

Disabled children and young people's experiences of social work services: a thematic review



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Glossary

Augmentative and alternative communication (AAC) are communication devices, systems, strategies and tools that replace or support spoken language.

The Association for Real Change (ARC) is an umbrella organisation representing the learning disability sector.

Commissioned services are social care services that have been identified, purchased and monitored by local authorities

Getting It Right For Every Child (GIRFEC) is a national policy designed to make sure that all children and young people get the help that they need when they need it.

The Promise Scotland was established to take forward the work of the Independent Care Review. In 2021, it published its plan for 2021-2024, outlining key outcomes that aim to ensure that Scotland's children and young people grow up loved, safe and respected, so they can realise their full potential.

Self-directed support is a way of providing social care support that empowers individuals to have informed choice about how support is provided to them with a focus on working together to achieve individual outcomes.

Statutory intervention are the social work functions which only registered social workers should be accountable for. They do not reflect every aspect of the contributions social workers make.

United Nations Convention on the Rights of the Child (UNCRC) is a widely ratified international statement of children's rights.

United Convention on the Rights of Persons with Disability (UNCRPD) is an international treaty that identifies the rights of persons with disabilities and outlines the obligations of State parties to promote, protect and ensure those rights.

1. Introduction and background

This report presents the key messages of our review of how well social work services contribute to ensuring disabled children have their rights respected and receive early care and support. It includes reflections and actions for social work services and Scottish Government to consider in order to improve outcomes for disabled children and young people. We considered children's experiences alongside their rights as enshrined in both the **United Nations Convention on the Rights of the Child (UNCRC)** and the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**. Our approach was built upon information already gathered through contemporary research and policy, using experiences of what good practice feels and looks like and what children have said matters to them.

Our review was carried out under Section 53 of the Public Services Reform (Scotland) Act 2010 and took place between May 2023 and May 2024. We considered the role of social work services within a **Getting it Right for Every Child (GIRFEC)** framework, including partnership working with other services. Our review did not include specific consideration of educational or health provision for disabled children and young people, as it was outside the scope of this review.

Background

Over the past 15 years, reviews and inspections of relevant services across the UK have highlighted variability in the experiences of, and outcomes for, disabled children and young people, compared to their non-disabled peers. **The Report of the National Review of Services for Disabled Children (2011)** concluded that to deliver better outcomes for disabled children, young people and their families services should work to Getting it Right for Every Child principles that include:

- creating a single system for the delivery of flexible, timely and appropriate services focussing on the needs of the child
- acknowledging that every child has views and preferences as well as a way of expressing them, and that disabled children have the same range of interests and aspirations as their peers
- within acknowledged constraints, endeavouring to empower children and families through the availability of greater choice and control.

More recently, Care Inspectorate Wales published a national review [Let me flourish](#) that highlighted similar findings that included strengthening the voice of disabled children, strengthening assessment and care and support, and early intervention.

The Scottish Government published [Transitions to adulthood strategy for disabled children and young people: statement of intent](#) in September 2023, recognising the well-documented evidence that planning

and support for disabled young people who are making the transition into young adult life could be improved. The strategy reiterated a commitment to [ARC Scotland's seven principles of good transitions](#). A publication that provides a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life.

The landscape across Scotland within which services for disabled children and their families are delivered has changed as a result of the Covid-19 pandemic. It continues to change with the continued squeeze on public spending. There is, however, an opportunity to build on the learning from the pandemic and the creative responses put in place by the services that support children.



2. Legislative and policy framework



We do all we can to ensure our children grow up in an atmosphere of happiness, love and understanding.... Our children are not left worried or isolated. We include and involve children in decisions about their lives and world, and protect their rights, dignity and wellbeing”.

“We respect, protect and fulfil human rights and live free from discrimination.”

Scottish Government (2016) [National Performance Framework](#)

The Scottish Government wants Scotland to become the best place in the world for a child to grow up, with opportunities for all in Scotland to flourish. Central to this is the recognition of, respect for, and promotion of children’s rights. As well as legislative and policy contexts such as the Children and Young People (Scotland) Act (2014), GIRFEC and [The Promise Scotland](#), Scotland also has duties to secure and enact the rights enshrined in both the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The policy and legislative context that impacts on the lives of disabled children and young people is varied and complex. This constantly changing landscape means that social work in Scotland has had to continuously review its role and adapt. The Scottish Government’s vision is for “a socially just Scotland with excellent social services delivered by a skilled and valued workforce, which works to empower, support and protect people, with a focus on prevention, early intervention and enablement”. ([Social services in Scotland: a shared vision and strategy 2015-2020](#))

However, social work services are facing significant challenges in respect of financial pressures, demographic changes, difficulties in recruitment and retention of staff and an increase in complexity and demand. These are impacting on social work services’ capacity to intervene early, build relationships with families with a focus on assessment of need and not resources. The [Setting the Bar](#) report highlighted that all these contributory factors have led to social work staff becoming involved later in supporting people and not until the point of [statutory intervention](#).

The national policy and legislative framework helped to inform the scope and areas of focus for our thematic review.

3. The aim and approach of our review

Our aim in carrying out this review was to learn and understand more about disabled children and young people's views and experiences of the support they received from social work services. We focused on social work's contribution to getting it right for every disabled child and considered how well disabled children's rights were being respected and upheld.

To help us keep disabled children and young people at the core of our review, it was vital we focused on hearing directly from children, young people and their families. We want this review to inform and influence policy makers and leaders in order to support services, plan for the future and improve the experiences of disabled children and young people.

Our approach

We were supported by our stakeholder community who helped us to develop the way we conducted our review. They helped us plan our approach to ensure disabled children, young people and their parents and carers could contribute.

The review took place between May 2023-May 2024. We gathered information in a variety of ways. At a national level, social work teams across the 32 local authority areas completed a survey that included data from their information systems and their perspectives on how well they believed they were supporting disabled children and young people. We reviewed publicly available data, research and reports which gave us an insight into what was important to children.

We worked with four areas who volunteered to be part of this review – Aberdeen City, Dumfries and Galloway, Dundee City and, Na h-Eileanan Siar (Western Isles). With the assistance of their social work services, we had the opportunity to meet with disabled children and young people and their families. We had conversations with social work staff, as well as other professionals involved as part of the team around the child support networks.

Disabled children and young people: Thematic review

- ▶ We reviewed publicly available data, research and reports
- ▶ National survey completed by **32** local authority social work teams
- ▶ We listened to the views and experiences of **83** disabled children and young people and **63** parents and carers in **4** local authority areas. This involved face to face or virtual meetings, either individually or as part of established groups; as well as via questionnaires issued on our behalf by local authorities. We were supported to do this by professionals who knew the child well, or by family members.
- ▶ Conversations with members of children's networks of support/team around the child
- ▶ We reviewed the journey of disabled children and young people through key processes such as assessment, planning and review by reading **117** records.
- ▶ We received **156** responses to a staff survey from a range of social work and social care professionals involved in supporting disabled children and young people. In addition to the staff survey, we met with **145** staff via **4** area focus groups, child support networks and other staff focus groups.
- ▶ We facilitated thematic focus groups that included social work staff and other professionals from the four areas. This provided an opportunity for the social work teams to reflect and share learning.

We recognise how important the use of positive and inclusive language is. We strive to continually challenge ourselves to ensure our language supports a rights-based approach. Across the country, there are different preferences in terms of the language to be used when discussing disability. In this review we have chosen to use the term 'disabled children and young people' in line the [Scottish Government's delivery plan, A Fairer Scotland for Disabled People](#).

We understand that, just like other groups of children, disabled children and young people are not a homogenous group and their experiences will be different.

When we refer to staff, we mean anyone who is employed in social work or social care services. In our key messages, we use the full term, social work and social care staff to highlight the point. When we use the term multi-agency staff, we mean all other groups of staff who work in services for children.

4. Key messages

- 1 Respectful relationships were key to building a culture of listening to and respecting children and young people's views. This ensured they were engaged in decisions about their care and support
- 2 Too many disabled children and young people's views, feelings and wishes were not being heard
- 3 When children and young people received the right support at the right time from social work services, this helped them to grow and develop
- 4 Increasing complexity of need and high demand for services was outweighing the availability of supports
- 5 Children and young people were not always provided with meaningful choices about the support they received.
- 6 Parents and carers routinely provide a significant level of care and support. Their wellbeing must be promoted and protected.
- 7 The quality of social work assessments, plans and reviews were variable and were not always properly addressing all the child or young person's needs.
- 8 The experience of transitioning into life as a young adult continues to be characterised by unpredictability and uncertainty for too many disabled young people.
- 9 Compassionate and dedicated social work staff were helping to improve the lives of children and young people. High workloads and recruitment and retention of staff significantly challenged staff teams.
- 10 The social work role was not always easily understood by families and/or other professionals.
- 11 Reliable data and a shared definition of disability are not available to inform future planning or to support the setting budgets.

Key message 1

Respectful relationships were key to building a culture of listening to and respecting children and young people's views. This ensured they were engaged in decisions about their care and support.



Article 12 UNCRC

Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.

Children, young people and their families told us that having a positive relationship with staff was important to help children and young people express their choices and feelings. The UNCRC makes it clear that the opinions of children and young people should be considered when adults make decisions about things that will affect them. They should be taken seriously, with their evolving capacities taken into account.

Building reciprocal relationships that engage with the child or young person's view of the world are at the core of meaningful participation. Children and young people valued spending time with staff, with one young person noting "we have fun together". We observed lovely, warm interactions, with children and staff communicating in a variety of ways, where it was clear that staff knew the child well and respected their choices. Participating in shared activities based on what staff knew about what the child or young person liked to do and using opportunities to talk together were important to children and young people.

Physical communication such as hugs, high fives and facial expressions were being used alongside visual symbols to support communication. This was especially important to sustain relationships with children and young people who used non-verbal communication. Parents and carers told us that when staff got to know their child this built trust and encouraged their child to express their views.

When staff had invested time to understand the child's preferred method of communication and worked alongside other important adults, this helped them to build a well-rounded picture of the child. Staff used a range of tools effectively to help children understand as much as possible about what was happening to them and to communicate their views. Conversations were well supported by drawings, play and **augmentative and alternative communication (AAC)**. We heard how some children and young people had been enabled by the multi-agency staff team around them to develop their use of communication aids to express their thoughts and feelings.

Staff recognised the key role of adults who spent the most time with children and the importance of ensuring opportunities to understand the child's view were captured in a variety of settings. This included asking speech and language therapists, school staff, **commissioned services**, parents and carers, and other adults who knew the child well to support communication. When adults worked together to promote participation, children and young people's voices were more likely to be heard.

Where advocacy had a positive impact, this was characterised by the advocacy worker having an appropriate level of skill and understanding about the child or young person's communication style and needs. This was only possible when the advocacy worker had had sufficient time to spend getting to know the child.

For many children and young people, their parents and carers played a key role in advocating on their behalf. This was particularly so in relation to children and young people with multiple and complex needs.

Our findings reflect previously reported views from children and young people. They have spoken of the importance of shifting away from one-off participation opportunities towards a culture of continuously listening to and respecting their contribution. This was important for children and young people who, due to the complexity of their needs, require a higher level of intervention than others. This included ensuring choices and decisions about everyday life were respected.



Key message 2

Too many disabled children and young people's views, feelings and wishes were not being heard.



Article 12 UNCRC

Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.

We found the most significant barriers to be high demand for services and pressures on resources. This meant that too often staff did not have the time to develop the relationships with children and young people necessary to support meaningful communication. When relationships were less secure, this was characterised by limited direct contact and frequent changes in staff. Staff were frustrated when they could not spend enough time getting to know the child or young person.

Parents and carers reported mixed experiences about relationships between staff and their child. One young person told us that poor experiences had affected their trust in staff. Delays in services being provided could also impact on relationships, as could staff having to prioritise other areas of work. For some children and young people it was more difficult to make and sustain relationships because of episodic involvement with staff, not having an allocated worker or where successive enquiries were handled by a different person each time through a duty system.

The situation was even more difficult for children and young people who were living in placements a significant distance away from their home authority. For these children and young people, the usual methods of keeping in touch when at a distance did not work. While video calls, phone calls and texts were helpful for staying in touch with parents and carers, they were not so helpful for these children and young people.

Some staff did not have the knowledge, skills or tools necessary to support meaningful communication with disabled children and young people. In our staff survey, just under half disagreed that they were knowledgeable in supporting disabled children and young people. Our survey results support the findings of the literature review we carried out.

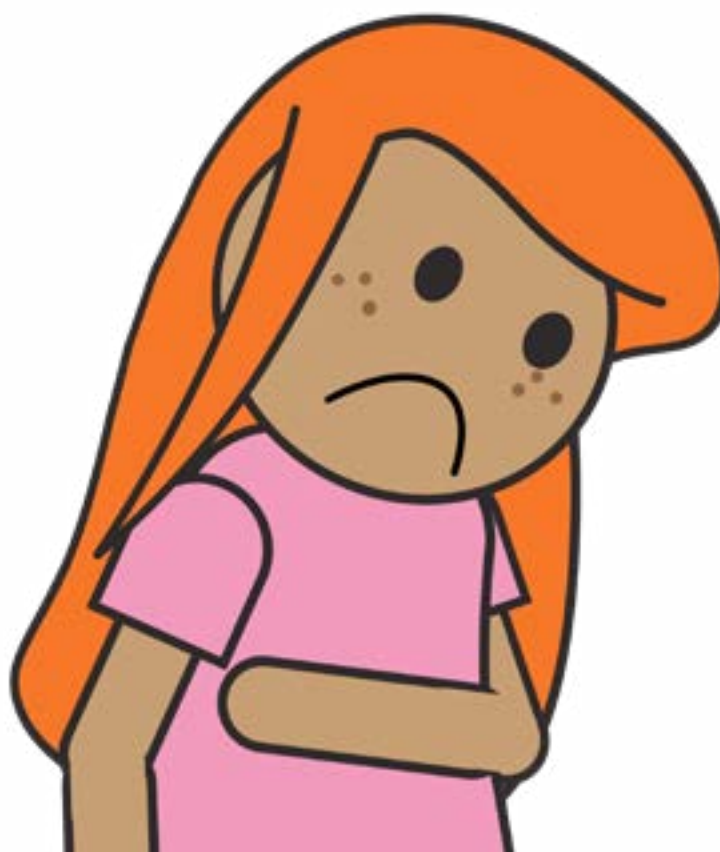
Most parents and carers were involved in making and reviewing plans for their child and appreciated when they were included in decisions and able to advocate for their child. Children's and young people's views were significantly less likely to be recorded in social work assessments and plans. In over half of the records reviewed, we found improvement was needed to ensure children and young people were listened to, heard and supported to make informed choices about their lives.

Independent advocacy worked well for a few children and young people. It was not available or its provision was delayed or less accessible for others. In some areas there were waiting lists for advocacy services for children and young people. Across Scotland there was no consistent approach to the delivery of advocacy services or in how these were experienced by children and young people.

We heard reports from children and young people about the impact of not having their voices listened to. For example, one young person told us they did not get to do some of the things that they wanted to and did not feel as though their views were always listened to.

Scotland's incorporation of the UNCRC into domestic law¹ is a significant step towards ensuring children's rights are fully embedded. As part of this, public authorities must take proactive steps to ensure compliance with children's rights in their decision-making and service delivery. Considerable effort by staff and organisations across the country is supporting progress towards this. The reality for many disabled children and young people, however, is that their choices and views often go unheard. This inequity is experienced acutely by those children and young people with multiple and complex needs.

¹ United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024



Key message 3

When children and young people received the right support at the right time from social work services, this helped them to grow and develop.



Article 15 UNCRC (Freedom of association)

Every child has the right to meet with other children and to join groups and organisations, as long as this does not stop other people from enjoying their rights.

Article 23 UNCRC (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community.

Article 31 UNCRC (Leisure, play and culture)

Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

The most valued supports were built around compassionate and meaningful relationships. Children and young people have said consistently that they need the people who look after them to love them and be kind, patient, respectful and have empathy and understanding. They value familiarity and routines and being supported by a combination of people they had come to know. We saw examples of close relationships between staff and children and young people, and of the importance of these in enabling access to both familiar activities and new experiences.

When available, the range of interventions provided through social work services and partner agencies often had a positive impact on children's lives. We heard about after school and outreach services, playschemes and clubs as examples of places children and young people went to have fun, relax and play alongside peers. Services which facilitated play were vital for children's health, wellbeing, happiness and development. Some services provided one-to-one support to enable children and young people experience the benefits of outdoor activities and interact with their environment, while being kept safe. Short overnight breaks were enjoyed by children and young people who required access to specialist equipment or additional support to participate in activities. We saw children and young people laughing, playing, being creative and learning new skills, while attending these services.

Access to play and leisure opportunities has consistently been highlighted as a priority by disabled children and young people and their families. Unfortunately, many disabled children and young people are still excluded from play and recreation spaces. Physical and social barriers mean that not every child feels welcomed or included in play spaces. Children and young people have said having friends, fun and laughter,

playing and having toys and having adventures is important for their healthy growth and development. They also value technology for playing and communicating.

As communities and universal services continue to struggle to provide accessible opportunities, we found social work and social care services made a unique contribution to reducing isolation, maximising participation in social and recreational activities and inclusion in local communities. Examples included the provision of the one-to-one care support required to enable children to go swimming or play safely in their local park.

Some children and young people who were unable to live at home benefited from specialised residential care commissioned by local authorities. They were supported in nurturing environments by care staff who were attuned to their individual wellbeing needs. The specialised supports provided at these placements were highly valued by families and we heard about the positive impact they had on children and young people's wellbeing. Many of these placements were far from the placing authority and it was, therefore, challenging to maintain connections between the child or young person and their home community. Local authorities also found it increasingly difficult to maintain these placements due to limited financial resource.

Highly committed and skilled foster carers made an important contribution to achieving positive outcomes for the children and young people who they cared for. We were able to observe warm and playful interaction between children and their carers. Temporary and long-term carers advocated on behalf of the children and young people in their care to ensure they had access to the help they needed to enjoy fulfilling childhoods.



Key message 4

Increasing complexity of need and high demand for services was outweighing the availability of supports.



Article 6 UNCRC (Life, survival and development)

Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.

Article 15 UNCRC (Freedom of association)

Every child has the right to meet with other children and to join groups and organisations, as long as this does not stop other people from enjoying their rights.

Article 23 UNCRC (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community.

For those children and young people who received supports provided or commissioned by social work services, this was usually a positive experience which was valued highly by families. However, we found too many children and young people's experiences were negatively impacted because of the limited capacity of these services.

Increasing demand and complexity of need was being experienced across the country. The majority of responses to our national survey reported social work and social care services did not have sufficient capacity to support disabled children and young people well enough. Respondents reported, for example, an increase in social work referrals for neurodiverse children and young people and their families. Alongside the increase in need, most services have experienced significant budget pressures and workforce challenges which has put pressure on whole support systems.

Limited capacity and growing demand were increasing the multiple inequalities faced by disabled children and young people. Across communities, the lack of inclusive mainstream activities was contributing to the demand for additional support for disabled children and young people. Families and staff told us about times when children and young people did not receive any support, enough support, or experienced delays before the right support was provided. This had a more significant impact on those children and families with the least resources to mitigate shortfalls in support, transport and opportunities to participate in activities in their community.

Services had to be prioritised for families who were in crisis. As a result, social work interventions were often about providing short breaks to support adult carers, protecting children where risks had been identified, and providing full-time care for those children and young people who could not remain with their parents. Maintaining a wider focus on supporting children and young people to reach their full potential and be active participants in their community has been increasingly difficult for staff and their leaders to achieve. Local authorities were increasingly making decisions based on availability of resources.

These challenges were experienced differently across Scotland's diverse geographical spread and, as such, local responses varied in terms of their own unique strengths and circumstances. Consistent access to specialist support was a significant challenge for rural populations. Children and young people living outside the main population centres experienced difficulty in accessing the right supports. However, they did benefit from easily accessible outdoor space, including parks, beaches and woodlands. Staff made great use of the natural world to provide opportunities for children to explore and enjoy sensory play.

In more urban populations, examples of maximising resources to meet need included developing hubs where children and young people could be supported effectively by a range of professionals who were co-located. Disability specific services provided opportunities for children and young people to spend time with their peers and engage in fun activities. However, increasing demand and reduced provision in these services meant some had high accessibility criteria or that they were not always available early enough.

Even in the better resourced areas, there was consensus across families and people who provided and commissioned services that resourcing for supporting children and families impacted by disability was inadequate.

Key message 5

Children and young people were not always provided with meaningful choices about the support they received.



Article 23 UNCRC (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community.

Article 12 UNCRC (Respect for the views of the child)

Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.

Self-directed support

- Option 1 – a direct payment, which is a payment to you or third party to pay for your own support.
- Option 2 – you direct the available support.
- Option 3 – the local council arranges the support.
- Option 4 – a mix of the above.

Self-directed support enables people to have control over their support. They should be able to use the funding allocated to them in a flexible way. It has the potential to enable children, young people and their families control over the use of funding and resources to provide timely and creative support. It plays an important role in ensuring children and young people can contribute to meaningful decisions about their lives.

In our national survey, most areas agreed that widespread use of self-directed support effectively delivered a range of options to promote choice and flexibility. When self-directed support was working well, we found this was characterised by clear processes, self-directed support leads or champions and training opportunities for staff. Third sector services were able to have a positive impact where they had been able to attract some investment.

Meaningful delivery of self-directed support was hampered by lack of choice of available services in some areas and difficulties with recruiting and retaining enough staff. Some parents had successfully used self-

directed support Option 1 to recruit personal assistants through their own community networks. However, in many instances, Option 1 was offered as the only alternative when commissioned services lacked capacity.

We found the effectiveness of implementing self-directed support for children and young people mirrored the findings and recommendations of the [Care Inspectorate's Thematic review of self-directed support in Scotland: Transforming lives \(June 2019\)](#). While capacity challenges have made it difficult to implement the full range of options, self-directed support continues to have the most potential to enable creative, flexible solutions to ensure the right support is available at the right time.

We heard from children and young people who wanted more choice about aspects of their support. Examples included wanting to be able to have more of a choice about activities they were enabled to participate in. Some activities were not accessible or available for some children and young people. For some, a lack of personal care support or one-to-one staffing meant they were unable to participate in community activities. The reality for some children and young people and their families was that they had no choice but to accept whatever support was available at the time or have no support at all.

More than one in three children and young people who completed our survey felt that they were unable to make choices about things that were important to them. Children and young people did not routinely have a choice about who they spent time with during their support, both in terms of workers and other children and young people. Opportunities to build lasting and meaningful friendships were not routinely considered as part of planning and review processes, despite the importance of this to many of the children and young people we met.

Key message 6

Parents and carers routinely provide a significant level of care and support. Their wellbeing must be promoted and protected.



Article 18 UNCRC (Parental responsibilities and state assistance)

Governments must recognise parental responsibilities and provide resources and support to help them fulfil their responsibilities.

Children and young people's experiences are inextricably linked to their whole family wellbeing. The Promise highlights that families must be given support to nurture their love and overcome difficulties which get in the way. We found the effectiveness of family supports to be mixed.

Our inquiry into [adult carers' experiences of social work and social care services 2022](#) highlights key challenges experienced by adult carers. We found similar challenges to be reflected by the parents and carers we heard from during this review. The impact of caring was significant and support was found to be the most helpful when parents and carers experienced compassionate and transparent relationships with staff. Most parents and carers were involved in plans and reviews for their child and parents appreciated when they were included in decisions and when services could respond flexibly.

Staff understood the complexities of balancing the rights of children and young people alongside meeting the needs of parents and carers, but at times struggled to find appropriate and local supports to meet the needs of the whole family. Challenges were compounded by the lack of accessible activities which increased reliance on parents and carers and hampered choice for children and families.



Key message 7

The quality of social work assessments, plans and reviews were variable and were not always properly addressing all the child or young person's needs.



Article 6 UNCRC (Life, survival and development)

Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.

Article 23 UNCRC (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community.

We know how important it is for children, young people and families to be able to trust the adults who are there to support them and that this trust is built upon clear and transparent communication. Through the processes of assessment, planning and reviewing, children and families should understand and be kept informed about arrangements for their care and support. National survey respondents were confident social work services had the right processes in place to facilitate care and support. They reported quality assurance arrangements were in place to support child centred assessments and care plans.

We looked at the quality of practice through reading a sample of children's social work records across the four local authority areas noted earlier in this report. In the higher quality records, we found evidence that children, young people and parents and carers had been listened to, and that staff had put the child at the heart of decisions that affected their lives. It is widely accepted among policy makers and academics that a culture of listening to the child, as well as their parents or carers, is necessary to ensure these processes are robust, inclusive and rights-focused.

Overall, we found the quality of disabled children's experiences of assessment, planning and reviewing processes to be too variable. This reflected the self-reported findings from many areas shared through our national survey. Despite the commitment by staff to address the child's needs as an individual, there was a clear tension between needs-based assessment, against the reality of time pressures and priorities from other competing demands such as child protection processes. Plans which were heavily focused on crisis management and resource availability did not always give sufficient attention to the right to live a fulfilling life.

Reviews generally took place in a timely manner and involved all relevant partners to the child's plan. We saw examples of reviews being effective in progressing children's plans. Resource panels, the role of which was to review assessments of need and agree service provision, were rightly challenging but ultimately, decisions were felt by staff to be based on resource availability.

There was a mixed response from parents and carers we spoke with about their experience of contributing to assessments, care planning and reviews. Some parents and carers expressed a nervousness or anxiety about reviews in particular, fearing the purpose was about reducing or removing funding or service provision.

Key message 8

The experience of transitioning into life as a young adult continues to be characterised by unpredictability and uncertainty for too many disabled young people.



Article 23 UNCRC (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.

The challenges for young disabled people as they move into adulthood have been well documented over recent years. Our review findings provide further evidence that we still have a long way to go if we want to make meaningful improvements to the lived experience of young disabled adults.

The Scottish Government's ['Transitions to adulthood strategy: statement of intent'](#), published in September 2023, has captured the recent research, engagement and national conversations on the experiences of young disabled adults as they move into adulthood. As this work was already underway when we commenced our review, we decided not to focus on this area. However, as young people and their families shared their experiences with us, we considered it necessary to make comment.

A positive transition between children's and adults' services should be characterised by clear and accessible information, having designated staff to co-ordinate and ensure joined up, wraparound support. The Statement of Intent highlights the well documented evidence that "planning and support for disabled young people who are making the transition to young adult life could be improved". Some key quotes from young people within the Statement include,



Not everyone will have the same path; success looks different for everyone...people shouldn't dictate what you do, you should decide what support you need."

"I always get really anxious to the point of feeling sick about all transitions. Had to hit rock bottom before I got any form of support...it felt like a tick box."

Our findings reflected the common experiences that were highlighted in the Statement of Intent. For example, inadequate transition planning, stress and uncertainty for the young person, changes in eligibility for services and support arrangements, inadequate account being taken of young people's capabilities, views, needs and aspirations.

Along with staff, parents and carers were concerned that the thresholds and eligibility criteria applied by adult social work services in response to resource pressures was a barrier to person centred care. Too much focus on what individuals could not do rather than a more holistic strengths-based approach was felt by many staff to be a common way to assess the needs of young disabled people as they entered adulthood. Some young people had been offered a building-based day service which, although suitable for older adults, was not tailored to meet the needs of young disabled adults.

Staff struggled to balance the reality of promoting person centred planning and upholding young disabled people's rights against available resource provision within adult services. Overall, we concluded the system was over-reliant on traditional service provision for adults. The reality experienced by too many young people and their families was overly complicated and stressful.

Key message 9

Compassionate and dedicated social work staff were helping to improve the lives of children and young people. High workloads and recruitment and retention of staff significantly challenged staff teams.

[Scotland's Promise](#) highlights the importance of prioritising relationships and the need for staff to bring their whole self into the workplace. Scotland must retain and recruit a workforce that really wants to work with children, young people and families and make a difference.

We met enthusiastic and compassionate staff, with strong values built upon nurturing relationships and children's rights. They were attuned to children and young people's individual needs and were working hard to provide them with the right help and care. We observed warm and loving connections between staff and the children and young people they worked with. Through shared play and laughter, we saw the lovely impact of these relationships.

Parents and carers have told us support by knowledgeable and skilled staff is a key characteristic of a good service. Staff who worked consistently with disabled children and young people found their knowledge and skills developed as their experience grew. Having good support from partner agencies was also considered especially helpful. This included information and advice shared from occupational therapists, teachers, speech and language therapists, physiotherapists and nurses.

Staff advocated on behalf of children and families and worked more than their contracted hours to ensure children received the support they needed. Similar to the conclusions of [Scotland's Independent Care Review](#), we found some staff to feel overwhelmed and frustrated at not being able to provide the right help to children and young people early enough. Staff told us they feel frustrated when they do not have enough time to build meaningful relationships, or when they cannot access the right supports.

Staff were working hard to minimise the detrimental impact on outcomes for children and young people. Challenges in the recruitment and retention of staff and long-term sickness absence are indicators of the worrying impact on staff wellbeing. The increasing use of agency staff to fill gaps makes it harder to build trusting relationships. Staff turnover was often an added source of frustration for children, young people and parents and carers.

Key message 10

The social work role was not always easily understood by families and/or other professionals.

The role of social work services was not made clear to some families. This was often perpetuated by media stereotypes or misinformation, and limited good quality information about the role of social work services. Some families were wary of social work involvement and for others, the role of social work services was viewed solely as the gateway to other services. We saw examples of difficulties arising following holistic social work assessments which did not support access to the services recommended to parents and carers by other professionals. Parents and carers felt more could be done through the development of easily accessible web-based information and more transparent details of the role of social work services.

For many of the families we spoke with, their request for support was made after long periods of 'managing' and 'struggling' using their own family and social networks. We spoke with parents and carers who described being at a point of crisis before making contact with social work services. There was a lack of consistency in what families could expect when they approached social work services for help. While a few received a timely response, many did not.

Staff across services were confident that GIRFEC provided a shared framework and language to build support around children and their families. Staff considered GIRFEC to be well-embedded and child-centred. When statutory intervention was required, professional teams around children and young people understood their roles and responsibilities. For some of the parents, carers and staff we met, the role of social work was less clear when voluntary arrangements were in place. When children's needs could not be met through universal services alone, some families experienced the route to accessing social work services to be lengthy and complicated. Parents and carers told us difficulties were compounded by a lack of information about the role of social work services and how families could access social work support.

When joint working between social work services and other agencies was well embedded and working well, this had a positive impact on children, young people and their families. In some areas, co-location of services had helped other agencies value and understand the social work role. Strengths in joint working helped to ensure children, young people and families had a good understanding of the care and support social work services could provide. Shared review processes helpfully minimised the number of meetings that families were required to attend and maximised resources to meet need. We also found reassuring examples of flexible and early interventions which had been enabled through strong partnership working.

Key message 11

Reliable data and a shared definition of disability are not available to inform future planning or to support the setting budgets.



Article 7 of the UNCRPD calls on states to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

Article 31 of the UNCRPD calls on States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies.

Responses from our national survey revealed that disability was defined and recorded inconsistently within social work information systems and across partner agencies' systems. We suggest that this makes it harder for local authorities and other services to plan the right care and support to ensure equal access to services and funding, now and in the future.

This is replicated across Scotland's wider data collection processes. [Are disabled children visible in Scotland's children's statistics? A review of Scotland's statistics on disabled children \(McTier, 2024\)](#) highlights many factors which contribute to these inconsistencies. These include confusion between disability and additional support needs; whether a medical diagnosis is needed or whether a parent's, carer's or child's self-declaration is sufficient. This confused picture means policy makers, leaders, funders and researchers cannot and do not have a full understanding of the number and needs of disabled children and young people in Scotland.

Our findings support those highlighted in Scotland's Promise Implementation plan, most notably that the data we use to tell national stories of outcomes rarely includes the things that children and families said are important to them.

Little progress has been made to improve the collection of disabled children's and young people's data in Scotland. The Scottish Government's (2022) [Data collection and publication - Disability: guidance](#) paper does offer a way forward for supporting more consistent data collection that is in line with the social model of disability, but further work is needed to ensure the questions are child-centred, usable for children's services practitioners and used consistently by services for children and young people.

Now that the United Nations Convention on the Rights of the Child has been incorporated into domestic law, children's rights should be respected, realised and legally protected in Scotland. It means that public authorities must take steps to respect children's rights in their decisions and actions. They will have to identify and address the gaps in fulfilling children's rights as well as demonstrating how they have considered children's rights when setting budgets.

5. Reflections for social work leaders, managers and practitioners

In this part of the report, we outline reflective questions for staff, managers and social work leaders. We hope these will helpfully support services' own self-evaluation of practice and subsequent activity to improve experiences and outcomes for children and young people. These can be used alongside our quality framework.

At the end of this section, we highlight key actions that are required of policy makers, funders and national organisations to ensure the necessary scaffolding is place to enable the improvement actions required.

KEY MESSAGES	REFLECTIONS
<p>Key message 1 Respectful relationships were key to building a culture of listening to and respecting children and young people's views. This ensured they were engaged in decisions about their care and support.</p> <p>Key message 2 Too many disabled children and young people's views, feelings and wishes were not being heard.</p>	How effective are you in building quality relationships with children and young people? If things are getting in the way of this, who can you work with to identify solutions?
	How do you ensure that children and young people's choices and preferences are considered and recorded within assessments and care plans?
	If you are a manager or senior leader, how are you enabling your staff to prioritise quality time building relationships with the view to upholding children and young people's right to contribute to decisions about their care?
	If resource provision is limiting choice, how are you collating this information and using it to inform future service planning?
	What changes are necessary to current and future commissioning arrangements to ensure that, where available, advocacy provision is accessible to all children and young people?

KEY MESSAGES	REFLECTIONS
<p>Key message 3 When children and young people received the right support at the right time from social work services, this helped them to grow and develop.</p>	<p>How easy is it for children and young people to receive the right help at the right time in your area? What needs to change to make this easier?</p>
<p>Key message 4 Increasing complexity of need and high demand for services was outweighing the availability of supports.</p>	<p>How do you know if the work you are doing with disabled children and young people is effective?</p> <p>How well are disabled children and young people's needs considered as part of your strategic needs assessment? How are changing service requirements informing your children's services planning?</p>

KEY MESSAGES	REFLECTIONS
<p>Key message 5 Children and young people were not always provided with meaningful choices about the support they received.</p>	<p>To what extent are you confident your implementation of self-directed support for children and young people will improve their choices about the support they need?</p> <p>What are children, young people and their families telling you about this?</p> <p>How are you reviewing your implementation of self-directed support to ensure the self-directed support principles and standards are embedded in key processes?</p> <p>What action is required to ensure the following is available: accessible information, support and training for staff, support for children and families and an increase in support options in communities?</p>

KEY MESSAGES	REFLECTIONS
<p>Key message 6 Parents and carers routinely provide a significant level of care and support. Their wellbeing must be promoted and protected.</p>	<p>How accessible are your routes for parents and carers to access support? How do you know this?</p> <p>How do you ensure parents and carers are supported to take up the offer of a carers assessment, in line with carers legislation? For example, how do you promote the benefits of having an adult carer support plan? Is your communication about this clear and accessible in a variety of formats?</p>

	How transparent are your resource decision making processes, for example, your resource panels? What more could you do to involve families in these processes?
	If you are a senior leader, how do you understand the impact of unmet need on parents and carers? How is this used to inform future service planning?

KEY MESSAGES	REFLECTIONS
Key message 7 The quality of social work assessments, plans and reviews were variable and were not always properly addressing all the child's or young person's needs.	How confident are you that social work assessments are used to make informed judgements and provide a holistic understanding of children's wellbeing?
	How well are practitioners enabled to participate in audits of key processes to maximise opportunities for learning and improvements in this area?
	How do you ensure the learning from audits leads to practice change and improvement?

KEY MESSAGES	REFLECTIONS
Key message 8 The experience of transitioning into life as a young adult continues to be characterised by unpredictability and uncertainty for too many disabled young people.	How are you working with your partners to address the barriers and challenges to effective transitioning between children's and adults' services for disabled young people?
	How do your commissioning practices support forward planning for services for young disabled adults?
	What action is required to ensure services can respond to the needs of young disabled adults in line with ARC Scotland's seven principles of good transitions?

KEY MESSAGES	REFLECTIONS
<p>Key message 9 Compassionate and dedicated social work staff were helping to improve the lives of children and young people. High workloads and recruitment and retention of staff significantly challenge staff teams.</p>	<p>What needs to be in place to ensure a supportive working environment for all staff?</p> <p>If you are a manager, what supports do you have in place to ensure staff feel respected, valued and that their contribution is recognised?</p> <p>If you are a senior leader, how are you promoting leadership capacity across the workforce, encouraging creativity and ensuring staff are enabled to exercise appropriate initiative and professional judgement?</p> <p>How are you working with others to respond to recruitment and retention challenges?</p>

KEY MESSAGES	REFLECTIONS
<p>Key message 10 The social work role was not always easily understood by families and or other professionals.</p>	<p>How do you assure yourself that the information you share with families is accessible and describes what children and families can expect from social work services in your area? How do you gather feedback from children and their families about how well this is working?</p> <p>How well is the social work role understood by all agencies, particularly when working with disabled children and their families? What more can you do to help build a better understanding of the role of social work?</p>

KEY MESSAGES	REFLECTIONS
<p>Key message 11 Reliable data and a shared definition of disability are not available to inform future planning and setting budgets.</p>	<p>What action needs to be taken to ensure data relating to disabled children and young people is being consistently and accurately recorded?</p> <p>How well is data relating to disabled children and young people informing planning and budget setting, to meet the needs of disabled children and young people now and in the future?</p> <p>How well do you use children's rights impact assessments to identify, research, analyse and record the anticipated impact of any proposed law, policy or measure on children's rights and wellbeing?</p>

Actions required from policy makers, funders, national organisations and senior leaders in local authorities, health and social care partnerships and community planning partnerships.

The responsibility for improvement sits with us all. The actions noted below will require a shared approach across Scottish Government, local authorities, national and local organisations and public bodies, including the Care inspectorate.

Actions required:

- ▶ The views of disabled children and their families must be considered as part of service mapping, understanding unmet need and service planning.
- ▶ A robust approach to gathering and analysing data on disabled children and young people must be implemented, both in social work services and wider. This must be used effectively to inform service planning and improvement.
- ▶ We must take action in response to the views of disabled children and their families to ensure gaps in service provision are addressed.
- ▶ The role of social work services in providing care and support to disabled children must be clearly defined and understood across agencies. Clear and accessible information should be available and communicated to children and their families. This should include eligibility criteria.
- ▶ Opportunities for effective early intervention should be strengthened.
- ▶ Opportunities for play and friendships, along with other areas that are important to children, should be maximised. This will need a collective and holistic response.
- ▶ Adequate resourcing must be made available to enable services to develop and improve.

During our review, we were struck by the desire of staff to improve the service they provided. Some, however, noted they were not sure what they could do to make a difference. During our thematic focus groups, staff found the opportunity for reflection on practice to be helpful. Following on from this, we heard from staff and managers about their wish for a national community of practice to support information exchange and the dissemination of good practice examples. This would help facilitate creative and flexible responses to national challenges and provide momentum for change. We would encourage partners across local and national bodies to take this forward.

Conclusion

Much of what we say in this report is not new. Research and other reviews from Scotland and across the rest of the UK have provided strong evidence about the lack of equity of opportunity and services for disabled children and young people. Our work built on these findings as we engaged with young people and their families in different areas of the country to understand their experiences. We concluded that too many children and their families were not receiving the help they needed at the right time. We found that the necessary improvements have not been made.

Social work services often do not have the capacity to intervene early to prevent difficulties getting worse and to uphold children's rights. We found support was not available equally and disabled children's choices and views about how their care and support was provided, often went unheard. The pressures on the system have resulted in an over-reliance on parents and carers, who themselves, were not always well supported.

The messages from our review tell us that social work and social care services have an important contribution to make to the realisation of the principles of GIRFEC. Staff, managers and leaders responded flexibly and with dedication to new challenges brought by the Covid-19 pandemic and the ongoing financial pressures on families and public services. Disabled children and young people have better experiences when this is supported through the establishment of trusting relationships with those who are supporting them. Social work services need to be available at the right time and as part of a well-coordinated approach with other services.

Over recent years social work and social care services have faced unprecedented challenges which have had, and are continuing to have, a significant impact on the delivery of services. Throughout our review we saw the impact of continued funding challenges within public sector spending. Decisionmakers have had to prioritise statutory and safeguarding responsibilities for children. Disabled children and young people who do not fall into these categories are not afforded priority. Recruitment and retention of staff within the social work and social care sector further added to pressures on the whole system.

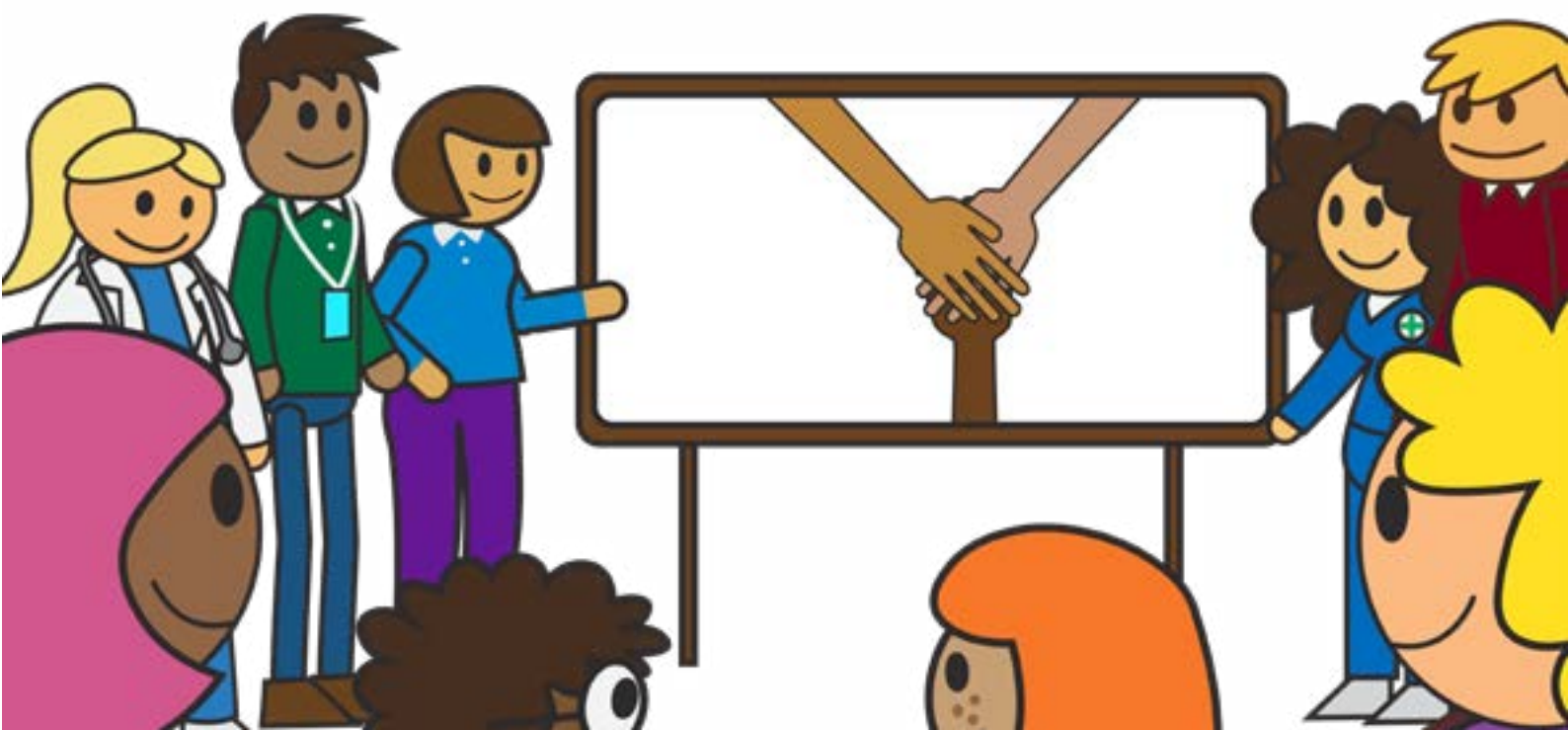
Funding and other resource pressures are compounded by inadequate recording systems and a lack of robust data about disabled children and young people. Scotland has an obligation to ensure that effective local and national systems are in place to protect the rights of disabled children and young people. This includes best use of children's rights impact assessments and improving the collection and analysis of disabled children's and young people's data in social work and more widely. This would help to identify gaps, better plan to meet needs and protect children's rights.

GIRFEC is well understood across the country and provides the policy framework for services which ought to be the driver to realise children's rights on a day to day basis. The aspirations of Scotland's Promise to all children and young people and the incorporation of The United Nations Convention on the Rights of the Child into domestic law presents an opportunity for real change. The responsibility for improvement sits with us all and cannot be made through local action alone. Scottish Government, public authorities, national and local

organisations must work alongside disabled children and their families to take the action collectively to respect and uphold the rights of disabled children and young people.

The examples we found of nurturing, compassionate care and support must become the norm and be experienced equally by all children and young people.

In light of current financial and resource pressures, a national conversation is required about the reality of resourcing and the impact on disabled children's lives. Only when all these elements come together will Scotland realise its ambitions to become the best place in the world for a child to grow up, with opportunities for all in Scotland to flourish.



Appendix 1: Stakeholder community

Our community was made up of representatives from the following organisations and networks.

Organisation

CELCIS

East Ayrshire HSCP (social work)

Disabled children's child protection network

Scottish Government

Scottish Commission for People with Learning Disabilities

Luna (Learning to Understand Needs and Abilities project)

Young inspection volunteers (Care Inspectorate)

Healthcare Improvement Scotland

Social Work Scotland

Health and Social Care Alliance Scotland

Disabled children and young people's advisory group

RNIB (Royal National Institute of Blind People)

University of Edinburgh, Tooled Up Education

The Children and Young People's Commissioner Scotland's office

In Control Scotland

Children in Scotland

The Promise Scotland

Appendix 2: Extract from national survey

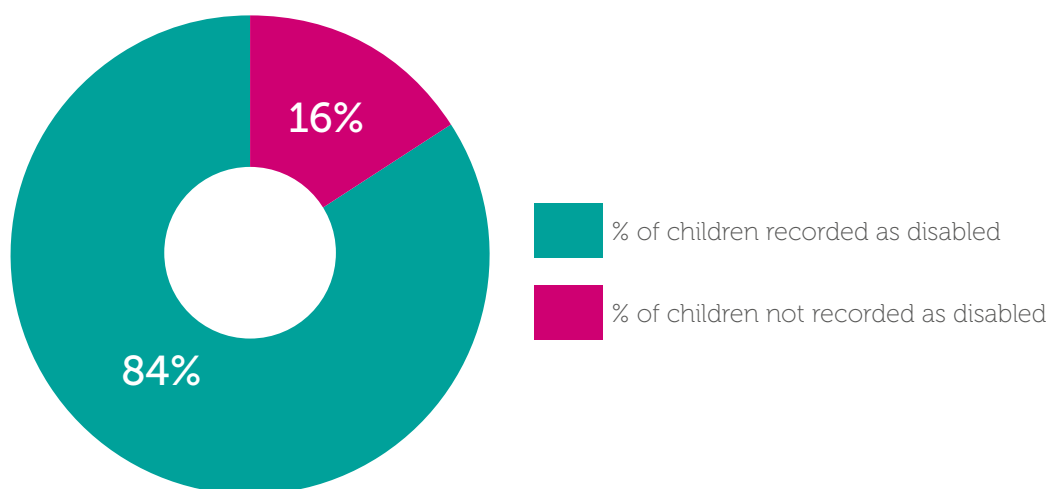
Information collected from social work information systems: Snapshot of 31 March 2023 data.

The following information has been extracted from the survey responses that were completed by social work teams across 32 local authority areas. The survey provided perceptual information that helped to contextualise our key messages. Across the questions almost all social work teams expressed uncertainty about the accuracy of their data.

Twenty-three local authority areas have specialist social work disability teams supporting children with the most complex needs.

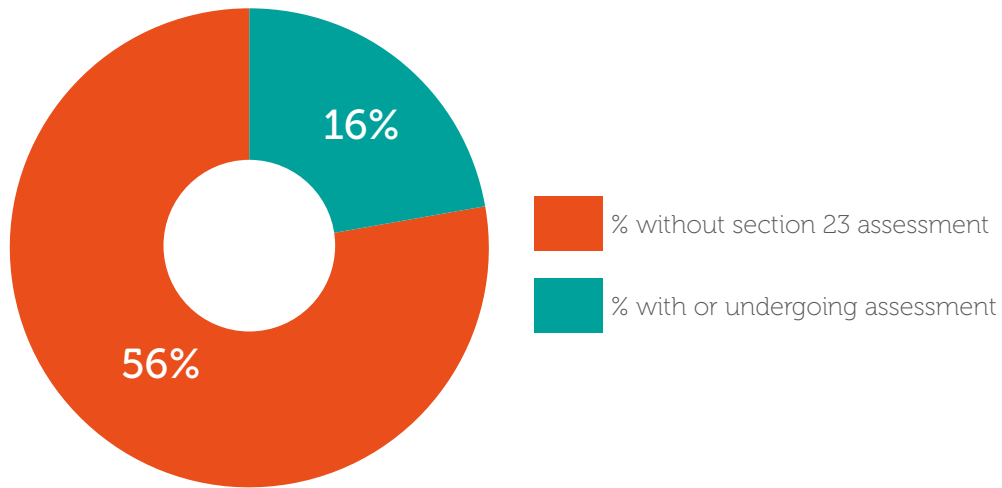
In Scotland 51,326 children and young people up to the age of 17 years were recorded on social work information systems and 16% (8,203) of them were recorded as disabled. There was significant variation across social work services in the proportion of children recorded as disabled from the lowest of 9% to the highest of 52%.

% of children and young people recorded as disabled

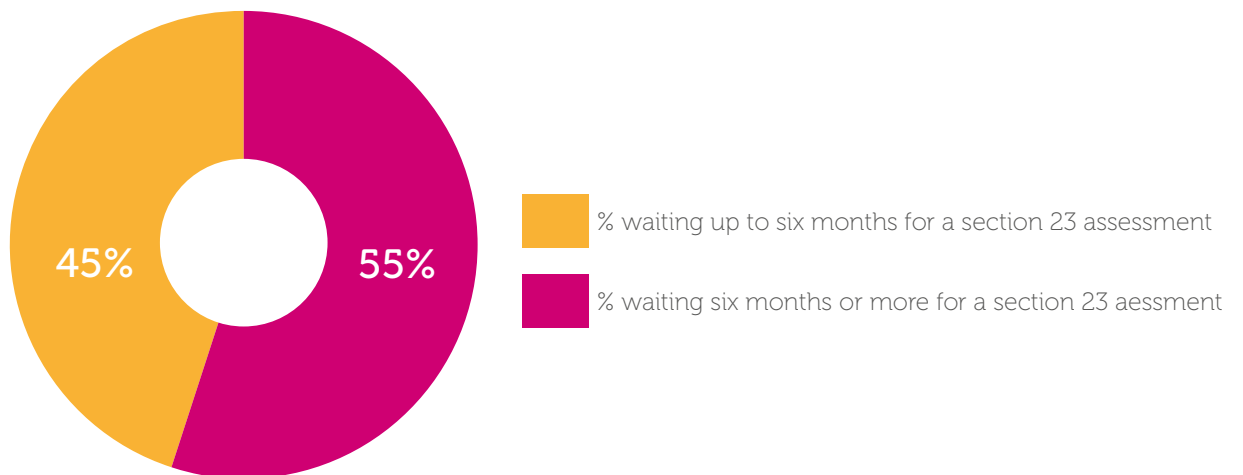


Section 23 assessment

% of disabled children and young people with or undergoing section 23 assessment*

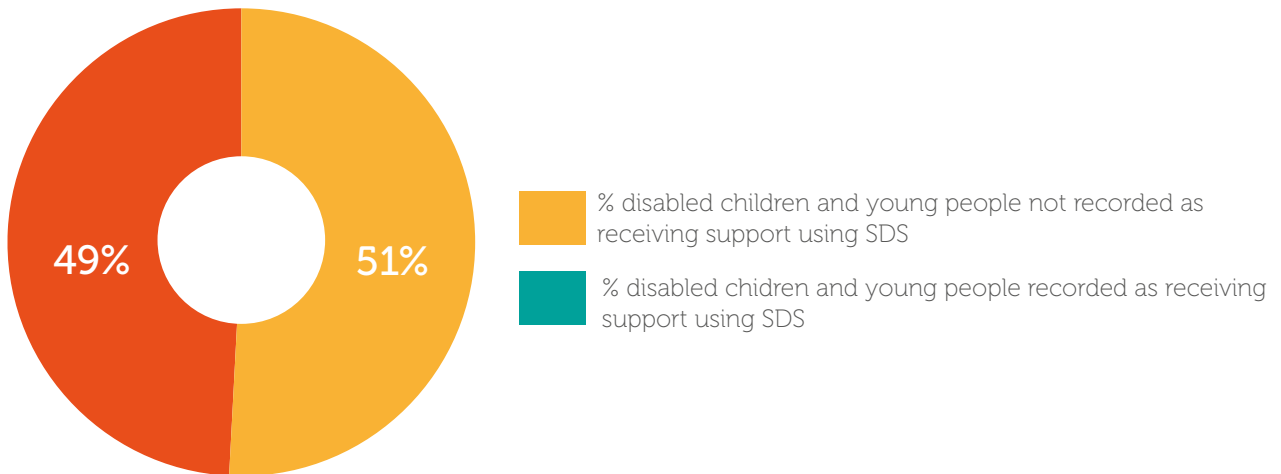


Length of wait for a section 23 assessment



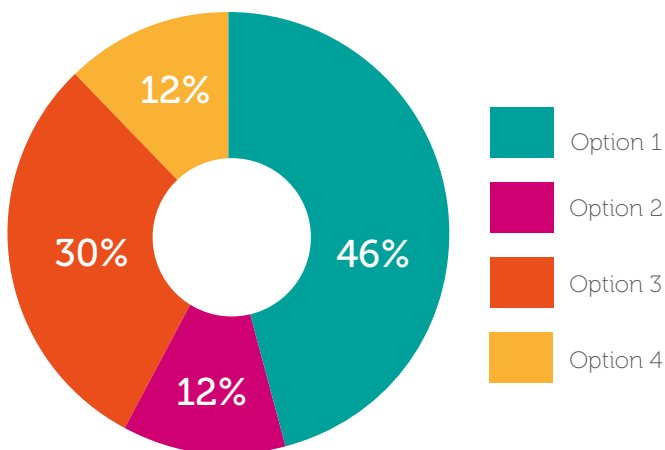
Self Directed Support

% of disabled children and young people receiving support through SDS*



*Two councils expressed uncertainty about the quality of their data in this area .

% of disabled children and young people using SDS options 1-4



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