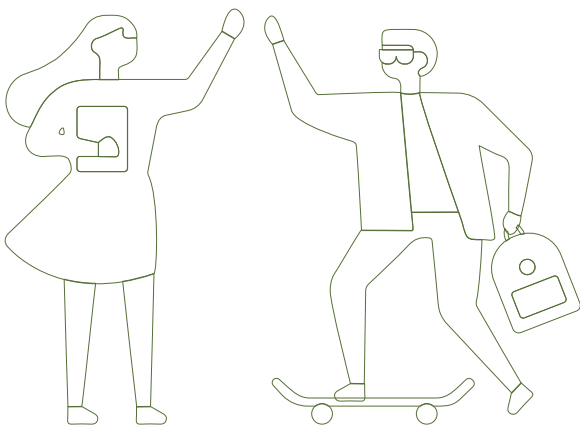
[“Ready to Act”](#), the first transformational Children and Young People's Service Plan, focuses on the support provided by Allied Health Professions, with a commitment to working collaboratively with children, young people and families in ensuring their full involvement in decisions that affect their support and wellbeing.

Case Study

Sleep Scotland has worked throughout Scotland developing sleep services and providing intensive sleep programmes for children with additional support needs by training sleep counsellors to work directly with families in need of sleep support.

Adam is a 7 year old boy on the autistic spectrum with learning difficulties. Adam wakes continually through the night, and is often ready to start his day at 2am. His mother, Dina, is exhausted. She also has 2 other children to care for, and a part-time job. She does have a partner, but he does shift work and, although he helps when he is around, he really isn't around very much. Dina is working with 2 sleep counsellors from Sleep Scotland. They helped her look at Adam's sleeping difficulties and drew up a programme, based on cognitive behavioural techniques. They have supported Dina throughout the period to implement this programme. Their aim is to empower Dina to get some control over her life again, through addressing Adam's sleep problems.

Sleep Support: Family fund conduct various types of **research** on sleep issues and how best to support children and families who face them. Much of this research has gone towards producing a website called **Tired Out**, which provides information, advice and resources on sleep support.



More Information? The [NHS Inform](#) website and helpline are the best way to access information on health, treatments, patient rights and long term conditions. [ALISS](#): A Local Information System For Scotland is a directory compiled by the Health and Social Care ALLIANCE.

I want to know more about Palliative and End of Life Care: The Strategic Framework for Action on Palliative and End of Life Care sets out the vision that by 2021 everyone in Scotland who needs palliative care will have access, with associated outcomes and commitments to support improvements in the delivery of palliative and end of life care.

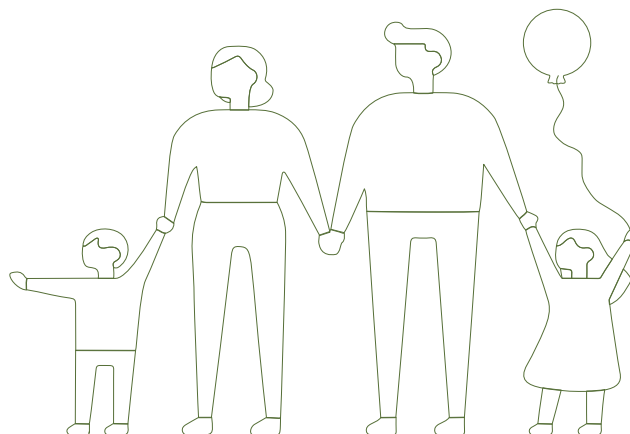
[Action on Palliative and End of Life Care](#) includes a particular commitment to 'Support and promote the further development of holistic palliative care for the 0-25 years old age group'. The Scottish Government is working with stakeholders including Children's Hospice Across Scotland, members of the clinical community and Health and Social Care Partnerships to take forward work associated with this commitment.

What about Social Workers and support in my local community?

Local councils have a duty to assess a child or family's community care needs and decide whether to arrange any services. Any assistance should be based on an assessment of your family's care needs and should take account of your preferences.

Social workers will want to discuss what is important to your child and family, what goals to set for care; including how support will improve quality of life. Social workers will help families agree upon what support options are best suited to achieving this. After a social worker has confirmed that an individual is eligible for support, the family will have a discussion with them in which they can expect several key areas to be addressed.

The Scottish Government is committed to continuous improvement of services provided to all children and young people. The [Realigning Children's Services](#) programme supports local improvement in improving the commissioning of children's services. One of the distinctive features of the programme is its commitment to compiling the best evidence about the circumstances, characteristics and experiences of children and young people.



Where can I find more information?

Scottish Government funded charity, Contact, has a [resource centre](#) with advice for families focused on health and social care.

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

If you are unhappy with NHS services you have a right to make a complaint, raise a concern, give comments and give feedback. Complaints should be made through the national [Complaints Handling Procedures](#) which are the same for every NHS Board in Scotland.

It focuses strongly on the early, local resolution of complaints, wherever that's appropriate. There are two main stages of dealing with complaints:

Stage one: The NHS aims to resolve complaints quickly. If possible, this could mean immediate action to resolve the problem. However, it is sometimes necessary to make enquiries before responding to a complaint. They aim to provide a decision at Stage one within five working days or less, unless there are exceptional circumstances. If this is the case, the NHS will explain why your complaint cannot be resolved and offer advice on what to do next. They may suggest that you take your complaint to the next stage.

Stage two: This deals with two types of complaint; those which are more complex and require a detailed investigation; and those which have not been resolved at Stage one. The NHS aims to deal with these within 20 working days.

Where possible, it's best to speak with a member of staff or to the service concerned as it can help to make sure your complaint is dealt with quickly and directly. You can also complain by phone, email or in writing. For details on how to contact your local NHS board, visit their [website](#). If you are uncomfortable with complaining directly, a representative of your choosing, such as a relative, friend, carer or advocate can make the complaint on your behalf.

If you have followed this procedure and are not satisfied with the way in which your complaint has been managed, you can contact the [Scottish Public Services Ombudsman](#) (SPSO), who have published a helpful guide to making complaints, which you can access [here](#).

More Information? If you need more support with any issue relating to NHS healthcare, including making a complaint, you can contact [PASS](#), the Patients Advice and Support Service.

MENTAL HEALTH AND WELLBEING

The principles of Getting It Right For Every Child ensure that mental health and wellbeing needs of disabled children and young people are also prioritised. Some mental health conditions cause disability, while poor mental health can also be experienced as a result of an impairment or long-term condition. The [Mental Health Strategy](#) will work on achieving parity between mental and physical health.

Child and Adolescent Mental Health Services (CAMHS) are usually planned and provided by the local NHS board. They assess and treat children and young people, including those with disabilities, who have mental health, emotional or behavioural difficulties. The local teams can be made up of nurses, psychologists, social workers and other professionals.

The Scottish Government is working with partners from the public and third sector to produce a 10-year Child and Adolescent Health and Wellbeing Action Plan which will cover both physical and mental wellbeing. It will take a cross-policy, rights based approach and will be published during 2018, the Year of Young People.

What happens if my child experiences bereavement?

Ensuring that children across Scotland receive the best possible support and access to bereavement services is of great importance. There are many avenues through which children and their families can access bereavement [support](#).

More information? [Breathing Space](#) is a national mental health support information service and helpline for Scotland.

SUPPORT FOR THE WHOLE FAMILY

Bringing up, and caring for, a disabled child can and should be a positive and rewarding experience. It is crucial that such families are supported at an early stage to enable them to cope with the stresses and demands of their particular caring role, and to look after their own health and wellbeing. For families wondering where to start, the Scottish Government funds [Care Information Scotland](#) which also runs a Helpline on 0800 011 3200.

Family members may need access to their own practical and emotional support. To achieve this, the Scottish Government has been clear that we need to accelerate the pace of change so that both adult carers and young carers are wholly supported. In addition to a [carer's assessment](#) and any services your local council provides, there are many other sources of help for carers, including [carers' centres](#) and carers organisations.

The [Carers \(Scotland\) Act 2016](#) came into effect from April 2018. This legislation brings new rights and support for carers – ensuring that they can continue to support, in better health and have a life alongside caring. Some of the provisions in the Act include: a requirement for local authorities to support carers, a specific Support Plan, as well as information and advice and a responsibility to consider whether short breaks may be provided.

[Family Friendly Working Scotland](#) (FFWS) is a partnership comprising [Working Families](#), [Fathers Network Scotland](#), [Parenting Across Scotland](#) and the Scottish Government. FFWS works with employers, families, government and others to promote a culture of employment that is flexible and family friendly. Their key aim is to encourage employers to provide flexible working options and to ensure that all employees have good long-term employment prospects and posts that reflect their abilities. The work of FFWS is of particular benefit to those with caring responsibilities, who often need to work flexibly.

How are we supporting parents and carers with learning disabilities?

The Keys to Life Learning Disability Strategy and Supported Parenting: Refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability aim to improve the lives of people with learning disabilities.

NHS Health Scotland is committed to providing accessible information to advance equality and reduce discrimination. NHS Health Scotland has worked with [CHANGE](#), who are a leading national human rights organisation, led by disabled people to provide three pregnancy and parenting resources: My Pregnancy My Choice, You and Your Baby and You and Your Little Child which are Easy Read resources specifically designed to support parents with learning disabilities. These are available as an alternative to (or as well as) Ready Steady Baby! (RSB!) and Ready Steady Toddler! (RST!)

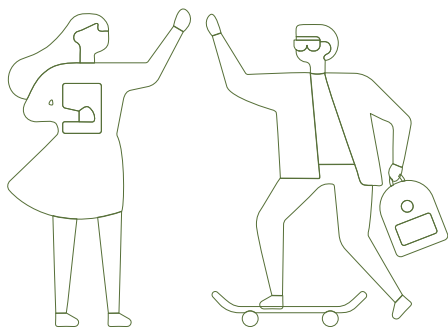
Right Click is an online programme for families of individuals on the autism spectrum who are in particular need of information and support. The service is administered by **Scottish Autism** who also have an advice line and various family support services.

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

There are a number of useful services and resources to support you in caring for a child or young person with complex or exceptional needs.

The National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) is one of many National Networks which work across professional, organisational and geographical boundaries to support the Scottish Government's policy aim of safe, effective healthcare which is designed around patients, carers and families. In order to do this, National Networks bring together all of the people and services involved in providing specialist care for patients with rare and/or complex healthcare needs. Each network designs pathways of care with the aim of providing all patients and their families with equal access to the highest standard of care, regardless of where they live in Scotland. CEN works specifically on providing these services for children with complex and exceptional healthcare needs.

Their [website](#) has a number of useful resources for both healthcare professionals, carers and families, such as information on transitions and signposts to other helpful services.



They have also put together a [booklet](#) for parents and carers of children with exceptional healthcare needs which offers practical and emotional support on a number of issues. Discovering that your baby or child has complex healthcare needs and learning to care for them can cause you to feel a wide range of emotions and everyone will experience them differently. This booklet deals with complex information in a sensitive way and supports you to find ways of coping which work best for you and your family. They also have a useful section which has links to other services with testimonials about them from other parents who have a child with exceptional healthcare needs.

More Information? [NHS Choices](#) is an online resource which provides information on a wide range of topics, from education to respite care.

All of my children deserve support: Siblings of disabled children will often need to demonstrate maturity beyond their years. It can mean they face emotional and practical strains in their own lives; struggling to receive appropriate time and attention from their parents, and experiencing anxiety and mental health issues. Young carers are specifically supported by the *Carers (Scotland) Act 2016* which puts a duty on local authorities to offer a Young Carer Statement. Young Scot has a [resource hub](#) for young carers.

Case Study

Perth Autism Support Siblings Programme:

A referral was made for a young person who was a target of aggression at home by their sibling with Autism Spectrum Disorder. The young person felt insecure in their friendships which resulted in occasional isolation from peers.

A plan was developed for the young person to attend weekly social groups with other siblings to encourage friendships and provide respite from the home environment. The young person would also attend a sibling training sessions (Time for Us) to provide an opportunity to explore and express feelings about their sibling as well as find out more information about autism.

The young person attended a term time social group each week, where they knew some other young people from previously attending residential camps for siblings with Perth Autism Support. However, following a difficult time at school paired with an increase in incidences of challenging behaviour from his sibling, relationships within the group began breaking down. Weekly 1:1 sessions with the sibling coordinator were started to allow focused reparative work where things had been more difficult with peers and to provide an opportunity for reinforcement of positive aspects of friendships within the group.

The young person attended the full course of Time for Us and engaged well with the activities. The topics covered allowed for conversations to take place surrounding feelings about the young person's sibling and promoted awareness of supports that were in place. At the conclusion of the 6 week programme an evaluation showed that the young person felt that they understood what having a sibling with autism meant for them and knew where they would go to get help if they had a question about their sibling or about autism.

The young person also accessed activity days during the school holidays, the aim of which was to ensure that continuous support was offered throughout the school year. The relationship built up between the young person and the sibling coordinator during 1:1 sessions was useful during this time as issues or misunderstandings arising with their peers could be dealt with promptly, avoiding prolonged feelings of instability in the group.

In conclusion, the young person regularly accessed respite opportunities with peers in a similar situation. With this extra support, the young person had positive interactions and formed new friendships. They were more informed about their sibling's autism and made aware of support networks.

What is Family Fund?

Family Fund is a UK based charity, who receive funding from the Scottish Government. Their primary role is to provide financial grants to families raising disabled children and young people; however, they also provide information and signpost to other charities and services which families may find useful. They focus strongly on children's rights: their work aligns closely with the 14 values and principles of the [GIRFEC](#) approach and they are a member of [Together](#), which is the Scottish Alliance for Children's Rights.

How can I access their services?

Family Fund's [website](#) has information on how families can apply for grants and access their other services. It also has a section which [signposts](#) to other useful and relevant services.

Family Fund provides home visits to introduce families to the support and services they provide. They are mostly aimed at families who are applying to family fund for the first time or who meet certain criteria, such as families with a young person who is approaching the transition to adulthood, or children and young people who are cared for by a kinship carer.

These visits are carried out by local professionals who will assess the child or young person's additional support needs as well as the family's circumstances. This information will be made into a report that can be used to decide how Family Fund can best support them and to inform their eligibility assessment for the grant making process.

These visits also provide an opportunity for families to discuss any issues they face or problems they need extra support with. Based on this, the person carrying out the visit can provide information on local statutory services and support groups.

Does Family Fund do more than give grants?

Family Fund offers a variety of [services](#) to make it easier for children and families to access computers and the internet. They have gathered a selection of [online resources](#) and can also provide a group training session for parents and carers of children and young people with a disability in the community.

The Scottish Government are fully committed to improving the quality and quantity of short breaks for carers and young carers. [The Short Breaks Fund](#) consists of:

The Creative Breaks programme: Providing grants to third sector organisations to develop new and existing short breaks provision in line with the fund's overarching aims of promoting greater choice, flexibility and personalisation of services and support. It also provides opportunities to channel funding to carers, via local support organisations, to enable carers and people with support needs to arrange the break of their choosing.

The Better Breaks programme: Providing grants to third sector organisations working in Scotland to develop additional, responsive and creative short break opportunities for disabled children, young people and their families. [Take a Break](#) is a fund which gives families who care for a disabled child or young person to take a break from caring in order to improve their physical and emotional wellbeing.

The Short Breaks Learning Exchange: Supporting the sharing of good practice, information, experience and learning across the funded projects, and to a wider audience.

In the development of this resource we are keen to explore what more can be done to support family relationships and wellbeing. Families are the fundamental cornerstone of our society, and the single most important influence on a child's life.

Just as we need to ensure that all disabled children can achieve their potential, we must not lose sight of the fact that a fairer Scotland can only be realised when we secure equal rights for everyone.

Case Study

Three year old Lailyn has Down's Syndrome. She loves going to the park, playing with her dolls, and sensory play. Her family first learned about Family Fund when Lailyn's Speech and Language therapist started helping her to learn Makaton. She was responding much better to the therapist's Makaton iPad app than the cards, so the therapist suggested that her family apply for an iPad to help develop her communication. Lailyn's mum said: "It's been brilliant and she has come on leaps and bounds. Lailyn has so much potential, it just might take her a little longer to learn than me or you, but having the technology really helps".

This year, the family also decided to apply for a playhouse so that Lailyn can make the most of being outside. Lailyn loves her playhouse

and her mum has said: "So far we've put in some big bean bags, and are hoping to turn it into a full sensory den, as she really enjoys sensory play. Her big brother finds sensory toys really relaxing too and it would be nice for them to have something they can do together, as it can be tricky trying to balance family life".

Speaking about Family Fund, Lailyn's mum said: "I wasn't sure about applying at first as I didn't know if we would be eligible, but I'm so glad we did as the grants have made a big difference. We wouldn't have had the means to buy Lailyn an iPad or a playhouse without the help from Family Fund but these things have such an impact on her life. I would encourage any family in a similar position to apply, there's nothing to lose and it can make a world of difference for children."

HOUSING

It is one of our ambitions that disabled people in Scotland should live life to the full in homes built or adapted to enable them to participate as full and equal citizens. The [Fairer Scotland for Disabled People Delivery Plan](#) set out a number of housing related commitments that support this ambition.

What are we doing to provide more housing?

Each local authority is required by law to produce a Local Housing Strategy, which is commonly reviewed annually, setting out its priorities and plans for the delivery of housing and housing related services. The strategy should set out how high quality housing and housing related services will be delivered to meet identified need in each council area. This includes how the needs of disabled children and young people and their families will be met.

We are investing over £3 billion in affordable housing to deliver at least 50,000 affordable homes by 2021. Most of these homes will be delivered by housing associations and councils and will be sufficiently flexible to 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 give priority to, among others, 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?

Disabled children and young people who would benefit from adaptations to their home should be able to access these services when needed. Owner occupiers and people who live in the private rented sector, who believe they need an adaptation, or other day to day help, should contact their local social work department; people who live in council or housing association housing should contact their landlord.

[Care and Repair](#) provide 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](#); This organisation recognises that every housing situation is unique and specialises in providing personalised, person-centred advice and support to people with disabilities and their families.

I need help heating my home: The Scottish Government operates a number of schemes to help households who may need help heating their home. To apply for any of these schemes applicants should 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 passing of the [Social Security \(Scotland\) Bill 2017](#) through the Scottish Parliament in April 2018 marks a historic moment, and represents the next significant milestone in delivering the new Scottish social security system. The Bill

establishes a framework for the new system, and transposes the eleven existing social security benefits that are becoming devolved onto a Scottish legislative platform, allowing the Scottish Parliament to shape a distinctly Scottish social security system with dignity and respect at its heart.

Example Benefits which remain reserved to the UK Government	Example Benefits being devolved to the Scottish Government
<p>Universal Credit which replaces:</p> <ul style="list-style-type: none"> ■ Jobseeker's Allowance ■ Employment Support Allowance ■ Income Support ■ Working Tax Credits ■ Child Tax Credits and ■ Housing Benefit 	<p>Ill Health and Disability Benefits:</p> <ul style="list-style-type: none"> ■ Disability Living Allowance ■ Personal Independence Payment ■ Attendance Allowance ■ Severe Disablement Allowance ■ Industrial Injuries Disablement Benefit

Disability Living Allowance for children is a benefit for under 16's who, due to a disability or health condition, have mobility issues and/or require substantially more care, attention and supervision than children their age normally would.

The allowance is non-means tested, non-taxed, rises with inflation and acts as a passport to other types of support, such as Motability, Blue Badge, Housing Benefits, Carers Allowance, Child Tax Credit, Universal Credit and exemption from the benefit cap. It is designed to contribute to the additional costs that those with long-term health conditions or disabilities face. The benefit is split into a Care component and a Mobility component. Either or both can be claimed, depending on need.

Following assessment, a 3 month qualifying period applies before entitlement begins, and it is important to note that the allowance claim cannot be backdated. Application packs are available in accessible formats.

The Personal Independence Payment is an allowance very similar to the DLA, for people of working age, which assists with the extra costs of living caused by long-term ill-health or disability. The delivery of DLA will remain the responsibility of the UK Government until Scottish infrastructure is in place.

What support is available for Carers?

Carer's Allowance is financial support for someone who is caring for another person for at least 35 hours a week. The [Scotland Act 2016](#) devolves powers over Carer's Allowance to the Scottish Parliament. From summer 2018, the Scottish Government will increase the rate of Carer's Allowance so that it is paid at the same level as Jobseeker's Allowance to people in Scotland. Carer's Allowance will continue to be paid by the Department for Work and Pensions at the usual rate, and the increase – called the Carer's Allowance Supplement – will be paid by the Scottish Government as two lump sums per year. Payments will be backdated to April 2018.

From autumn 2019, a £300 annual payment will be made available for young adults with significant caring responsibilities who do not qualify for Carer's Allowance. It will be delivered on an entitlement basis to those young carers who meet the eligibility criteria and are between the ages of 16 to 17, or up to 18 if still at school. The aim of the grant is to help improve their quality of life and enable them to take part in opportunities that they may otherwise not engage with due to their caring role, for example, undertaking further education, employment or leisure opportunities. From 2020-21 recipients of the grant will also be eligible for free bus travel, following piloting.

The Scottish Government will also introduce an additional payment for people in receipt of Carer's Allowance who are caring for more than one disabled child.

Who can I speak to for more information?

Families can be eligible for a number of national benefits and tax credits, particularly if they are on low or single incomes. Benefits also exist at local level to help with Council Tax, housing and health costs. Local Councils have a Benefits Office where individuals can visit or call to discuss their specific circumstances. [Citizens Advice Scotland](#) is a good place to start and you can [find your local bureau](#) for face-to-face advice and information.

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

The Scottish Government has committed to implementing the Best Start Grant (BSG) which will be delivered by Summer 2019. The Grant will provide support to those who need it at the key points in a new baby and young child's life. Importantly for disabled children and their families, the BSG application windows have been extended to allow an individual to take up the payment at a point relevant to the child's development and payments are not dependent on the child taking a place at nursery or school.

I need support with arranging Childcare: The Scottish Government is trialling the Childcare Deposit Guarantee Scheme to help families with upfront childcare costs. The aim of this is to reduce barriers to affordable early learning and childcare, which may help parents who wish to return to work or further education. This will be open to families of 0-2 year olds who are in receipt of any tax credits or any level of universal credit. The pilot local authorities will be City of Glasgow; City of Edinburgh; and Dumfries and Galloway.

I need help with finances: In 2018, the Scottish Government will begin the roll-out of a Family Financial Health Check Guarantee. It is aimed at families on low incomes with children and will help them to access a 'financial MOT', including advice on benefit eligibility and managing money. Its main goal is to allow families to claim everything they are entitled to and to access the best deals on financial products and services, as well as energy bills.

Family Fund is the UK's largest charity providing grants for families raising disabled or seriously ill children and young people. The Fund provide grants for a wide range of items, such as washing machines, sensory toys, family breaks, bedding, tablets, furniture, outdoor play equipment, clothing and computers.

EARLY LEARNING AND CHILDCARE

What am I entitled to now?

All children aged three and four are entitled to free early learning and childcare. Free places are also available to some families with two-year-olds if their parent or carer receives certain benefits. Find out how to claim [online](#).

How are we strengthening inclusion?

Early Learning and Childcare (ELC) provision must ensure equality of access for, and account for the varying needs of all children. This only becomes more important as entitlement is expanded. Needs can vary depending on a number of factors, including whether a child is disabled and/or has additional support needs (ASN).

The *Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)* ensures children's additional support needs are identified and provided for in ELC settings. This duty applies where it is established by the education authority, possibly via [assessment](#), that they do have such needs.

Where a child has identified additional support needs, parents can request that schools start planning for this up to 6 months before the child starts pre-school. Where a child has a disability, which may give rise to additional support needs, the Health Visitor can make the local authority aware right from birth to enable appropriate support to be provided.

Additional support may be provided outside education, such as from an occupational therapist from social work services or a speech and language therapist from health services. The statutory guidance to the *Education (Additional Support for Learning) (Scotland) Act 2004*, the [Supporting Children's Learning Code of Practice](#), was updated in December 2017. This update included making the responsibilities in the Act clearer so that everyone involved can better understand what kind of support should be expected.

The importance of accessibility is also strongly promoted in the good design guide for new and existing ELC settings. The physical environment can make a lot of demands on disabled children, and good design principles need to recognise this. For example, the provision of relaxed calm spaces can be key for those with some developmental disabilities.

ELC Inclusion Fund

As part of the expansion in entitlement the Scottish Government will also create a new £2 million Inclusion Fund. This will enable staff to support disabled children and those with ASN, by covering one-off funding for specialist training or equipment. This new Fund will complement the range of legal and policy provisions already in place that promote inclusion in ELC for disabled children.

The Scottish Government is currently in the process of delivering a transformative change in the provision of Early Learning and Childcare; almost doubling the free entitlement to 1,140 hours per year from 2020.

The driving force behind this is ensuring that all children have the best possible start in life. Research demonstrates that the provision of universally accessible and high quality ELC enriches children with skills and confidence to carry into their schooling, and is a cornerstone for closing attainment and inequality gaps.

More information? The [Scottish Family Information Service](#) provides free, impartial information on ELC for all families.

EDUCATION

The Scottish Government wants all children and young people to get the support that they need to reach their full learning potential. The [Curriculum for Excellence](#) enables all young people in Scotland to gain the knowledge and skills for learning, skills for life and skills for work which will help them become successful learners, confident individuals, responsible citizens and effective contributors.

How are we supporting learning for all?

There are legal requirements for Local Authorities to provide adequate education to all children. In addition the *Equality Act 2010* requires schools to actively deal with inequality, and to prevent discrimination against people with a disability, whether it is direct (such as bullying) or indirect (such as being unable to access a facility).

Schools also have a duty to make reasonable adjustments for disabled pupils and provide assistance and services, such as communication tools and support staff. All educational bodies, such as schools, have duties to develop and publish accessibility strategies to increase pupils access to the curriculum, access to the physical environment and to improve communication with pupils with disabilities.

Education authorities and other agencies also have duties under the *Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)* to identify, provide for and review the additional support needs of their pupils, including those with disabilities. Education authorities can ask other agencies, such as NHS Health Boards and social work services for help in carrying out their duties.

Changes were made to the *Additional Support for Learning Act*, which extended the age range of some of the provisions, so that they now cover children aged 12-15, as well as young people and parents. This means that children can now ask for their additional support needs to be identified and planned for; receive advice and information about their additional support needs; be part of discussions about the support that they will receive; and access dispute resolution procedures to resolve concerns.

These rights are balanced by safeguards and supported by a new children's service called: 'My Rights My Say', which will help children to access advice and support at every stage of the 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 representation for children who are appealing to the Additional Support Needs Tribunal.

Further information on the extension of children's rights and *My Rights My Say* can be found [here](#) for parents and carers or [here](#) for children and young people.

More Information? Further information about the range of related policies can be found in the *Supporting Children's Learning Code of Practice's* links to [Legislation, Policies and Guidance](#).

What options are available for schooling?

The law states that children and young people should be educated in a mainstream school, unless doing so would; not suit the child's ability, negatively impact upon the learning of other children in the school or cost the local authority an unreasonable amount of money to facilitate.

In Scotland, there is a range of provision available to meet children and young people's additional support needs. These include:

Mainstream provision, defined in legislation as provision that is provided usually by the catchment area primary or secondary school, or within a local primary or secondary school. Some mainstream schools also have a unit or base within them.

Special school provision, are also defined in law as schools who make provision wholly or mainly for pupils with additional support needs. Units or bases which are attached to mainstream schools (and which are wholly or mainly for pupils with additional support needs are in law, captured within the definition of a special school).

Provision where the pupils' needs are met through a mixture of provision, either within a unit within a mainstream school or through a mix of two different provisions. This forms a package of learning and support to meet individual needs, often referred to as **flexible provision or shared provision**.

What if we are not happy with the placement?

Information on all rights and responsibilities are included within the [Parent's Guide](#) to additional support for learning on the Enquire website. This includes information on what to do if you are not happy with your child's placement. There are a range of mechanisms available under the Additional Support for Learning Act to help resolve disagreements. A [factsheet](#) produced by Enquire sets out the various routes for raising concerns.

What about post-school transition?

The Additional Support for Learning legislation has specific provisions relating to transitions. Where a child or young person is expected to leave school (at the end of primary school or when leaving secondary school) the education authority has a duty to seek and take account of information from the appropriate agencies as thought fit, as well as information about provision which the agency/agencies are likely to make for the child or young person on leaving school. This should take place no later than 12 months before the expected leaving date. Similarly, they must provide information to other agencies no later than 6 months before a child or young person is expected to leave school. In both circumstances, where a child or young person decides to leave unexpectedly (i.e. changes school) this should take place as soon as reasonably practicable. More information can also be found in the Transitions chapter of this resource.

Case Study**Woodlands School, Edinburgh City Council (2014):**

This school makes provision for young people of secondary age who have a range of additional support needs. A key aim is to ensure that each young person leaves school equipped with the skills they will need for life, learning and work.

In order to achieve this, staff have developed a robust whole school approach to transitions. Planning for each transition, including primary to secondary and moving on from school, is highly personalised and designed to ensure that young people's learning needs are clearly identified and met. A strong feature of their approach is partnership working, especially with parents. This is highly developed with responsibilities and timeframes clearly defined. Young people benefit from access to a wide range of innovative programmes of learning and support, that help them to develop their confidence, communication and employability skills. Many of these programmes are delivered by a wide range of community based partners. The school regularly asks for the views of young people, their parents and other partners in order to improve its approaches to transitions and ensure success. All young people leaving this school over the past few years have achieved positive post school destinations.

More information? [Enquire](#), the national advice and information service for additional support for learning, provides a range of advice and information about parents' and carers' rights under additional support for learning, via their website. Their helpline can provide advice tailored to your circumstances, which you can call on: **0345 123 2303** from 9:00am to 4:30pm Monday-Friday. They also have a website called '[Reach](#)' specifically for children and young people.

Case Study**St. Peter the Apostle Secondary School, West Dunbartonshire Council (2014):**

St. Peter the Apostle is a large denominational secondary school which places great emphasis on children with additional support needs and their parents experiencing a successful P7 to S1 transition. A whole school commitment to inclusion, quality information gathering and sharing, personalisation of the curriculum, on-going flexibility in meeting learners' needs and a highly effective pupil support department are the key elements of their approach. Transition planning begins at P6/7 with information sharing across both schools and with involved agencies, parents and the child. A number of enhanced transition visits, including school/department tours, sample timetables, treasure hunts, canteen and break experiences, visits to the pupil support area and introductions to key staff including pupil support assistants help share expectations, allay anxieties and address emerging issues. These run in parallel to joint Assessment team meetings, and focused discussions within the Pupil Support Department. For a few children this will result in a referral to the Intensive Support Team which supports the most vulnerable learners. A pupil profile and passport are shared with subject teachers both at the start of S1 and following the post-placement review. The school has developed an exceptionally flexible approach to meeting the learning needs of all young people. This includes flexibility in timetabling that allows for a few vulnerable young people to have some of their lessons delivered in groups of four. One to one sessions are provided as are opportunities for quiet time. All staff and pupils benefit from high-quality awareness raising presentations on aspects of additional support needs and equality and diversity.

COMMUNITY LIFE

Children of all ages benefit and thrive from being able to play and socialise in their community, and encounter new places. Such experiences are key to developing the social and emotional skills that become so important in later life.

The UN Convention on the Rights of the Child upholds the importance of these interactions, declaring that every child has the right to relax, play and take part in a wide range of cultural and artistic activities. Yet barriers to accessing such activities still exist for many of our disabled children and young people.

In seeking to support activity that addresses social isolation and loneliness, we have invested significant resources in local community based projects.

Our Social Isolation and Loneliness Fund enabled 36 organisations to deliver programmes locally that were focused on reducing the effects of social isolation and loneliness in people experiencing disadvantage. Although the fund welcomed applications from projects aimed at a wide variety of cohorts, 25% of the successful applications focused on delivering for children, young people and families.

Case Study

Interest Link:

Interest Link Borders is an organisation that has a specific focus on improving the quality of life for children and young people with learning disabilities. Through their yearly reports, it is clear to see the positive impact that their one-to-one and group befriending services have on children and young people with disabilities. In the period 2016/17, 92% of service users reported as having more friends as a result of the work of Interest Link Borders, with 94% reporting better social skills and 96% reporting increased self-esteem.

Who has the right to play?

We want Scotland to be a nation which values play as a life-enhancing daily experience for all our children and young people. Evidence shows that play allows them to become more active, more confident and better able to develop key skills.

The Scottish Government, through its National Play Strategy, is therefore committed to improving the play experiences of all children and young people. However, it also recognises that disabled children and young people may face a number of barriers to being able to play successfully at home, nursery and school, as well as in the community. These barriers impact on their rights in relation to health and wellbeing, optimum development, inclusion in society and their right to enjoy their childhood.

Case Study**The Yard:**

Sam is almost 18; he has a learning disability. He has been a chatty, fun-loving member of The Yard's Thursday teen club for four years. Sam's mum, Jackie, says:

"The Yard is an amazing place. My son has been attending since he was four years old; he is nearly 18 and loves it as much today as when he started. He gets so much from the Thursday teen club – he cannot manage mainstream clubs so having the Thursday club is an absolute godsend.

Sam has become less fearful of new experiences and enjoys all the activities on offer to him. His confidence levels have skyrocketed since joining the club; he now feels confident enough to talk to someone if he is worried about an activity, and the staff are then able to encourage him and provide him with more information to enable him to participate. He often ends up loving the thing he was so worried about initially! Sam loves the fact that the Thursday club is his club – it lets him go and meet his friends to do all the regular things that teenagers do. As his mum, I know that he gets fed up of going to the cinema with his mum – the Thursday club allows him his freedom and independence to do things with his friends.

The club benefits my family in two ways. Firstly, it provides me with some much needed and much enjoyed time to do my own thing, and knowing that if it is a bad week, Thursday will be here and everyone will have time to re-group. Secondly, the enjoyment Sam gets from going to the club with his friends with no parents fussing over him, giving him the opportunity to be independent, is also a massive plus. When Sam is at the club, I can relax, and for a short while I do not need to worry about whether he is ok. I know 100% that he is being well cared for and having fun. This gives me time to recharge my batteries and de-stress."

Making play more inclusive is a priority and in order to understand how best to do this, 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 a wide range of additional support needs.

How are we helping communities?

[CashBack for Communities](#) is a unique Scottish initiative which takes funds recovered from the proceeds of crime and invests them into free activities and programmes across Scotland, with a particular focus on young people and those from the most disadvantaged communities in each local authority – those same communities which are likely to be hardest hit by crime and anti-social behaviour.

For the latest phase of the program (up to 2020) all CashBack projects have a sharpened focus on providing more opportunities for young people to get into positive destinations, such as further education, volunteering and employment. CashBack has boosted its youth employment projects, working in partnership with various organisations, such as the National Autistic Foundation who have been funded £583,000 through CashBack to support 300 young people with autism, who are also living in areas of deprivation, to overcome barriers to employment.

How are we making Sport more inclusive?

Both the Fairer Scotland for Disabled People Delivery Plan and the Curriculum for Excellence make reference to the importance of removing barriers for disabled children and young people to participate in sport activities at school and in the community.

[Scottish Disability Sport](#) in conjunction with Home Country Disability Organisations, has developed a UK Disability Inclusion Training course, which is partially funded by the Scottish Government.

It is aimed at helping those who are interested in getting involved with sport for people with a disability, such as coaches, teachers and leisure service providers. The workshop will allow participants to positively include people with a disability in physical activity and sport, for example, by recognising specific barriers to participation and considering ways in which any challenges can be addressed and potentially overcome or by recognising different communication styles.

Scottish Disability Sport are also working with various organisations across Scotland to improve access to sporting facilities for all disabled people to develop opportunities and improve performance in disability sport in Scotland. They want to ensure that any child, young person or adult with a disability can participate in sport and physical activity – regardless of their ability, geography or age.

They published their [first national strategy](#) in 2012, which helped to guide their work through to 2017 and they have recently published a [strategic plan](#) which sets out their aspirations for 2021 and beyond.

SDS organise national events every year in a range of sports such as swimming, athletics, boccia and wheelchair curling. They also have an annual programme of festivals, education and training opportunities for leaders, coaches and athletes. The aim of these programmes is to develop new and existing sports and to help athletes to realise their full potential.

They have a strong commitment to children and young people and established a [Young Persons' Sport Panel](#) in 2015. The panel consists of 12 members from all over Scotland and it aims to:

- give young people with disabilities a voice in sport
- support young people to develop as individuals
- help young people to gain experience across various areas within sport

What about Theatre and the Arts?

[Time to Shine](#) is Scotland's arts strategy for children and young people aged 0-25. Its core purpose is to enrich young people's lives through arts and creativity. Since its introduction, Time to Shine has enabled over 45,000 young people to take part in creative activities across 24 local authorities. This includes thousands of young people who have a disability, are from minority, ethnic or other backgrounds or are socially excluded.

It has three main strategic objectives which set out what it wants to achieve:

- Participation:** address inequalities and develop mechanisms which allow access for all
- Progression:** To create and develop mechanisms to nurture and celebrate ambition, enthusiasm and talent
- Provision:** To create and develop infrastructure for the children and young people's arts sector and ensure continuous quality improvement

INCLUSIVE PLACES

Families with disabled children repeatedly state that they feel unable to take full advantage of what Scotland has to offer owing to accessibility concerns. [VisitScotland](#), the national tourism agency, has been striving in recent years to make visitor and tourism facilities across the country more inclusive – be that for holidays, short breaks, or simply day trips in the local area.

VisitScotland has also launched an entirely revamped [Accessibility Guide](#) online tool – which helps all businesses in the tourism industry to develop a clear concise accessibility guide of their venue and service. The Scottish Government have also committed to improving physical and online access to Scotland’s historic environment and collections by 2019.

Public transport should be accessible to everyone who wishes to use it. The connectivity that it provides is a key enabler for disabled children and young people, and their families, to live a life of freedom and equal opportunity. We know that disabled children and young people face particular barriers on the transport network, and so emerging work will look to specifically take into account their needs and wishes. We must also be aware of the particular issues affecting disabled people living in rural or island communities.

To push forward improvement, Scotland’s first [Accessible Travel Framework](#) was launched in September 2016. This was the product of a two-year process of partnership working between disabled people, disability organisations, transport operators, and government. Co-production has been pivotal to this new approach, aiming to build on the assets we already have, and promote partnership working.

We continue to reform blue badge scheme, for example, expanding the eligibility criteria to include those children who, as a result of their disability may pose a risk to themselves or others in traffic. We are also considering provision of access to a companion bus pass to disabled under fives, where needed.

One of the areas of work in the Travel Framework involves enabling staff to support disabled people through awareness and training. We want to support those involved in transport to know how to provide an excellent customer service to disabled people across the range of impairments, including those with hidden disabilities. To this end, we will co-produce the development of a training module for all transport service and infrastructure providers in Scotland.

Why do we need Changing Places Toilets?

Despite improvements in other areas, the absence of fully accessible toilets can therefore mean some disabled children and young people continue to be excluded from everyday activities.

Many disabled children and young people need assistance with their personal care needs. Ordinary 'accessible toilets' in settings such as shopping centres and transport hubs do not always have the suitable space or equipment needed for the safe, dignified toileting of those with more complex disabilities.

The provision of [Changing Places toilets \(CPTs\)](#) can remove barriers to disabled children and young people enjoying public spaces with dignity. Expanding their presence is central to making Scotland a truly inclusive society.

Thanks to the work of PAMIS, a charity dedicated to people with multiple and complex needs, there are now over 150 in Scotland, located in an array of community settings, as well as a mobile Changing Places toilet – which removes barriers for disabled children and young people to attend pop-up events such as music festivals.

In 2017, a process of gathering information across all 32 local authorities began. We hope this will lead to novel solutions to encourage the provision of CPTs in these areas. Officials from Building Standards are currently working with PAMIS to establish building types and sizes that should always feature a CPT.

The expansion of CPTs has already brought tangible results. For example, since installing a Changing Places Toilet at Blair Drummond Safari Park in Spring 2017, there has been a marked increase in the number of families with disabled children visiting the venue, as well as school trips. This reinforces the value so many place on these facilities, but also the economic incentive for more businesses to provide good access for all.

Case Study**Michael Woods Sports and Leisure Centre:**

Located in Glenrothes, Fife, the centre highlights a commitment to inclusion for all. Fife Sports and Leisure Trust prioritised accessibility from the outset, consulting with Scottish charity PAMIS throughout the planning and design phase to ensure the building promotes accessibility for all by creating two Changing Places toilet facilities. One is located on the reception floor (dryside) and one in the changing rooms (wetside). Each of the 12 meters square toilet facilities feature:

- Bench – height adjustable, adult sized, wall mounted as well as free standing
- Hoist – ceiling, loop
- Non slip floor
- Emergency alarm
- Privacy Screen
- Accessible shower
- Peninsular toilet

The leisure centre also has disabled parking and a heated pool with tracking hoist. As a result of installing Changing Places facilities within the leisure centre, PAMIS have been able to develop an extensive programme of sports and leisure activities which promote the health and wellbeing of people with profound and multiple learning disabilities including Boccia sessions – indoor court games designed for people with profound and multiple disabilities. The centre is also used extensively by Disability Sports Fife to deliver a wide ranging programme of sporting activities for children and young people.

Andrew Smart, Leisure and Culture Programme Manager for PAMIS states “Changing Places toilets are always at the centre of developing our activities programme. They are life changing for local communities allowing families to access sports and leisure and improve their physical wellbeing. We only wish that every sports centre had these facilities.”

Annemarie (a parent): “My son requires full support. He loves swimming but requires a changing place. He is 11 years old and hoisted. We can only attend facilities that have a changing place facility. Sadly that rules a lot of places out and is a barrier. “

Kelly (a parent): “Having a changing place in Leisure centres means I can take my 16 year old son to participate in one of the few leisure activities that he can enjoy as a disabled person. It allows him to be changed in a dignified and comfortable way, as well as safe. Without this option we would opt to not leave the house as due to my son’s size and weight lifting him out of his chair onto a floor just isn’t an option. Having the brilliant changing facilities at the Michael Woods Centre really has made a massive difference to social opportunities for Kieran.”

Without fully accessible Changing Places toilet facilities, Fife families would not have access to leisure activities that promote improved health, wellbeing and quality of life. It is facilities like these that enables children and people with complex healthcare needs to have the same rights as everyone else and enjoy valued activities within their communities.

The expanding provision of Changing Places toilets is an important step towards Scotland embracing more inclusive public spaces. Similarly dedicated community spaces which are more sensitive of people with additional needs such as the expanding [Sense Scotland TouchBase](#) network or initiatives such as autism-friendly shops are vital steps that this resource will seek to drive forward.

Sense Scotland Case Study:**TouchBase Centres:**

Driven by a compelling vision to establish an inclusive centre of excellence for people with communication support needs, Sense Scotland embarked on a journey to create a new and vibrant community space for the people it supports and their families.

TouchBase Glasgow opened its doors in April 2008 to provide a welcoming and vibrant space for children, young people, adults and their families.

Located in Kinning Park in Glasgow, the centre offers a bright, welcoming and fully accessible venue where children and young people can safely access a wide range of creative, vocational and social experiences. Personal care suites to Changing Places standards are incorporated within the centre and a bustling courtyard with community café is the centre-piece of this pioneering, life-enhancing facility. The evidenced success of **TouchBase Glasgow** has led Sense Scotland to work with families in Lanarkshire and in Ayrshire to deliver two more TouchBase centres – one in Hamilton (**TouchBase Lanarkshire**) opened in April 2016 and one in Ardrossan (**TouchBase Ayrshire**) opened in June 2017. Sense Scotland has now secured a site in Dundee and **TouchBase Dundee** will take shape over the next two years.

The TouchBase developments are more than bricks and mortar – they offer a welcoming and safe environment which is rooted in the local community. TouchBases bring people together in a space where everyone can feel connected and included as part of the community. Individual day services are provided on 1:1 basis or in a group service dependent on the needs of the individual

supported. A wide range of added-value services are also provided including Early Years support, Family Advisory support and support for Young People transitioning from school in to adult life.

In this latter regard, **TouchBase Glasgow** has been home to an innovative transition programme for young people and their families called **One Giant Leap**.

One Giant Leap is Sense Scotland's lottery funded youth group programme which aims to work with young disabled people who are preparing to leave school. It focuses on providing social, educational and development opportunities for young people through youth groups which are now being developed across Scotland in each of the new TouchBases and also in Dundee.

Mum: 'One Giant Leap provides a consistency in my son's life when everything else is going pear shaped.'

Past research on this key transition stage for young people recognises the importance of friendships and places a strong focus on peer group support. **One Giant Leap** provides a safe environment, where activities and leisure are central to self-development in terms of practical, social and emotional skills. Awareness of rights and access to vocational training combine to improve the readiness of individuals with communication support needs to tackle the journey towards adulthood.

Mum: 'The school reported that since joining the Dundee group, R's confidence and interaction has surprisingly excelled within most subjects where group work is carried out; what are you doing, we have been trying for years to develop these areas?'

As part of this resource we will seek to ensure that the particular needs of disabled children and young people, and their wider families, are increasingly reflected in such developments.

SAFETY AND JUSTICE

Everyone has the right to feel safe when going about our daily lives, however, we know that some children and young people with disabilities experience discrimination, bullying and even violence because of perceived differences.

What if I'm worried about bullying?

The Scottish Government takes the issue of bullying very seriously. Bullying of any kind including bullying based on any type of disability is unacceptable and must be addressed quickly, whenever it arises.

The Scottish Government continues to fully fund [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. [respectme](#) work with everyone who has a role to play in the lives of children and young people to give them the practical skills and confidence to deal with bullying behaviour, wherever it occurs.

The Scottish Government recently updated its anti-bullying guidance: '[Respect for All: The National Approach to Anti-bullying for Scotland's Children and Young People](#)'. This guidance is for everyone working with children and young people and provides a holistic approach to anti-bullying. The approach forms part of our wider attempts to improve the health and wellbeing of our children and young people. It fits in with our on-going work to ensure children and young people feel safe and secure and are able to build up strong and positive relationships with their peers and with adults as well as our work to promote positive behaviour.

More Information? You can visit [respectme's website](#) for more information or call them on 0844 800 8600.

What is Hate Crime and how do I report it?

Hate Crime is wrong. It is against the law and everyone has the right to live their lives free from hate or harassment and without fear.

Hate crime is any crime that is motivated by malice and ill-will towards someone or a group because of their actual or perceived characteristic that is protected by the *Equality Act 2010*. You do not have to be physically assaulted or injured to be a victim of hate crime, hate crime can include having your belongings stolen, your property vandalised and abusive remarks made.

In some cases victims/witnesses of Hate Crime do not feel comfortable reporting the matter directly to the Police and may be more comfortable reporting it to someone they are familiar with. This is known as Third Party Reporting.

Why is Third Party Reporting important?

To try and help increase the reporting of hate crimes, Police Scotland is working with a variety of organisations that act as Third Party Reporting Centres allowing crimes to be reported in places other than Police Stations. Staff within these Centres have been trained to support a victim or witness in making a report to the police. They can also make a report on your behalf.

There are Third Party Reporting Centres throughout the country and they are just one of a number of ways to report a hate crime.

You can report a Hate Crime as follows:

- By Telephone 999 (emergency) 101 (non-emergency)
- In person at any Police station,
- [Find your nearest Third Party Reporting Centre](#)
- Or by clicking the following link - [Hate Crime Reporting Form](#)

How are we tackling Hate Crime?

Keep Safe is a national partnership with I Am Me Scotland and Police Scotland to create a network of Keep Safe places where anyone feeling lost, scared, vulnerable or has been a victim of crime can seek assistance. The Keep Safe network are volunteer premises (businesses and community buildings) who receive training to recognise hate crime and know how to report incidents safely. Keep Safe will be working with British Transport Police and Transport Scotland to expand the project across the public transport network, helping to encourage people to travel independently across local authority boundaries. [I Am Me Scotland](#) also have a suite of training resources that are available for use in schools, businesses, groups and communities.

How are we making communities safer?

[Building Safer Communities \(BSC\)](#) is one of the key areas that contributes to achieving the vision of a safe, just and resilient Scotland, where people live in communities that feel safe and are safe, allowing individuals, families and businesses to thrive.

Managed by the Scottish Government, Building Safer Communities is a collaborative partnership with local and national partners and communities, to drive forward and champion community safety. This means enabling everyone in Scotland to live in communities where they feel safe and secure, focusing not only on the consequences of crime and unintentional harm but investing in preventative approaches and tackling the underlying causes.

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 encounter problems in their lives may be asked to go to a meeting called a 'children's hearing'.

One of the fundamental principles of the Children's Hearings System is that children and young people who commit offences, and children and young people who need care and protection, are dealt with in the same system because these two groups often overlap.

Children and young people might need a hearing because some aspect of their life is causing concern. This could be for a variety of reasons, including not attending school or committing offences, but it is generally because there are significant concerns 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.

Anyone can make a referral to the Children's Reporter. However, they are usually made by social work, the police, health or education services. The hearing consists of three members of the local community who act as lay tribunal members, called Panel Members.

The Children's Reporter is supported by an organisation known as '[The Scottish Children's Reporters Administration \(SCRA\)](#)'. Their role is to:

- Facilitate the work of Children's Reporters,
- Deploy and manage staff to carry out that work,
- Provide suitable accommodation for Children's Hearings
- Provide information about the Children's Reporter and the hearings process

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. They are currently trialling Easy Read letters for those who need it. To receive this service from SCRA, you can ask them directly or your social worker can contact them for you. Similarly, their website 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](#) or 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 improved. As part of this, work has begun to examine how accessible hearings centres currently are in terms of facilities such as disabled access, hearing loop inductions and other auxiliary aids, so that SCRA can provide the right supports to children, young people and their families. SCRA have also created equalities ambassadors who plan to link in with the third sector to find out what kinds of auxiliary aids and tools children, young people and their families may need in order to understand the information SCRA provide and to be able to effectively participate in children's hearings.

More information? A number of different agencies work together within the Children's Hearings System to deliver care, protection and support services to the children and young people involved. The [Scottish Child Law Centre](#) and [Community Law Advice Network](#) provide free legal advice and information.

What about children or young people with offending behaviour?

The Scottish Government want to make sure that, where possible, children and young people who are involved in offending behaviour are diverted away from the criminal justice system and formal processes by providing them with the right support to improve their life chances and interventions which tackle the underlying causes of their offending behaviour.

The [Whole System Approach](#) (WSA) highlights the importance of supporting children and young people on a multi-agency basis, to provide streamlined and consistent planning, assessment and decision making processes and supports, to ensure they receive the right help at the right time.

If it is not possible to prevent them from entering the criminal justice system, children can be supported through the Children's Hearings System or they can be prosecuted if the offence is sufficiently serious.

It is crucial that children and young people are supported so they are aware of their rights and understand the complex legal processes. There are a number of resources to help them with this:

[Youth & Criminal Justice in Scotland: the young person's journey](#) is an online resource that guides young people, their families and professionals through each stage in the youth and criminal justice process for under 18s in Scotland.

[Journey through Justice](#) is an interactive guide that will help children and young people understand the journey through the justice system, following being charged with an offence by the police.

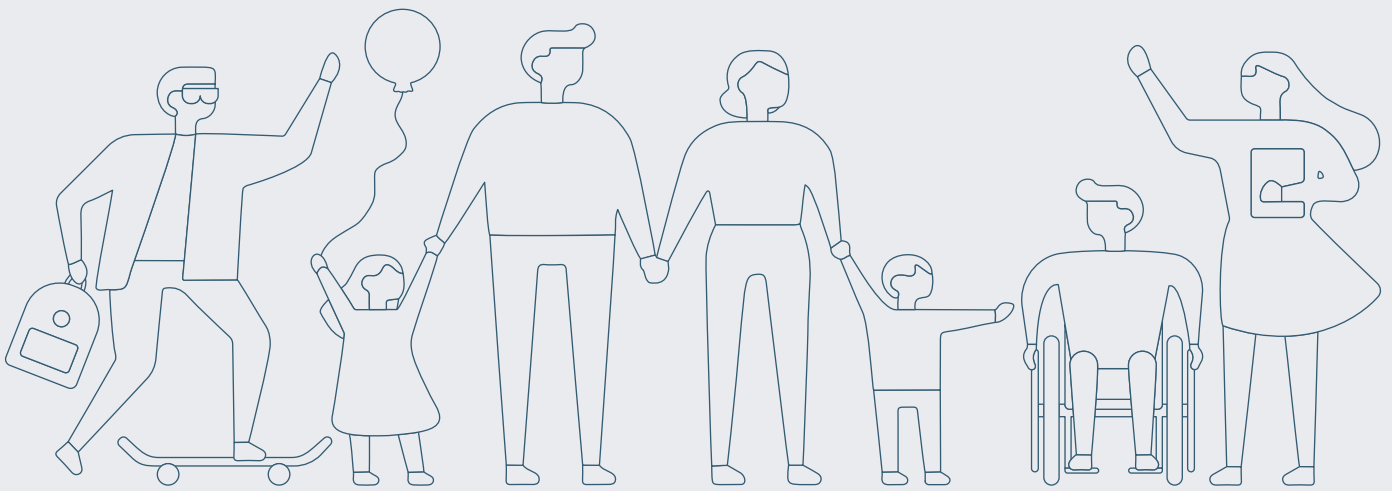
What about speech, language and communication needs?

Speech, Language and Communication Needs (SLCN) are extremely common in young people who offend. It can mean they are not able to communicate properly with police, children's hearings and justice staff. They may also struggle to understand the information they are given or what kind of help and support they can receive.

In order to tackle this, the Scottish Government's [Youth Justice Strategy](#) includes an action to improve awareness and support of SLCN of children involved in offending.

The Centre for Youth and Criminal Justice has also developed guidance for practitioners and managers who work with children and young people who offend or are at risk of offending. This includes a chapter on [Speech Language and Communication Needs in Youth Justice](#).

3. Transitions



Transition is the period when young people develop from children to young adults. It is not a single event, such as leaving school, but rather a growing-up process that unfolds over several years and involves significant emotional, physical and intellectual changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or those who care for the young person.

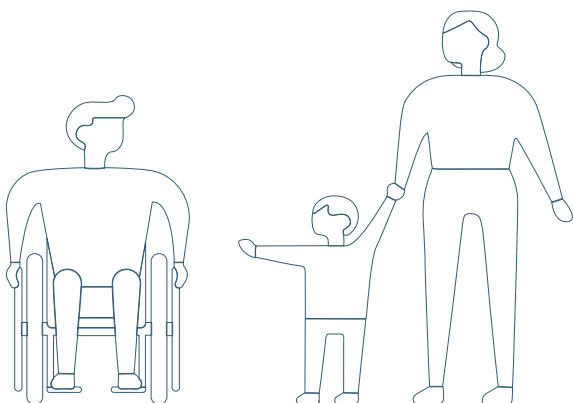
The policy context of this issue is multi-faceted, with a wide range of Scottish Government policies impacting on transitions for young people with additional support needs. These include: The *Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)*, The Right Help at the Right Time in the Right Place ([the Doran Review](#)), The *Children and Young People (Scotland) Act 2014*, Self-Directed Support and Welfare 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 – to name just a few.

The Health and Social Care Alliance, known as the ALLIANCE, were funded by the Scottish Government to produce a [report](#) which explores the transitions experiences of disabled young people and their families.

The study was wide-ranging and involved 29 young people and their families from across Edinburgh, East Lothian, West Lothian, Midlothian and Scottish Borders Council areas. The discussions undertaken with them, key professionals and managers of relevant services form the basis of this report. The aim of the report is to make a practical difference to improving transitions, using information, themes and solutions gathered from people who have lived experiences of transition.

It focused on a number of key issues, for example, the ways in which the principles of the Getting it right for every child approach have been applied and whether these are helpful to families. There was also a specific interest in the experiences of a co-ordinating lead professional and in the experience of planning which is based on a holistic consideration of wellbeing. Special attention was paid to the extent to which these core components are experienced in service transitions.

The report recognised and highlighted approaches which have contributed to effective transitional support and positive outcomes for the young people who experienced them. Conversely, it also looked at approaches which have contributed to negative experiences of transition. Based on these, it put forward a number of recommendations which are intended to support practitioners and managers in their practices, services and strategic developments.



PRINCIPLES OF GOOD TRANSITIONS

To achieve their full potential, young disabled people often require support in different areas of their lives, including the move from school or college, or the transfer from child to adult services. These may include: identifying and achieving participation in employment, education or training, managing welfare and housing changes, reviewing healthcare needs, providing information and advocacy, assessing capacity and managing risk.

The Principles provide a basis to inform, structure and encourage the continual improvement of professional support for young people with additional needs between the ages of 14 and 25 who are making the transition into young adult life.

The content of each principle has been predominantly informed by the work of the Scottish Transitions Forum, alongside relevant national legislative and policy developments. Crucially, the principles also align with the rights-based approach of the UN Convention on the Rights of the Child.

Principle 1: Planning and decision making should be carried out in a person-centred way.

Principle 2: Support should be co-ordinated across all services.

Principle 3: Planning should start early and continue at least to age 25.

Principle 4: Young people should get the support they need.

Principle 5: Young people and their families must have access to the information they need.

Principle 6: Families need support.

Principle 7: A continued focus on transitions across Scotland.

As set out in the 'Fairer Scotland for Disabled People' Delivery Plan, the Scottish Government is committed to driving forward positive momentum on this issue.

The [Scottish Transitions Forum](#) is funded by the Scottish Government and now has over 800 members representing a wide range of professionals, young people and their families. Membership is free and open to anyone who is committed to improving transitions for young people with additional support needs.

The forum's explicit aim is to improve the experience of young people (14 to 25 years) as they make the transition to adult life.

Its work is guided by three objectives:

- To guide and inform improved approaches to transitions across Scotland.
- To support people to work collaboratively, share learning, identify gaps in provision and generate solutions.
- To involve young people with additional support needs and their families in the work of ARC Scotland, the charity which facilitates the forum.

COORDINATED TRANSITIONS SUPPORT

Most young people are broadly optimistic about their transition and their future. However, young people and parents consistently comment that support for transitions should be more joined up with a single point of contact. Effective co-ordination of transition planning and support at a local level is therefore critical, particularly for those with learning disabilities or multiple and complex needs.

Co-ordinated approaches can be delivered in a number of ways. The most frequently used strategic approaches are transitions co-ordinators or local transitions forums or networks. Example partners who should be involved include:

- Children and young people themselves
- Parents and carers
- Health and allied health professionals from child and adult health services
- Primary and secondary health-care representatives
- Skills Development Scotland/careers services
- Local Opportunities for All representatives
- Child and adult social work services
- Third-sector services – such as support, advice and advocacy
- Education professionals pre- and post-16 education
- Local area co-ordinators
- Housing and accommodation providers

Young people and their families should always be at the centre of transitions planning and be provided with clear information about support available to them from all partners.

Independent Living Fund – Transition Fund

The Scottish Government created a five million pound scheme to support disabled young people in transitions (aged 16-21). This will be a broad discretionary scheme to support individuals to live independently and contribute to communities.

Short term grants will be awarded to allow the young person to explore, plan and achieve outcomes that they have themselves identified; and for which other sources of support are not actually available. It is not the role of the new scheme to replace existing statutory services, or substitute for delivery of their wider duties for provision of social care.

Work has taken place directly with disabled people to develop this fund, and the co-production process is continuing in the scheme's set-up. This includes development of the application process, making sure it is as accessible as possible and ensuring that help is available to an interested young person.

Further work is required to develop more consistent and joined up approaches to transitions that provide a single point of contact and accountability, for young people and their parents and carers.

More information? [ARC Scotland](#) facilitates the Scottish Transitions Forum.

ADULT HEALTH AND SOCIAL CARE

The wishes of children and young people should be at the centre of any decisions made about their health or social care support. This follows the belief that young people and those who care for them are best placed to know what they need, provided they have access to the right information and support. Legally, professionals and decision makers must have regard to the views of the child.

My transitions should be Planned and Co-ordinated: Care planning into adulthood should provide reassurance to children and young people that plans and systems are in place to avoid rushed or abrupt transitions. The national guidelines for best practice developed by various partners all stress the importance of planning transitions early - usually around age 14 - or immediately for young people entering support after that age.

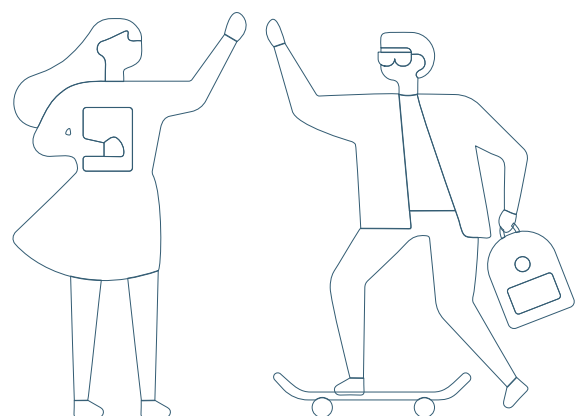
There is evidence that person-centred approaches provide a way to improve outcomes for young people in transition. Person-centred planning explores a young person's aspirations and is not limited by eligibility or entitlement. The focus is on what matters to the person before allocation of the budget; and identifies individual needs as well as strengths and assets of the young person and their network.

The Getting It Right For Every Child approach which places wellbeing at the centre of all considerations should also apply to transitions experiences. Adult assessments used during transitions need to be holistic and explore the personal outcomes of the young person regardless of whether they will be met with support from statutory or universal services.

My family should be Informed and Supported:

The needs and roles of family are likely to change as the young person they care for grows up. Families are often central to the continuing care of young people with additional support needs and are the people most likely to provide guidance and support during transitions.

Families should be provided with the information they need to make important decisions, such as those about self-directed support, and information should be provided in an accessible format. For example, NHS Scotland has developed an Accessible Information Policy committing to provision of information that is as easy to access and use as possible by the intended audience.



Case Study:**ALLIANCE Report “Experiences of Transitions to Adult Years and Adult Services”:**

B, is 16 years old and lives at home with parents and siblings. Although B’s case is an example of well co-ordinated planning and early thinking about transitions to adult services, B and her family still face some serious practical concerns.

B has cerebral palsy affecting all four limbs and is fed by gastric tube. She has some visual impairment. She has needed to be ventilated since she was 9 years old. She needs 24/7 care and so to assist her parents there are 2 shifts of carers. Nobody comes on weekends or evenings between 4.45-8pm.

The changeover in staff can be problematic because handover processes at night when family are tired can be prolonged every time there is a change. Also there are times when new staff are not familiar with the signs of something not being right.

The family rarely have the home to themselves. It is an essential part of the balance that they have some time to themselves – not so much apart from B as to themselves ‘as a family’. No professional carer can be left alone with B because of the complexities of caring for her. This means that even for a short visit to the shops, she would have to be dressed and fitted in to a wheelchair and taken with her mother. The option of two professional carers at home would not be funded.

The biggest concern about transition to adult services is that the formula for calculating respite will change and the number of nights that they get to themselves is likely to be 40-42 per year.

Even a small reduction makes a significant difference to the emotional and practical sustainability of this complex care at home equation. The advice the family received is that if the care for a young adult cannot be sustained on 40 nights per year, the alternative is full time nursing care. The financial cost of full time nursing or hospital care is apparently many times the cost of maintaining the level of respite on offer to B as a child. Her health and care needs will not get any simpler as she gets older and as her parents get older.

There is a service which provides respite as well as nursing and healthcare to those with profound and multiple health needs. This option will shortly be closing. B’s parents have guardianship for her and progressed this quickly when she turned 16. There are annual reviews at the school involving a range of professionals and there is a composite plan consistent with the Getting it Right for Every Child approach expectations. Parental perspective on the inter agency reviews is that while an integrated plan may be useful on paper, it is not necessary for all professionals to be present.

In short, transitions have begun and been considered early. By the time B needs respite in adult services and a day-care centre beyond school she will have some familiarity with care staff and setting so changes have been incremental. B’s close family will remain the foundation for all co-ordination and care.

Further work is required to explore the scope for developing a more unified national approach to identifying and measuring transitions outcomes and opportunities to share learning, tools and resources between local authority areas.

FURTHER AND HIGHER EDUCATION

Children and young people have a right to education and further education plays an important role in supporting many young people's personal and career development.

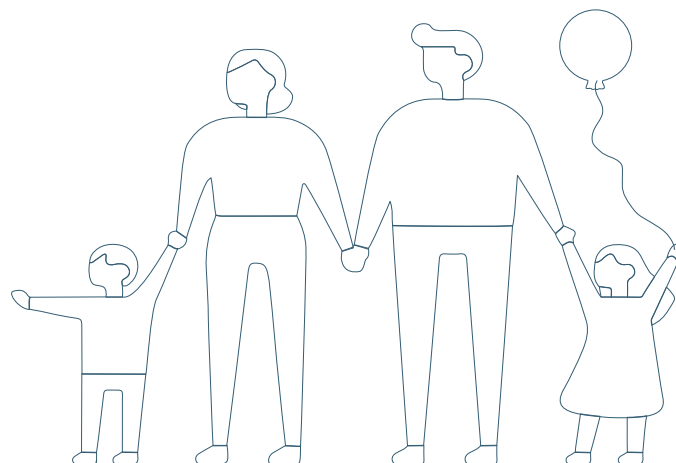
Where young people choose to attend further education, it is important that they receive the support they need while in college and to make the transition successfully. Following transition, further and higher education falls outside the supportive legislation provided by Getting It Right For Every Child and the *Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)*. There are a number [measures](#) in place to widen access to further and higher education.

Work is in hand through the Scottish Funding Council and with other partners to support young people with disabilities in both college and university; for example, improving the 15-24 learning journey; reviewing the Further and Higher Education student support package, and delivery of the (non-income assessed) Additional Support Needs for Learning Allowance.

All colleges and universities have a duty under the *Equality Act 2010* to make reasonable adjustments to ensure that students with disabilities which affect their studies are not placed at a disadvantage. This duty requires education providers to continually review and anticipate the general needs of disabled people, rather than simply waiting until an individual requests a particular adjustment.

Disabled students studying a course of higher education can apply to the Student Awards Agency Scotland for the [Disabled Student Allowance \(DSA\)](#). DSA is a non-income assessed allowance to cover any extra costs or expenses a student might have while studying, which arise because of their disability or learning difficulty.

This resource will seek to support work already undertaken to review and improve accessibility of further and higher education to all children and young people with disabilities.



EMPLOYMENT AND VOLUNTEERING

For many young people the transition into adult years is accompanied by a passage into employment, and living with a disability should not be an impediment to this route. Every disabled young person who can and wants to work ought to have the opportunity to find a fulfilling job, suitable to their skills.

As set out in the Fairer Scotland for Disabled People Delivery Plan, the Scottish Government is committed to better enabling disabled people of all ages to participate in the workforce. A key objective will be to (at least) halve the employment gap between disabled

and non-disabled people, recognising the much-needed talent, skills and innovation that they can bring.

One of the desired outcomes of the [Developing the Young Workforce: Scotland's Youth Employment Strategy](#) is to increase the employment rate for young disabled people to the population average by 2021. The [Equalities Action Plan](#) for Modern Apprenticeships (MA) in Scotland is a five-year plan includes specific improvement targets for MA participation by disabled people, including part-time and flexible engagement, to be achieved by 2021. This provides young disabled people with the highest level of MA funding until the age of 30.

Case Study:

Steven was initially referred to the Employability and Skills team in February 2015 after leaving school and began on Activity Agreement straight away. Previously due to his social and emotional needs, Steven found it difficult to manage day to day. Living in a rural village, travelling was going to be a big part of Steven's day and he was not overly confident about this. Steven took part in travel training and soon after was able to travel independently from his home to the Employability and Skills office for appointments and to take part in a Personal Development group. Attending the personal development group uncovered that Steven was keen to start in a work placement as soon as possible, and one was sourced at a golf course. Steven received excellent feedback from his supervisor at the golf course and did really well, but he felt that it was not the right setting for him and did not suit his needs.

Another placement was sourced for Steven and he began working in the kitchen of a restaurant. Again, Steven received excellent feedback, enjoyed this placement and got on with the rest of the team, but due to his needs, felt the noisy environment was too much for

him. A third placement was found for Steven and he began working in his local grocery shop in the stock room and on the shop floor. Steven formed positive relationships in this placement and, again, received excellent feedback with the manager of the store stating he would have loved to have offered Steven a job but unfortunately, due to him being under eighteen, it was not possible.

A placement was then sourced in the petrol garage in a nearby town. Steven continued to excel in this placement, so much so that he was offered a job, which he accepted. Steven says of his progression: "In my opinion, the Step programme helped me boost my self-confidence and public communication, by finding me a place of work." Steven's supervisor says: "Whilst Steven's work ethic and qualities have never been in question, his confidence and customer relations have gone from strength to strength. Such to the point Steven is an integral part of the team now at the store. We couldn't ask more of him as an employee." Steven's Employability and Skills officer, Maggie, says: "Steven was a pleasure to work with and I am extremely proud of the journey he has made."

As part of our commitment to prepare and support disadvantaged young people into and during employment we provide funding to the [Scottish Council for Voluntary Organisations \(SCVO\)](#) to deliver the Community Jobs Scotland programme (CJS). CJS provides support and job training opportunities for unemployed young people aged 16-29 who face additional barriers to employment, and confirms the Scottish Government's commitment to working with the third sector to provide that support.

A £500,000 Workplace Equality Fund aims to address long standing barriers to accessing the labour market. It is anticipated that the Fund will help to identify and promote practice that reduces employment inequalities, discrimination and barriers, including recruitment and progression for disabled young people.

In April 2017, the Scottish Government delivered a new approach to employability support. Using newly devolved powers we put in place transitional services that focus on helping disabled people and those with long-term health conditions find work in a manner not driven by the threat of benefit sanctions.

We are building on this by introducing [Fair Start Scotland](#), a distinctly Scottish employment support service which will have a focus on helping people with disabilities and those most disadvantaged in the labour market move into and sustain fair work.

Devolved employment services is just one of a number of levers that could provide more effective employment support for people, and in turn, create a fairer labour market and more inclusive growth. Our approach will require more effective integration and alignment of support and services to make the current landscape easier to navigate and which will ultimately deliver better outcomes for people. We will shortly publish an Action Plan that will set out how we can join up employability support with other services and systems, principally health, justice and housing as we know their ability to work together is critical to help those groups facing the most severe labour market inequalities.

We are currently funding 13 projects operating across 18 local authority areas that are testing innovative approaches to joining up employment support with health and social care, justice and housing services. Projects include early intervention approaches to help young people with convictions with developed pathways to training and employment at the earliest point that they enter the Justice system and helping people with mild to moderate health conditions to better manage their condition allowing them to return to work or to start looking for work.

Such enhanced integration and coordination is never more important than in the transition period for a disabled young person. It provides an opportunity to embed employment discussions and support much earlier in the transition planning process, enabling participation to be better identified and prepared for. In cases where employment is a viable option, it will also allow health and social care processes to be designed with this in mind, ensuring that such support does not become the cause of inadvertent barriers.

Case Study:

The Single Gateway Health and Work project commencing early 2018, in Fife and Dundee, will trial new solutions to help more people with disabilities and health conditions stay in or move into work. The project is aimed at enhancing the integration and alignment of health, employment and other services, to support ease of access and engagement with appropriate services for each individual. This will ensure that people can access the support they require at an early stage and before falling into long-term unemployment.

The project will include three key strands of work which will ensure people are able to access the right employment and health services at the right time. This includes:

The introduction of a new “Single Gateway” access channel – to provide quicker, more effective access to a range of existing, funded, health and work support services. This Single Gateway will act as a single point of contact not only for employers, healthcare professionals and Job Centre Plus, but also for self-referral, allowing people with health issues or disability, (struggling to stay at work or looking to access work) to have more choice in how they access services, more say in the support and intervention they need and fast support in managing their health condition and employment status.

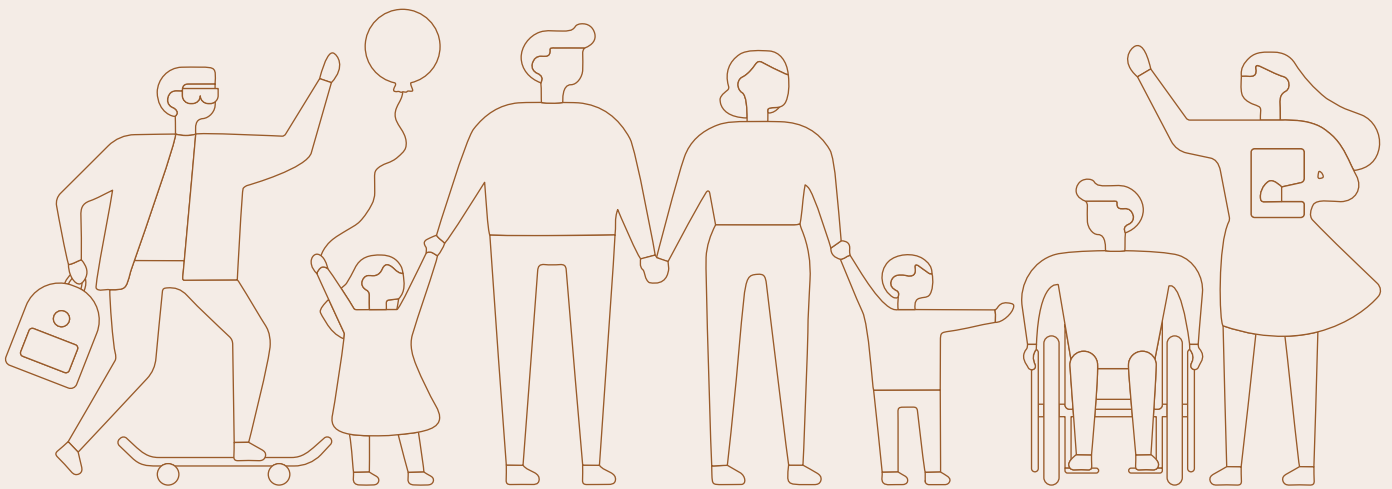
Alignment and enhancement of core health and work services – to more effectively integrate our health and social care and employability services to help disabled people and people with long-term health conditions move into and remain in sustainable employment.

A programme of improvement work with affiliated health, social care and other services to enhance the effectiveness and extend the reach of the gateway. This improvement work will focus on promoting better identification, referral and coordination practices, better triage/targeting of resources and better knowledge and behaviours in relation to physical health, mental health and work.

The mobilisation phase of the project has already started, with pre go live testing in Spring 2018 and full service delivery from Summer 2018 until Summer 2020. With an interim evaluation report to be provided in 2019 and final evaluation publication in Spring 2021, the lessons learned from the project will allow us to identify service and beneficiary outcomes, to inform wider application across Scotland.

We need to be much more proactive in recognising that employment is, with the right support, a valuable option for disabled young people. It is widely acknowledged that being in work can be good for an individual’s health and wellbeing, boosting confidence and independence. A number of schools for learners with additional support needs are currently developing career pathways for young people, in collaboration with employers, tailored to help them focus positively on their career aspirations. As these services develop we need to consult widely with disabled young people and their families, and take account of their views.

4. Concluding statement



In 2016, the Scottish Government funded a survey of families with disabled children and young people across Scotland to gather evidence about their information needs. Families said they would favour a centralised resource which signposts to relevant information and organisations. In response to these wishes, we began to develop the preceding resource in collaboration with a wide range of partners.

When families were asked what information they would most like to access, recurring themes included: types of professional support for their child, the law and their child's rights, transition, and leisure and social activities. This resource provides opportunities to signpost to existing sources of information about these topics and invites feedback on how these could be improved.

Families also reported a lack of sufficient information if their child has multiple conditions or complex needs or if they are looking support that is not condition-specific. Therefore, this resource does not set out to be an exhaustive list of condition-specific information, nor a directory of local services; there will be a focus on clarifying national policy and entitlements.

Families sought an improved understanding about the range of choices they felt they could make about support. Similarly, we know that access to clear and reliable information empowers families. Information needs to be shared consistently and in ways which are accessible for everyone. This resource aims to communicate information as inclusively as possible and makes particular note of how families can achieve more choice and control over the care and support that they need and are entitled to.

End of consultation document



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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: 978-1-78851-756-0

Published by The Scottish Government, June 2018

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS288006 (06/18)

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