Children in Northern Ireland

Left Out:

Disabled Children's Rights and Experiences in Northern Ireland

New evidence from a representative survey of parents and carers

June 2026

Contents

Foreword

Disabled children and young people have the same rights as every other child: the right to participate, to be included, to access education and healthcare, to play, to feel safe and valued and to reach their full potential. These rights are clearly set out in the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Yet the findings in this report demonstrate that, for many disabled children and their families in Northern Ireland, these rights are not being realised in practice.

This report provides important new evidence on the experiences of disabled children and their families across a wide range of areas, including access to services, education, healthcare, participation, financial wellbeing, play and leisure and inclusion. The findings reveal persistent and significant inequalities between disabled children and their non-disabled peers, alongside the cumulative pressures experienced by families caring for disabled children.

Throughout the research, parents and carers consistently described systems that are difficult to navigate, slow to respond and insufficiently coordinated to meet their children's needs. Families spoke about long waiting lists, barriers to accessing support, financial pressures, social isolation and the emotional toll of continually having to advocate for their children. Many also described feeling unheard, unsupported and left to manage increasingly complex challenges alone.

At the same time, this report also reflects the strength, resilience and determination of disabled children, young people and their families. Despite the barriers they face, families continue to advocate for inclusion, participation and better opportunities for their children. Their experiences and voices are central to this report and provide a powerful account of the realities facing many families across Northern Ireland today.

The findings highlight the urgent need for coordinated and sustained action across government and public services. Improving outcomes for disabled children requires more than isolated policy commitments or short-term interventions. It requires a rights-based, cross-government approach that recognises the interconnected nature of the challenges families face and ensures that disabled children are meaningfully included in decision-making, policy development and service design.

Importantly, this report comes at a time of significant policy development in Northern Ireland, including the development of a Disability Strategy and ongoing reform across education, childcare and children's social care. These developments provide a critical opportunity to address many of the inequalities identified throughout this report. However, meaningful change will require leadership, investment, accountability and a sustained commitment to improving the lives of disabled children and their families.

We hope that this report will contribute to a greater understanding of the barriers disabled children continue to experience, while also providing a strong evidence base to inform policy, practice and future action. Most importantly, we hope it will help ensure that disabled children and young people in Northern Ireland are supported not only to access services, but also to participate fully, feel included and enjoy the same rights, opportunities and quality of life as their peers.

Natalie Whelehan
Chief Executive, Children in Northern Ireland (CiNI)

Terminology

This report primarily uses the term, “disabled children,” in recognition of the social model of disability, which understands children to be disabled by barriers within society rather than solely by impairment or condition. However, some quotations, survey responses and legal or policy references may use alternative terminology, including, “children with disabilities”.

Executive Summary

This report presents new evidence on the experiences of disabled children and their families in Northern Ireland, based on a representative survey of 1,105 parents and carers conducted by Social Market Research (SMR) on behalf of Children in Northern Ireland (CiNI).

The findings reveal a consistent and deeply concerning pattern of inequality across multiple areas of children's lives. **Disabled children are significantly less likely than their non-disabled peers to have their rights fulfilled across access to services and support, education, health, participation, play and leisure, family life and standard of living.** These inequalities are not isolated or occasional; rather, they reflect structural and systemic barriers that affect everyday life.

Across every area examined, parents and carers of disabled children report poorer experiences and outcomes than those of other families. The evidence consistently points to systems that many families perceive as difficult to navigate, slow to respond, fragmented and insufficiently resourced to meet the needs of disabled children and their families.

The research identifies particularly stark inequalities in relation to access to services and support. Families of disabled children were significantly more likely to report difficulties accessing support, lower confidence that services are meeting their child's needs and greater frustration navigating complex systems. **Only 44% of parents and carers of disabled children agreed that they receive the right support to meet their child's needs through public services,** compared with **67% of parents and carers of non-disabled children**.

More than three-quarters (77%) of parents and carers of disabled children said their child needs more support than they are currently receiving through public services, compared with **39% of parents and carers of non-disabled children**. Similarly, **73% said it is a struggle to access public services to support their child's needs**, compared with **39% of parents and carers of non-disabled children**. Many families described feeling left to "fight" for support, often navigating fragmented systems with limited guidance or coordination.

The findings also demonstrate the impact on family life caused by the cumulative pressures experienced by families caring for disabled children. **95% of parents and carers of disabled children report experiencing at least one significant impact on family life, compared with 63% of parents and carers of non-disabled children.**

Parents repeatedly described emotional exhaustion, stress, social isolation and financial pressure while attempting to secure support for their children. **Almost seven in ten (67%) parents and carers of disabled children reported high levels of stress or anxiety because of caring responsibilities**, compared with **41% of parents and carers of non-disabled children**. **One-third (33%) reported having been diagnosed by a GP with anxiety, stress, or depression, compared with 18% of parents and of non-disabled children.**

The findings also show high levels of emotional exhaustion and burnout among parents and carers. **Almost half (47%) of all respondents reported feeling emotionally exhausted or burnt out, while 30% reported difficulties sleeping because of their caring role.**

Parents and carers of disabled children were significantly more likely to report every health and wellbeing impact measured in the survey. **Overall, 93% of parents and carers of disabled children report experiencing at least one negative impact on their health and wellbeing because of their caring responsibilities, compared with 47% of parents and carers of non-disabled children.**

Difficulties in navigating the system and accessing support was a clear issue for parents and carers of disabled children, with **90% reporting at least one difficulty navigating systems and accessing support**, compared with 45% of parents and carers of non-disabled children.

Healthcare emerged as a major area of concern throughout the research. **Almost two-thirds (65%) of parents and carers of disabled children reported difficulty accessing the healthcare services and treatment their child needs**, compared with **36% of parents and carers of non-disabled children**. Many families describe waiting for assessment, diagnosis or treatment for their children. **Approximately three in ten (31%) parents and carers of disabled children reported that their child was currently waiting to be assessed or diagnosed**, while a similar proportion (32%) said their child had already been assessed or diagnosed but was now waiting to receive treatment. Only around one-quarter (26%) reported that their child was currently receiving treatment.

Families described lengthy waiting times for autism and ADHD assessments, difficulties accessing therapies and mental health support, poor communication between services and inconsistent follow-up after diagnosis. Many children were reported to be waiting years for assessment, diagnosis, or treatment, often without appropriate support while waiting. Among those waiting to be assessed or diagnosed, the most common waiting periods were between one and two years (37%) and between two and five years (31%). **Nearly one in ten (9%) reported waiting more than five years for assessment or diagnosis.** Of those families waiting for treatment for their children, half reported waits of between one and five years. **Again, nearly one in ten (8%) reported waiting more than five years for treatment.**

87% of parents and carers of disabled children reported that delays or difficulties accessing healthcare had negatively impacted their child in at least one significant way, including increased anxiety, worsening health conditions, missed developmental milestones and reduced participation in education and community life.

More than one-third (36%) of parents and carers of disabled children believed their child's right to the highest attainable standard of healthcare under Article 24 of the UNCRC was not being met, compared with 19% of parents and carers of non-disabled children.

The research also highlights significant inequalities within education. Parents and carers of disabled children were substantially more likely to report difficulties accessing educational support. **More than half (53%) of parents and carers of disabled children reported difficulty accessing the educational services their child needs**, compared with **23% of parents and carers of non-disabled children**. **One in five (20%) parents and carers of disabled children stated that their child attended a mainstream school that did not meet their needs, while almost three-quarters (73%) believed their child required more educational support than they currently receive**.

Parents and carers of disabled children were substantially more likely to report school-related anxiety, bullying, exclusion and unmet educational needs.**1 in 4 disabled children (24%) had been bullied or intimidated in school**; **1 in 5 (21%) had been excluded from particular classes or activities, absent for long periods (19%) and been put on a reduced timetable (19%)**. **Overall, 85% of parents and carers of disabled children report that their child had experienced at least one significant school-related issue, compared with half (50%) of non-disabled children.**

Families with disabled children were also much more likely to highlight the impact of a lack of educational support and delays in accessing support on their child's education than those with non-disabled children. **Nearly half (47%) of parents and carers of disabled children, compared with 22% of parents and carers of non-disabled children, believed their child is falling behind because their educational needs are not being met. Almost two-thirds (64%) of parents and carers of disabled children agreed that delays in accessing educational support have negatively impacted their child's education, compared with 26% of parents and carers of non-disabled children.**

Families frequently described having to continually advocate for support, long delays in assessment and statementing processes and educational environments that they felt were insufficiently flexible or inclusive. **Almost three in ten (29%) parents and carers of disabled children believed their child's right to an effective education under Articles 28 and 29 of the UNCRC was not being met compared with 10% of parents and carers of non-disabled children.**

Participation, inclusion and social isolation also emerged as major themes within the research. **More than four in five (81%) parents and carers of disabled children reported that it is difficult for their child to participate fully in society**, compared with **21% of parents and carers of non-disabled children**. Parents consistently described their children feeling excluded from activities, lacking opportunities to participate in decisions affecting their lives and experiencing loneliness and isolation. **Eighty percent of parents and carers of disabled children expressed concern about their child's social isolation**, compared with **37% of parents and carers of non-disabled children**. **Only a third (36%) of parents and carers of disabled children believe society generally has a positive view of their child, compared with nearly three quarters (72%) of parents and carers of non-disabled children.**

There is also strong support among parents and carers for strengthened legal protections. **More than four in five (82%) parents and carers of disabled children agree that more laws are needed to protect their child's rights, while 83% agree that more laws are needed to protect their own rights as parents and carers.**

More than one-quarter (26%) of parents and carers of disabled children believed their child's right to participate in society under Article 12 of the UNCRC was not being met, **compared with 17% of parents and carers of non-disabled children.**

Barriers to play and leisure opportunities were also significant. **Almost two-thirds (62%) of parents and carers of disabled children reported that it is difficult for their child to access play and leisure services, compared with fewer than one-fifth (18%) of parents and carers of non-disabled children.** Disabled children were substantially less likely to have access to inclusive recreational opportunities, accessible facilities, or appropriately trained staff within leisure settings. **Only around one-third (34%) of parents and carers of disabled children agree that their child finds it easy to participate in social activities, clubs, or informal play with other children, compared with almost three-quarters (74%) of parents and carers of non-disabled children.**

Parents repeatedly described children being excluded from clubs, sports and social activities because environments and activities were not designed to accommodate their needs. **Seventy percent of parents and carers of disabled children said their child often feels left out of activities other children routinely participate in**, compared with **25% of parents and carers of non-disabled children**. Families described the emotional impact of exclusion, with **two-thirds (66%) of parents and carers of disabled children agreeing that their child feels lonely or socially isolated because of limited access to leisure opportunities, compared with 22% of other parents and carers.**

More than one-third (38%) of parents and carers of disabled children believed their child's right to access play and leisure services under Article 31 of the UNCRC was not being met, compared with 10% of parents and carers of non-disabled children.

The research further demonstrates the severe financial pressures experienced by many families caring for disabled children. Families reported higher costs associated with disability, including transport, therapies, specialist equipment and increased energy costs, combined with reduced employment opportunities resulting from caring responsibilities. **Almost half (48%) of parents and carers of disabled children reported increased costs related to their child's needs**, while **more than one-third (38%) reported struggling financially to meet those needs**. **Three-quarters (75%) of parents of disabled children said the financial support currently available does not reflect the true cost of living with a disability.**

Parents repeatedly described the inadequacy of current financial support and the emotional toll associated with financial insecurity, benefit systems and unmet need. **91% of parents of disabled children report experiencing at least one significant financial or employment-related impact, compared with 57% of other parents.**

One in four parents of disabled children (25%) said that their child's right to an adequate standard of living under Article 27 of the UNCRC was not being met compared with 11% of parents and carers of non-disabled children.

Almost four in ten (39%) parents and carers of disabled children believed their disabled child's right to be supported to reach their full potential and be provided with opportunities to participate actively within their communities under Article 23 of the UNCRC was not being met.

The evidence throughout this report highlights that the issues faced by families with disabled children are interconnected. Difficulties accessing healthcare affect education and wellbeing. Financial pressures limit participation and inclusion. Delays in support contribute to stress, anxiety and worsening outcomes. The findings therefore point to a pattern of inequality that is cumulative, multidimensional and systemic, rather than isolated to individual services or circumstances.

The report also raises important questions regarding the extent to which disabled children's rights are being realised in practice in Northern Ireland. While a range of legal protections and international human rights frameworks exist, including the UNCRC and the UNCRPD, many families described experiences that suggest a significant gap between legal rights and lived reality.

The evidence points clearly towards the need for coordinated, cross-government action to improve outcomes for disabled children and their families. In particular, the findings highlight the importance of:

- improving access to services and reducing waiting times;
- strengthening early intervention and preventative support;
- addressing the additional costs associated with disability;
- improving inclusion within education, leisure and community settings;
- increasing investment in disability support services;
- strengthening coordination between services;
- improving support for parent carers;
- ensuring disabled children and families are meaningfully involved in decision-making; and
- delivering stronger legal protections and accountability mechanisms.

The development of the Northern Ireland Executive's Disability Strategy, alongside ongoing reform within special educational needs and disability (SEND), childcare and family support and children's social care, provides an important opportunity to address the inequalities identified throughout this report. However, families' experiences suggest that meaningful change will require sustained investment, leadership, accountability and practical action across government and public services.

Disabled children are entitled to the full realisation of their rights under the UNCRC and the UNCRPD. This report provides robust evidence demonstrating where these rights are not currently being realised in practice and identifies the urgent need for action to ensure disabled children in Northern Ireland are able to participate fully, access appropriate support and reach their full potential.

Introduction

Disabled children and their families are a significant part of the population in Northern Ireland, yet there remains a lack of robust, up-to-date local evidence about their lives, experiences and the challenges they face. There is currently no clear or consistently agreed figure for the number of disabled children in Northern Ireland. One of the key challenges in understanding prevalence is the absence of a single agreed definition of disability across government departments, services and datasets. Different statistics use different measures, including disability, long-term health conditions, SEN, or receipt of disability-related benefits, making direct comparison difficult.

Census 2021 data indicates that around 5% of children aged 0–15 in Northern Ireland had a limiting long-term health problem or disability.[1] In addition, Census data recorded approximately 19,000 children with autism or Asperger syndrome, many of whom are aged under 18.[2] More broadly, administrative data suggests the number of disabled children and young people under 18 is significantly higher when wider definitions are used: around one in five pupils in Northern Ireland schools are identified as having SEN.[3] Together, these figures demonstrate that tens of thousands of children and young people across Northern Ireland are living with disabilities or additional support needs.

The lack of consistent definitions and robust local data presents significant challenges for service planning, policy development and resource allocation and risks many children and families remaining invisible within systems intended to support them. While a growing body of UK-wide research highlights the inequalities experienced by disabled children and young people, there has been comparatively limited Northern Ireland-specific research examining the realities of family life, access to services, participation, financial pressures, health inequalities and broader wellbeing outcomes for these children and their families. This report seeks to help address that evidence gap.

Policy Context

The need for this research is underscored by evidence from across the UK demonstrating the disproportionate challenges experienced by families with disabled children. National data suggests there are approximately 1.8 million

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[1] NISRA (2021) Census Main Statistics: Health, Disability and Unpaid Care: https://www.nisra.gov.uk/publications/census-2021-main-statistics-health-disability-and-unpaid-care-tables

[2] UK Data Service (2022) Second phase of Northern Ireland census data released: https://ukdataservice.ac.uk/2022/12/21/second-phase-of-northern-ireland-census-data-released

[3] O'Connor et al. (2023) The prevalence of special educational needs in Northern Ireland: A comparative analysis: https://doi.org/10.1080/08856257.2022.2127082

disabled children and young people aged up to 19 living in the UK,[4] the vast majority of whom are cared for at home by their families.[5] Research consistently shows that these families are more likely to experience poverty,[6] social isolation,[7] poor mental health,[8] and reduced employment opportunities.[9] Families with disabled children are more than twice as likely to live in poverty as those without a disabled child,[10] while many parents are forced to reduce working hours or leave employment entirely because of caring responsibilities.[11] Existing research also highlights the emotional impact of caring, with over half of parent carers reporting treatment for stress, anxiety, or depression.[12]

Disabled children and young people also face significant inequalities across education,[13] healthcare,[14] participation and community life.[15] Evidence points to higher rates of school exclusion,[16] unmet Special Educational Needs,[17] delays in

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[4] DWP (2026) Family Resources Survey: financial year 2023 to 2024: https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2023-to-2024/family-resources-survey-financial-year-2023-to-2024

[5] Contact (2026) Key statistics about families with disabled children: https://contact.org.uk/help-for-families/campaigns-and-research/research/

[6] JRF (2026) Disability and Poverty: https://www.jrf.org.uk/uk-poverty-statistics/disability

[7] Bacon et al. (2025) Disability, loneliness and relationships: a thematic report: https://www.gov.uk/government/publications/disability-loneliness-and-relationships-a-thematic-report/disability-loneliness-and-relationships-a-thematic-report

[8] Disabled Children's Partnership (2022) Left Behind – Six Months On The impact of reduced support for Disabled Children, their Parents and Siblings: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2022/03/Left-Behind-6-months-on-DCP-Report-2022.pdf

[9] Support SEND Kids (2024) Fighting for your SEND child: the Hidden Costs report: https://supportsendkids.org/content/resource/515/fighting-for-your-send-child-the-hidden-costs-report

[10] DWP (2025) Below Average Resources: developing a new poverty measure: https://www.gov.uk/government/statistics/below-average-resources-developing-a-new-poverty-measure

[11] Contact (2024) Counting the Costs: https://contact.org.uk/wp-content/uploads/2024/12/Counting-the-Costs-Survey-2024-Full-results.pdf

[12] Disabled Children's Partnership (2021) Give it Back: https://disabledchildrenspartnership.org.uk/families-of-disabled-children-call-on-government-to-giveitback/

[13] National Audit Office (2024) Support for children and young people with special educational needs: https://www.nao.org.uk/wp-content/uploads/2024/10/support-for-children-and-young-people-with-special-educational-needs.pdf

[14] Kuper et al. (2024) Building disability-inclusive health systems: https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667%2824%2900042-2/fulltext

[15] Hollomotz et al. (2025) The lived experience of disabled people in the UK: a review of evidence: https://www.gov.uk/government/publications/the-lived-experience-of-disabled-people-in-the-uk-a-review-of-evidence/the-lived-experience-of-disabled-people-in-the-uk-a-review-of-evidence

[16] Contact (2023) Disabled children still excluded from school more than non-disabled peers: https://contact.org.uk/about-contact/news-and-views/disabled-children-still-excluded-from-school-more-than-non-disabled-peers/

[17] Ofsted / CQC (2025) Beyond the classroom: the experiences of children with SEND who are not in school: https://www.gov.uk/government/publications/the-experiences-of-children-with-send-who-are-not-in-school-a-thematic-review/beyond-the-classroom-the-experiences-of-children-with-send-who-are-not-in-school#introduction

accessing diagnosis and treatment,[18] fragmented healthcare provision,[19] and reduced opportunities to participate in leisure, play,[20] and decision-making.[21] Research further highlights that inaccessible environments, a lack of inclusive activities, inadequate support and societal attitudes continue to create barriers to full participation and inclusion for many disabled children and young people.[22]

Despite these findings, relatively little is known about how these issues are experienced specifically within Northern Ireland, particularly in the context of increasing pressures on health, education and social care systems, rising living costs and wider societal inequalities. This research therefore aims to provide timely, locally grounded evidence about the lives of disabled children and their families, while also identifying gaps in support, barriers to participation and opportunities for policy and systems change.

At the heart of this report are the voices and experiences of families themselves. Their insights provide a powerful account of the realities of caring for disabled children in Northern Ireland today and highlight both the resilience of families and the urgent need for more responsive, inclusive and adequately resourced systems of support.

Legal Context

The key legal and human rights frameworks applicable to disabled children in Northern Ireland include:

The Disability Discrimination Act 1995

The Disability Discrimination Act 1995 (DDA) provides the main legal protection against disability discrimination in Northern Ireland. The legislation makes it unlawful for employers, service providers and public authorities to treat disabled

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[18] Children's Commissioner (2024) Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions: https://www.childrenscommissioner.gov.uk/resource/waiting-times-for-assessment-and-support-for-autism-adhd-and-other-neurodevelopmental-conditions/

[19] Council for Disabled Children (2024) Disabled Children's Social Care – Briefing #2 Families' experiences of social care: https://www.researchinpractice.org.uk/media/o5wlri0v/cdc_pf2-fam-exp_final.pdf

[20] DCMS (2025) Barriers and enablers to participation in youth activities: executive summary: https://www.gov.uk/government/publications/barriers-and-enablers-to-participation-in-youth-activities-research/barriers-and-enablers-to-participation-in-youth-activities-executive-summary

[21] Greenaway-Clarke and Franklin (2023) What about my voice? Facilitating the participation of disabled children and young people with complex communication needs through independent advocacy: https://www.taylorfrancis.com/chapters/edit/10.4324/9781003367758-11/voice-facilitating-participation-disabled-children-young-people-complex-communication-needs-independent-advocacy-jo-greenaway-clarke-anita-franklin

[22] Snape et al. (2022) Disabled people's experiences with activities, goods and services, UK: February to March 2022: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabledpeoplesexperienceswithactivitiesgoodsandservicesuk/februarytomarch2022

people less favourably because of their disability and requires organisations to make reasonable adjustments to reduce substantial disadvantage in accessing employment, services and public life.

Under the DDA:

- public bodies and service providers have a duty to make reasonable adjustments;
- disabled people are protected from discrimination in employment and access to goods, facilities and services; and
- providers of leisure, transport and recreational services must take reasonable steps to ensure accessibility for disabled people.

Under section 49A of the DDA, amended by Article 5 of the Disability Discrimination (Northern Ireland) Order 2006, public authorities are required, when carrying out their functions, to have due regard to the need to promote positive attitudes towards disabled people and encourage participation by disabled people in public life.

Section 49B places a duty on designated public authorities to prepare a Disability Action Plan explaining the practical steps and arrangements the public authority will take to fulfil its section 49A duty.

The Special Educational Needs and Disability (Northern Ireland) Order 2005

The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO) strengthened legal protections for disabled children and young people within education in Northern Ireland. SENDO makes it unlawful for schools, colleges and education bodies to discriminate against disabled pupils and places duties on educational settings to make reasonable adjustments to ensure disabled children can access education and participate fully in school life.

Schools and education bodies must:

- avoid less favourable treatment;
- make reasonable adjustments;
- promote inclusion; and
- ensure access to education.

Special Educational Needs and Disability Act (Northern Ireland) 2016

The Special Educational Needs and Disability Act (Northern Ireland) 2016 (the SEND Act) is the main piece of legislation that reformed the legal framework for supporting children and young people with special educational needs (SEN) and disabilities in Northern Ireland. The SEND Act forms the basis for the current SEN

Reform Agenda and was intended to create a more child-centred, rights-based and collaborative system by strengthening the duties of schools, the Education Authority (EA) and Health and Social Care Trusts. However, many of the SEND Act's provisions have not been implemented, and it has taken 10 years for the Department of Education to bring forward the required secondary legislation, the Special Educational Needs (SEN) Regulations (Northern Ireland) 2026, to enable commencement of the remaining substantive changes. The SEN Regulations (2026) provide the legal framework for:

- Learning Support Co-ordinators (LSCs) in all grant-aided schools;
- Personal Learning Plans (PLPs) for pupils on the SEN Register;
- EA annual plans for special educational provision;
- Statutory assessment and statementing procedures, including timescales and evidence requirements;
- Annual reviews and transition planning for children and young people with SEN;
- Independent mediation arrangements for SEN disputes;
- Cooperation duties between the Education Authority and Health and Social Care Trusts;
- Joint planning arrangements between education and health services;
- Participation rights for children and young people in SEN decision-making;
- Rights for young people over compulsory school age, including assessment, mediation and appeal rights;
- Capacity procedures for determining whether a young person can exercise SEND rights independently; and
- Implementation of key SEND Act 2016 provisions through detailed operational procedures.

Section 75 of the Northern Ireland Act 1998

Section 75 of the Northern Ireland Act 1998 is one of the key equality protections in Northern Ireland. It places a legal duty on designated public authorities, including government departments, Health and Social Care Trusts and councils, to actively consider equality and good relations in the development of policies and delivery of services.

Under Section 75, public authorities must:

- promote equality of opportunity for disabled people; and
- have due regard to the need to promote good relations.

Public authorities must assess how policies affect disabled people and seek to reduce or mitigate inequalities.

The Children (Northern Ireland) Order 1995

The Children (Northern Ireland) Order 1995 is the primary piece of legislation governing the care, protection and welfare of children in Northern Ireland. It places legal duties on public authorities, particularly Health and Social Care Trusts, to safeguard and promote the welfare of children in need, including disabled children and to provide services and support designed to help children achieve and maintain a reasonable standard of health and development.

Disabled children are explicitly recognised as children in need under the legislation.

Public authorities are expected to:

- assess needs;
- provide services;
- support families; and
- promote wellbeing and development.

Human Rights Act 1998 and European Convention on Human Rights

The European Convention on Human Rights (ECHR) is an international human rights treaty designed to protect fundamental rights and freedoms. Through the Human Rights Act 1998, the rights contained within the ECHR were incorporated into UK domestic law, meaning public authorities in Northern Ireland must act in a way that is compatible with these rights.

Several ECHR rights are relevant to disabled children, including:

- Article 8: Right to private and family life;
- Article 14: Freedom from discrimination; and
- Protocol 1, Article 2: Right to education.

The United Nations Convention on the Rights of the Child

The United Nations Convention on the Rights of the Child (UNCRC) is the international treaty that sets out the civil, political, economic, social and cultural rights of all children. It provides a key children's rights framework, outlining a basic set of minimum standards that all children and young people should be entitled to across all areas of their lives. It places obligations on governments and public authorities to ensure that children's rights, wellbeing, participation and best interests are protected and promoted in law, policy and practice.

The survey was explicitly structured around several UNCRC rights, including:

- Article 23 – Rights of Disabled Children;
- Article 24 – Right to Health;
- Articles 28 and 29 – Right to an Effective Education;
- Article 12 – Right to Participation;
- Article 27 – Right to an Adequate Standard of Living; and
- Article 31 – Right to Play and Leisure.

The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international human rights treaty designed to protect and promote the rights, dignity and equality of disabled people, including disabled children and young people. The UK is a signatory to the Convention and is therefore required to take steps to ensure disabled people can participate fully and equally in society, free from discrimination and have access to education, healthcare, services, participation and independent living opportunities.

Key principles include:

- non-discrimination;
- full participation and inclusion;
- accessibility;
- equality of opportunity; and
- respect for dignity.

The Children's Services Co-operation Act (Northern Ireland) 2015

The Children's Services Co-operation Act (Northern Ireland) 2015 places a legal duty on government departments and public authorities in Northern Ireland to work together to improve the wellbeing of children and young people.

The Act recognises that children's wellbeing is shaped by a range of interconnected factors, including health, education, safety, family support, social inclusion and participation. It requires public bodies to cooperate in the planning, commissioning and delivery of services affecting children and young people.

Under the Act, children's wellbeing is defined across eight key areas:

- physical and mental health;
- the enjoyment of play and leisure;
- learning and achievement;

- living conditions;
- safety and stability;
- economic and environmental wellbeing;
- the contribution made by children to society; and
- respect for the rights of children and young people.

The legislation aims to promote joined-up working across services and improve outcomes for children by encouraging earlier intervention, coordinated support and more effective use of resources. Public authorities are required to consider how their functions can contribute to improving children's wellbeing and to cooperate with one another where appropriate.

Legal Protections and Lived Experience

The findings of this research raise significant concerns regarding the extent to which disabled children and their families in Northern Ireland are able to realise the rights and protections afforded to them under existing domestic and international law.

The Equality Commission for Northern Ireland has highlighted a number of significant gaps in legal protections for people with a disability in Northern Ireland and has been calling on the Northern Ireland Executive to make urgent changes address these for many years.[23] These changes are aimed at addressing inconsistencies within disability equality legislation and strengthening the rights of disabled people and their carers. They argue that disability law in Northern Ireland needs to be harmonised simplified and strengthened and equality law in Northern Ireland needs to be updated to keep pace with legislative changes that have taken place in Great Britain.

Northern Ireland does not have a single, consolidated piece of equality legislation, unlike in Great Britain which has the Equality Act 2010. This has led to longstanding concerns regarding gaps in legal protection for disabled children, particularly within education settings where the protection afforded to disabled children across different types of education settings is piecemeal and fragmented. The Commission has recommended that Northern Ireland should go beyond

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[23] Equality Commission for Northern Ireland (2012) Strengthening Protection for Disabled People Proposals for Reform: Layout 1

changes made in Great Britain and instead reflect international human rights standards which centre on a, 'social model,'[24] of disability.[25]

While Northern Ireland has a range of legal protections intended to safeguard disabled children from discrimination and promote equality of opportunity, the evidence presented in this research suggests that many disabled children continue to experience systemic barriers when accessing services and support, across education, healthcare, play and leisure, participation, standard of living and family life. The extent and persistence of the disparities identified suggest that legal protections are not being fully realised in the lived experiences of disabled children and their families.

The research paints a compelling picture of systemic inequality experienced by disabled children and their families across Northern Ireland.

The research findings suggest that many disabled children continue to encounter:

- barriers in accessing services and support;
- barriers to education;
- unequal access to healthcare;
- exclusion from participation in community life;
- fewer opportunities for play and leisure;
- severe impacts on family life;
- financial hardship; and
- reduced fulfilment of fundamental rights.

The scale and consistency of the disparities identified suggest these are not isolated service failures, but structural issues requiring coordinated policy and legislative attention.

The evidence indicates a significant gap between legal rights and lived reality.

The Northern Ireland Executive Draft Disability Strategy commits to:

> *"A review and update of existing Disability Legislation in Northern Ireland to include how the UNCRPD can best be incorporated into local legislation*

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[24] The Social Model of disability understands barriers in society as disabling – under this view, society limits the participation of persons with impairments by creating obstacles. These may take many forms, including legal, attitudinal and physical barriers, as well as barriers to communication.

[25] Equality Commission for Northern Ireland (2024) Submission to the Committee for the Executive Office Inquiry into Gaps in Equality Legislation: Submission to the Committee for the... | Equality Commission NI

> *here. This work will include the commissioning of a legal scoping study to identify and compare benefits of and models for incorporation. We will also review and update our disability legislative framework to ensure that disability laws are fit for purpose and robust. In particular, we will review and update the Disability Discrimination Act 1995, including measures to protect against, and provide legal remedy for, indirect discrimination. In doing this we will look at good practice in disability law in a range of other jurisdictions, including looking beyond Great Britain and the Republic of Ireland. All this work will be carried out with a view to the full incorporation of the UNCRPD into domestic law."*[26]

Based on the experiences of the families who took part in this research, there is clearly a need for this review to be carried out as a matter of urgency. Throughout the research, parents and carers of disabled children report poorer experiences across all of the areas examined. If these inequalities are to be addressed, work must be urgently carried out to close the significant gaps in legal protections for people with a disability and afford disabled people stronger legal protections, in line with the recommendations of the Equality Commission for Northern Ireland. The findings throughout this report are statistically significant and reflect the realities of life for disabled children and their families.

Ultimately, the research raises important questions about whether existing laws, duties and rights protections are being implemented effectively enough to ensure disabled children in Northern Ireland can genuinely participate equally, access appropriate support and realise their full potential.

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[26] Department for Communities (2025) Consultation of the NI Executive Draft Disability Strategy 2025-2035: https://www.communities-ni.gov.uk/consultations/consultation-ni-executive-disability-strategy-2025-2035

Methodology

This report is based on research commissioned by CiNI and conducted by SMR. The research was undertaken to better understand the experiences of disabled children and their families in Northern Ireland, to amplify lived experience and to provide an evidence base capable of informing policy, practice and service development.

The research was conducted through a large-scale quantitative survey of 1,105 parents and carers of children in Northern Ireland. It was designed to capture the experiences of families with both disabled and non-disabled children. Fieldwork took place between October and November 2025 using an online survey methodology. The sample was weighted to ensure it was representative of the Northern Ireland parent population across key demographic characteristics and was structured to reflect the wider population, allowing for meaningful comparison between the experiences of disabled children and their peers.

The research was carried out in accordance with ISO 20252:2019 standards and Market Research Society guidelines, providing a robust and reliable evidence base on the experiences of families, including those with disabled children.

Due to the lack of an agreed official definition of disability, parents and carers who took part in the research were presented with the DDA definition of disability and asked whether they had a child aged under 18 whom they considered to have a disability. The DDA defines disability as:

> *"…a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities."*[27]

Of the 1,105 parents and carers who took part in the research, 43% (472 parents and carers) stated that, based on this definition, they had a child aged under 18 whom they considered to have a disability.

The survey explored the experiences and outcomes of parents and carers across a range of areas, including:

- access to services and support;
- health;
- education;
- participation and advocacy;

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[27] The Disability Discrimination Act 1995, Part I, Section 1: https://www.legislation.gov.uk/ukpga/1995/50

- play and leisure;
- standard of living and financial wellbeing;
- family life; and
- disabled children reaching their full potential.

Throughout the research, each thematic area examined was linked, where relevant, to corresponding rights set out within the UNCRC. Parents and carers were presented with the relevant UNCRC article under each thematic area and asked whether they believed their children's rights in that area were being upheld. This approach enabled the research to assess the extent to which families believe their children's rights are being realised in practice across Northern Ireland.

Responses were analysed to identify differences between families of disabled children and those of non-disabled children, with particular attention given to patterns of inequality across multiple domains.

In addition to quantitative findings, the survey included opportunities for parents and carers to provide qualitative comments. These insights have been used selectively throughout the report to illustrate lived experiences and provide context to the statistical findings.

While the survey provides robust and representative evidence, it is important to note that it reflects the perspectives of parents and carers. The findings should therefore be understood as an account of children's experiences as reported by their families. The research provides a reliable, evidence-based overview of the experiences of disabled children in Northern Ireland and highlights areas requiring further policy and service development.

Access to Services and Support

Recent policy developments have recognised the need for more coordinated and accessible support for children and families in Northern Ireland. The Children's Services Co-operation Act (Northern Ireland) 2015 places duties on public authorities to work together to improve children's wellbeing, while the Northern Ireland Executive's Draft Disability Strategy highlights the importance of improving access to services and reducing barriers experienced by disabled people and their families.

The research shows that many families experience significant difficulties accessing services and support for their children in Northern Ireland. When asked about public services provided by the statutory sector and services provided by the voluntary and community sector, parents and carers expressed concerns about the accessibility and responsiveness of services, as well as their ability to meet children's needs. Parents and carers of disabled children consistently reported poorer experiences and outcomes than parents and carers of non-disabled children, including greater difficulty accessing support, lower confidence in services and stronger views that their children require more support than they are currently receiving.

Throughout the research, parents repeatedly described challenges understanding the support available to them, difficulties accessing services, delays in receiving help and frustration with navigating fragmented pathways across services.

Among all parents and carers, awareness of support services was relatively high. More than two-thirds (68%) agreed that they are aware of support available through public services if their child needs it, while 62% agreed that they know how to access appropriate public support. Similarly, around two-thirds agreed that they are aware of support available through charities, voluntary organisations and community groups (64%), while 59% agreed that they know how to access this support if needed.

However, confidence in how effectively services meet children's needs was considerably lower across both sectors. **Less than half (45%) agreed that public services are meeting their child's needs, while only 41% agreed that public services respond well and in a timely manner.** Similarly, fewer than half (46%) agreed that voluntary and community sector services are meeting their child's needs, although slightly more than half (51%) agreed that these services respond well and in a timely manner.

Parents and carers also expressed substantial concern regarding unmet need and barriers to accessing support. More than half (55%) agreed that their child needs more support than they are currently receiving through public services, while **53% agreed that it is a struggle to access public services to support their child's needs.** Similar concerns were identified regarding voluntary and community sector support, with 54% agreeing that their child needs more support than they are currently receiving and almost half (47%) agreeing that it is a struggle to access voluntary and community sector services.

The findings suggest that many families perceive significant gaps between the support children require and the support that is currently available or accessible in practice.

Differences Between Parents of Disabled and Non-disabled Children

The research highlights significant inequalities in experiences of accessing services and support between families caring for disabled children and those caring for non-disabled children. Across almost every area examined, parents and carers of disabled children reported poorer experiences and greater dissatisfaction with both statutory and voluntary sector support.

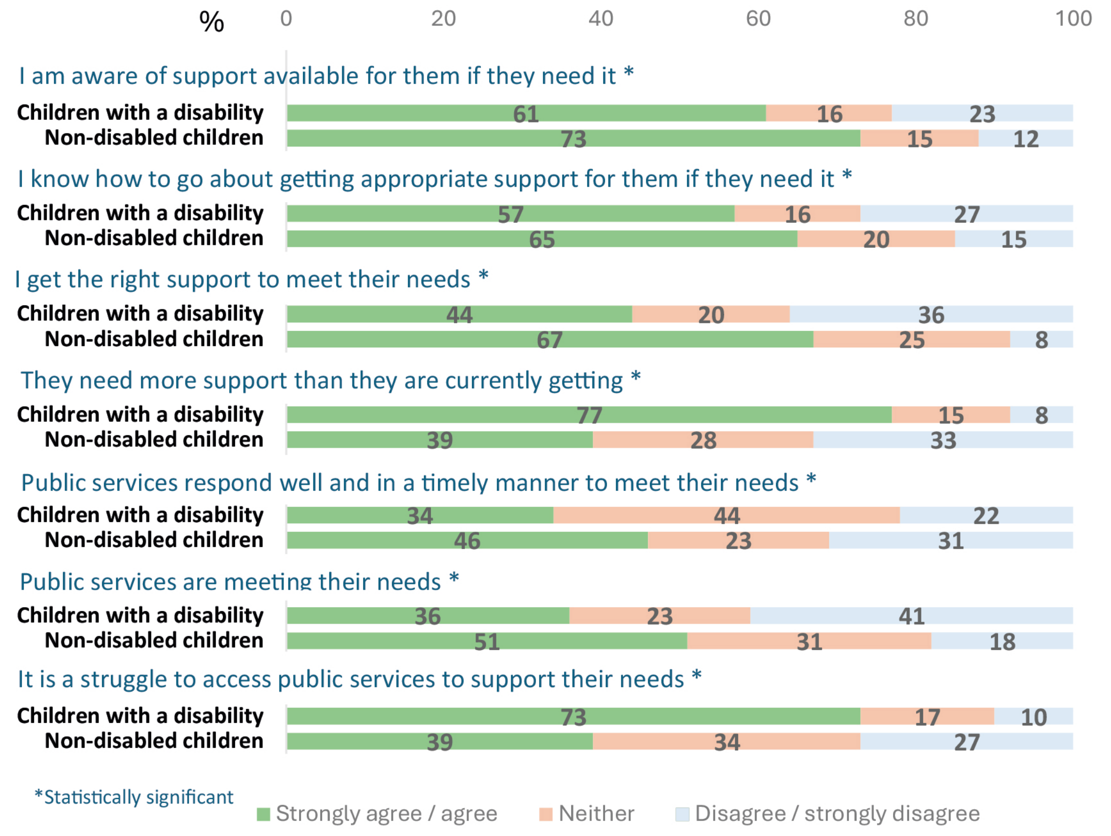
Parents of disabled children were **consistently less likely to agree** that:

- they are aware of available support;
- they know how to access appropriate support;
- they receive the right support to meet their child's needs;
- services respond well and in a timely manner; and
- services are meeting their child's needs.

Only 44% of parents and carers of disabled children agreed that they receive the right support to meet their child's needs through public services, compared with 67% of parents and carers of non-disabled children. Similarly, only 36% agreed that public services are meeting their child's needs, compared with just over half (51%) of parents and carers of non-disabled children.

A similar pattern emerged in relation to voluntary and community sector services. Only 39% of parents and carers of disabled children agreed that voluntary and community sector services are meeting their child's needs, compared with just over half (51%) of parents and carers of non-disabled children. Similarly, only 44% agreed that they receive the right support through these services, compared with 59% of parents and carers of non-disabled children.

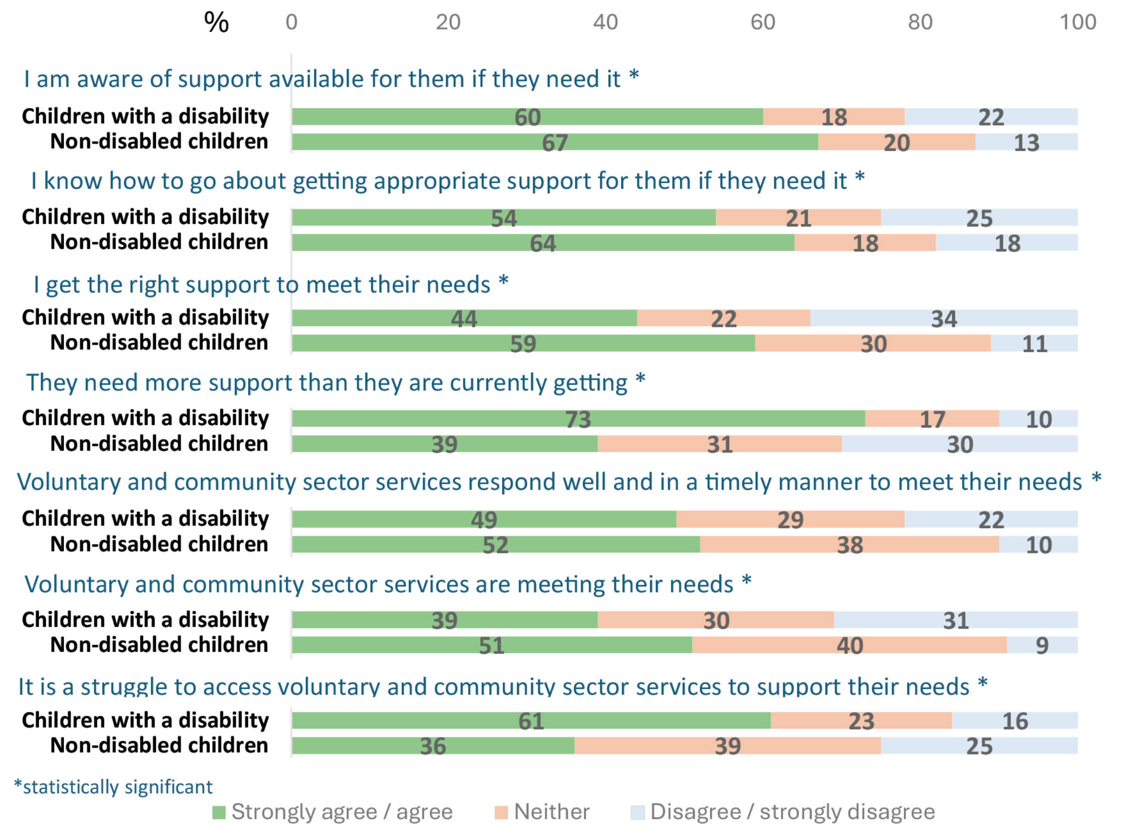
Figure 1: Please say to what extent you agree or disagree with each of the following statements about your child(ren) – Public Services Provided by the Statutory Sector



Parents and carers of disabled children were also substantially more likely to report unmet need and difficulties accessing services and support. **More than three-quarters (77%) agreed that their child needs more support than they are currently receiving through public services, compared with 39% of parents and carers of non-disabled children.** Similarly, 73% agreed that it is a struggle to access public services to support their child's needs, compared with 39% of other parents and carers.

Challenges were also evident regarding access to services provided by the voluntary and community sector. **Almost three-quarters (73%) of parents and carers of disabled children agreed that their child needs more support than they are currently receiving through voluntary and community services**, compared with 39% of other parents and carers. Similarly, 61% agreed that it is a struggle to access voluntary and community sector support, compared with 36% of parents and carers of non-disabled children.

Figure 2: Please say to what extent you agree or disagree with each of the following statements about your child(ren) – Services Provided by VCS



The findings show that families caring for disabled children report significantly greater barriers in accessing support across both public and voluntary sector services and are more likely to perceive current provision as insufficient in meeting their children's needs. This suggests persistent inequalities in the experiences of parents and carers of disabled children accessing services and support in Northern Ireland.

The research shows that difficulties accessing support are not confined to one service area alone, but instead reflect wider systemic challenges across health, education, play and leisure and participation. Indeed, **the qualitative data across every area examined highlights access to services and support as the primary reason given by parents and carers of disabled children who do not believe that their children's rights are being upheld**. Parents repeatedly describe fragmented systems, delays, a lack of clarity regarding available support and the need to continually advocate for their children in order to access services and support.

We recognise that current policy developments, including the Northern Ireland Executive's Draft Disability Strategy and ongoing SEN Transformation work, provide important opportunities to improve coordination, accessibility and responsiveness across services. However, the experiences of families throughout this research suggest that substantial gaps remain between policy ambition and lived experience, particularly regarding timely access to support and joined-up service provision.

The findings highlight the need for policy responses that recognise the cumulative impact of barriers to accessing services and support for families caring for disabled children.

This includes consideration of:

- improving awareness and provision of information regarding available support;
- creating clearer and more accessible pathways into services;
- reducing delays and improving responsiveness across services;
- strengthening coordination between statutory and voluntary sector provision;
- improving access to support for families caring for disabled children; and
- increasing investment in public, voluntary and community sector services to meet growing levels of need.

Challenges Faced by Parents and Carers

Existing research and policy evidence increasingly recognises the significant pressures experienced by parent carers of disabled children, including impacts on mental health, family wellbeing, employment and social participation.[28] The Northern Ireland Mental Health Strategy 2021–2031 also highlights the importance of early intervention, family support and improved emotional wellbeing services for children and families.

While parents and carers of all children report pressures associated with parenting and caring responsibilities, the challenges reported by families with disabled children were often more complex, intensive and emotionally demanding. The breadth of challenges experienced by families with disabled children extends across healthcare, education, financial wellbeing, emotional health, social inclusion and family life.

The survey findings indicate the cumulative pressures experienced by many families caring for disabled children, with practical, emotional and financial challenges often occurring simultaneously. Parents repeatedly describe feeling exhausted, isolated and unsupported while attempting to navigate fragmented systems and secure appropriate support for their children.

The qualitative evidence provides further insight into the challenges faced by parents and carers of disabled children. The most prominent themes identified include:

- difficulties accessing services and support;
- inadequate educational support;
- emotional and mental health pressures;
- social isolation and lack of inclusion;
- behavioural and emotional regulation challenges;
- financial strain;
- navigating complex systems and advocacy;
- physical and medical care demands;
- communication barriers; and

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[28] Disabled Children's Partnership (2022) The Cost of Caring 2022: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2022/03/Cost-of-Caring-2022-Full-Report.pdf

- stigma, discrimination and lack of understanding.

Access to services and support was the most frequently reported challenge among parents and carers of disabled children (30%). Families describe difficulties accessing timely and appropriate healthcare, therapies, respite support and educational services. Parents refer to long waiting lists, fragmented systems, a lack of clear pathways to support and being left to manage without adequate guidance or assistance.

One parent explained:

> *"Zero support, you get handed a diagnosis leaflet and are left to deal with it."*

The education system was also identified as a major source of pressure for many families with disabled children (19%). Parents describe difficulties securing appropriate support within schools, concerns about inclusion and frustration with educational systems that they felt were unable to adequately meet their child's needs.

> *"I think the biggest challenge is that there isn't full support in schools."*

Many parents and carers of disabled children also describe the substantial emotional and mental health impacts associated with caring responsibilities (17%). Feelings of exhaustion, stress, anxiety and uncertainty about the future were common across responses, with many parents describing the emotional toll of constantly advocating for their child while managing complex needs.

> *"I'm constantly shattered and lost."*

Social isolation and exclusion also emerged as significant concerns for families with disabled children (15%). Parents describe limited opportunities for disabled children to participate in activities or feel included within their communities, alongside isolation experienced by families themselves.

> *"My child has very little support or places they can go to feel included."*

Behavioural and emotional regulation challenges were frequently raised by parents and carers of disabled children, particularly among families caring for children with autism, ADHD, or additional emotional and behavioural needs (15%). Parents describe difficulties managing meltdowns, emotional outbursts, sleep disruption and distress, often without adequate support.

> *"Meltdowns, lack of sleep, no support."*

Financial pressures were also a significant challenge for many families caring for disabled children (13%). Parents describe the costs associated with therapies, equipment, transport, specialist diets and reduced ability to work because of caring responsibilities.

"Financial burden of replacing items… meeting restricted diets."

Many families with disabled children also highlighted the emotional and practical burden associated with navigating complex and fragmented systems across healthcare, education and social care (13%). Parents describe having to continually advocate for support while attempting to understand complicated processes and eligibility criteria.

"It is exhausting, constantly badgering the gatekeepers."

The physical and medical demands of caring responsibilities were also highlighted by many parents and carers of disabled children (13%). Families describe intensive physical care routines, lifting and mobility support, medical procedures and a lack of respite or practical support.

"All the physical care work is done by myself with no respite or help day to day."

Communication barriers were another recurring challenge, particularly for parents of children with communication difficulties or neurodevelopmental conditions (11%). Parents describe difficulties understanding and responding to children's needs and emotions.

"My biggest challenge is communication barriers."

Some parents and carers of disabled children also describe experiences of stigma, discrimination and lack of understanding from professionals, communities and wider society (11%). Parents expressed concerns about their child's future and the ways in which disabled children are perceived or treated.

"Thinking of their future and how cruel the world might be."

In contrast, while parents and carers of non-disabled children also report significant pressures, these were more commonly related to broader parenting and financial concerns. The most prominent themes among parents and carers of non-disabled children included:

- financial pressures and the cost of living;
- balancing work and family responsibilities;
- childcare access and affordability;
- mental health and emotional wellbeing;
- social media and online safety;

- education and school-related issues;
- healthcare access; and
- time management.

Financial challenges were the most frequently identified issue among parents of non-disabled children (25%), particularly rising living costs, childcare expenses and difficulties meeting daily household needs.

"Having enough money to feed and clothe them."

Many parents of non-disabled children also describe the challenge of balancing work commitments with family responsibilities and ensuring children feel emotionally supported despite time pressures (15%).

"Balancing work and family time while ensuring they feel loved, supported, and guided every single day."

Other parents of non-disabled children expressed concerns regarding childcare affordability (9%), mental health pressures (7%), educational pressures (6%), social media and technology (6%) and difficulties accessing healthcare services (5%).

The findings suggest that while all families experience pressures associated with parenting and caring responsibilities, parents and carers of disabled children often face additional and more complex challenges linked to disability, service access, inclusion, financial strain and systemic barriers.

The evidence points towards the cumulative and interconnected nature of these pressures. Parents repeatedly described how barriers across healthcare, education, financial support, leisure opportunities and public services combine to negatively affect family wellbeing, emotional resilience and quality of life.

We recognise that a range of policy initiatives, including the Mental Health Strategy 2021–2031 and wider family support and wellbeing programmes, aim to strengthen support for children and families in Northern Ireland. However, the findings from this research suggest that many parent carers of disabled children continue to experience significant unmet emotional, practical and financial support needs.

The findings highlight the need for policy responses that recognise the intensity and complexity of caring responsibilities for families of disabled children. This includes consideration of:

- improving access to healthcare, education and support services;
- strengthening respite and family support provision;

- reducing waiting times for assessments and interventions;
- improving financial support for families caring for disabled children;
- strengthening coordination between services;
- improving mental health support for parent carers; and
- promoting greater inclusion and understanding of disabled children and their families within communities and public services.

Health

Current health policy in Northern Ireland increasingly recognises the importance of early intervention, community-based support and improved mental health and wellbeing services for children and young people. The Health and Social Care NI Three-Year Plan emphasises the need for earlier support, improved service delivery and better outcomes for children and families.[29] Existing research highlights the significant barriers many disabled children and their families experience in accessing healthcare, including difficulties obtaining timely assessments, specialist services and appropriate support. A recent UK systematic review found that autistic children and their families experience persistent disparities in accessing healthcare services, with long waiting times, poor communication and fragmented systems identified as key barriers to care.[30]

The findings from this research suggest that many disabled children and their families experience significant barriers within the healthcare system in Northern Ireland. Across every area examined, parents and carers of disabled children report poorer experiences and outcomes than other families, including greater difficulty accessing healthcare services and treatment, longer waiting times for assessment and diagnosis and lower levels of confidence that the healthcare system is meeting their child's needs.

The evidence points to a system that many families perceive as under-resourced, difficult to navigate, slow to respond and unable to consistently provide timely and appropriate healthcare and support for disabled children. Parents repeatedly describe long waiting lists, fragmented services, poor communication between professionals and the need to continually advocate or "fight" for their child to access assessments, diagnosis, treatment and ongoing support.

Access to healthcare services and treatment emerged as a major concern within the research. **Almost two-thirds (65%) of parents and carers of disabled children report that it is difficult for their child to access the healthcare services and treatment they need, compared with just over one-third (36%) of parents of non-disabled children.**

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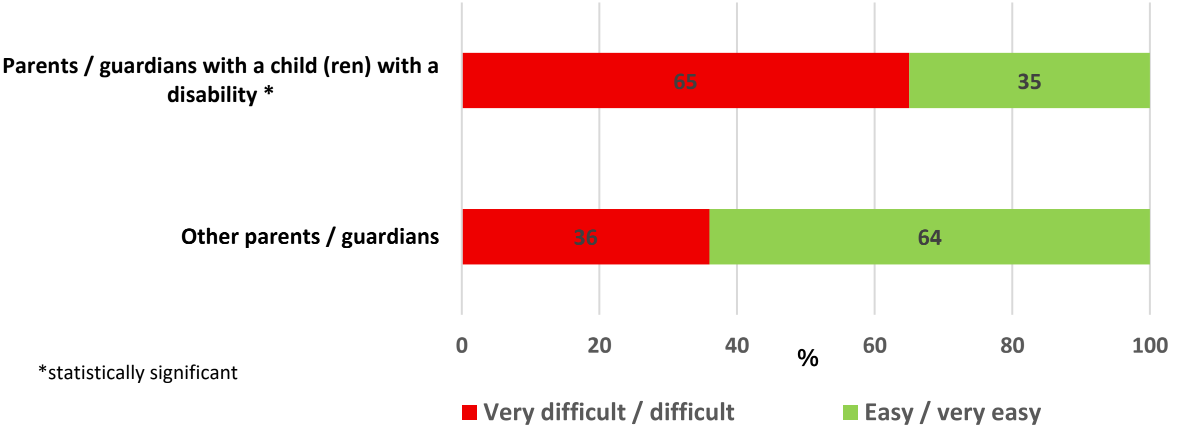
[29] Department of Health (2024) Health and Social Care NI – Three Year Plan: Health and Social Care NI - Three Year Plan | Department of Health

[30] Babalola et al. (2024) Barriers and Facilitators of Healthcare Access for Autistic Children in the UK: A Systematic Review: https://link.springer.com/article/10.1007/s40489-023-00420-3

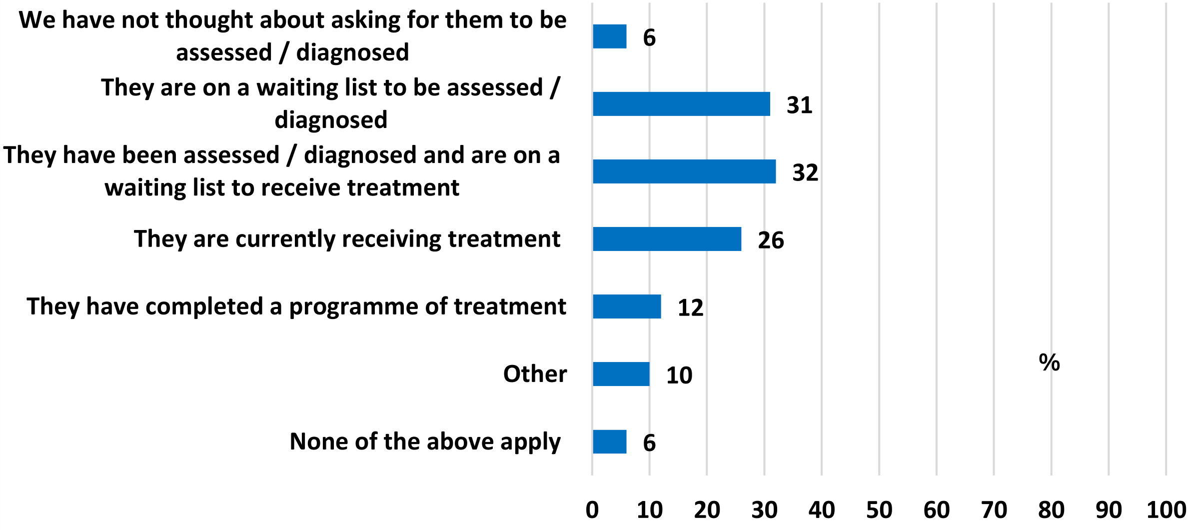
Figure 3: How easy or difficult is it for your child(ren) to access the healthcare, services and treatment they need?



*statistically significant

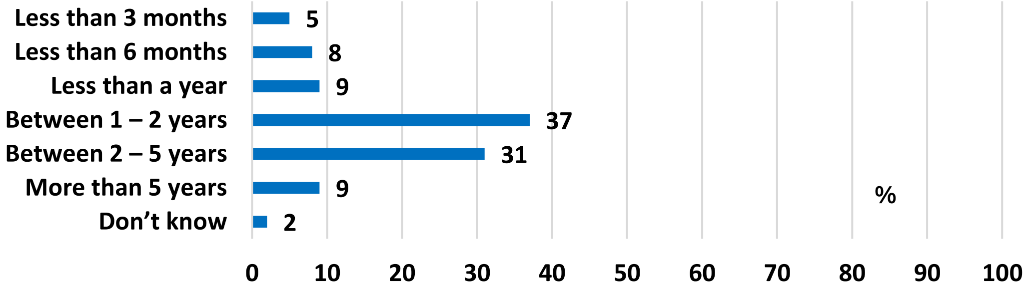
The research also highlights significant concerns regarding delays in assessment, diagnosis and treatment for disabled children. **Approximately three in ten (31%) parents and carers of disabled children reported that their child was currently waiting to be assessed or diagnosed**, while a similar proportion (32%) said their child had already been assessed or diagnosed but was now waiting to receive treatment. Only around one-quarter (26%) reported that their child was currently receiving treatment.

Figure 4: Thinking about your child(ren) with a disability, please say if any of the following apply



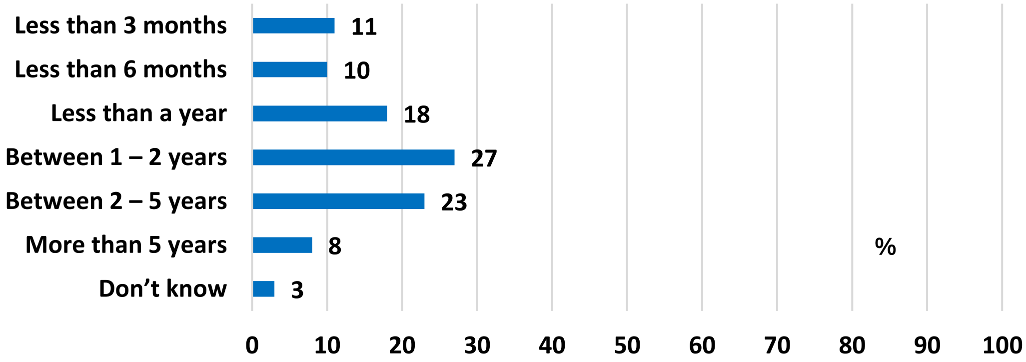
The findings suggest that many families continue to experience substantial delays in accessing healthcare. Among those waiting to be assessed or diagnosed, the most common waiting periods were between one and two years (37%) and between two and five years (31%). **Nearly one in ten (9%) reported waiting <u>more than five years</u> for assessment or diagnosis.**

Figure 5: How long has your child been waiting to be assessed / diagnosed?



Waiting times for treatment were also lengthy, with half of those awaiting treatment reporting waits of between one and five years. **Again, nearly one in ten (8%) reported waiting <u>more than five years</u> for treatment.**

Figure 6: How long has your child been waiting to receive treatment?



The findings also suggest that **many disabled children are experiencing significant negative impacts because of delays or difficulties accessing healthcare, treatment and support**. Parents and carers of disabled children were significantly more likely to report that their children:

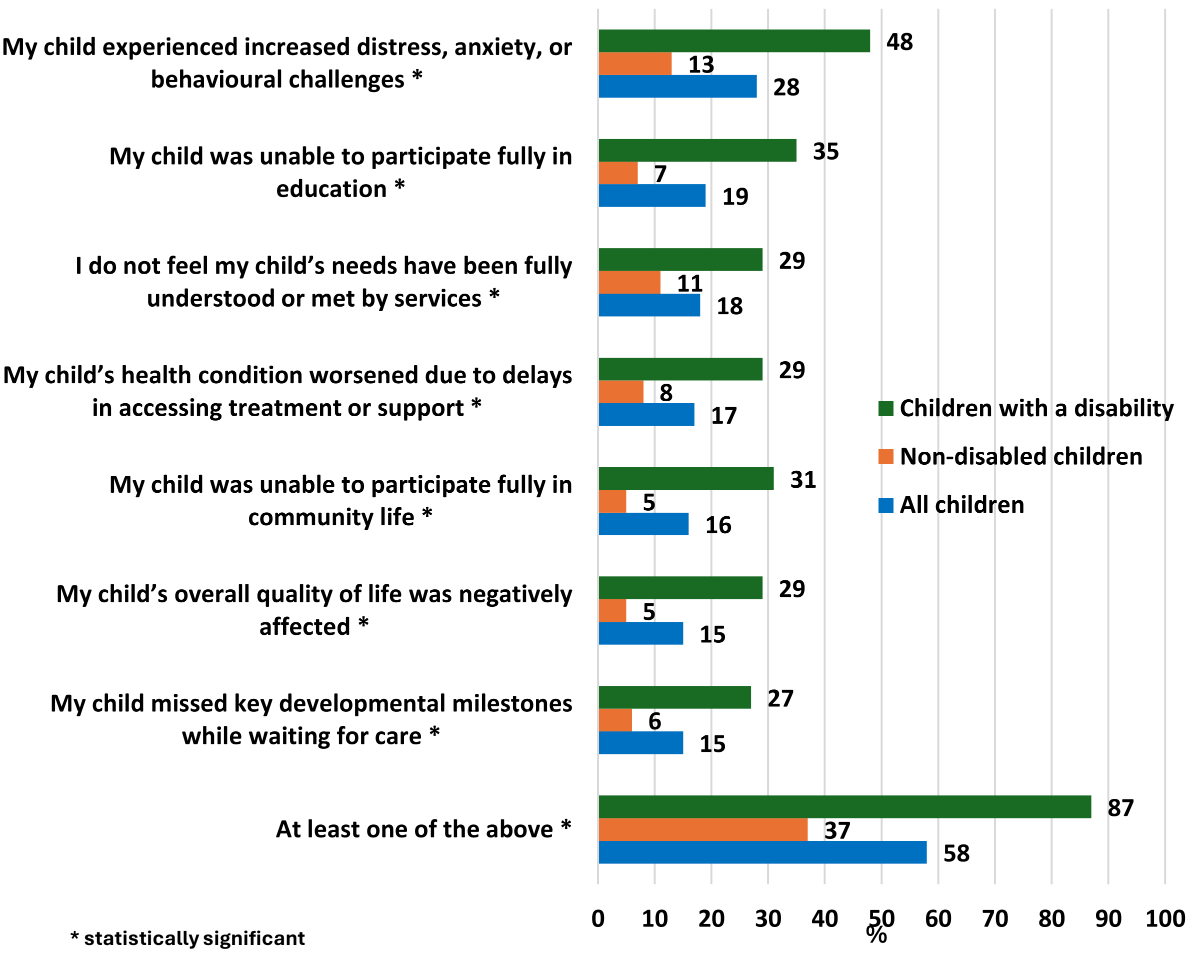
- experience increased distress, anxiety, or behavioural challenges;
- are unable to participate fully in education;
- have needs that are not fully understood or met by services;
- experience worsening health conditions;
- are unable to participate fully in community life; and
- experience reduced quality of life and missed developmental milestones.

Overall, **87% of parents and carers of disabled children reported that their child had experienced at least one significant negative impact because of**

delays or difficulties accessing healthcare, compared with 37% of parents and carers of non-disabled children. Parents and carers of disabled children were more than three times more likely to report increased distress, anxiety, or behavioural challenges because of delays (48% compared with 13%) and four times more likely to report that their child had been unable to participate fully in education because of delays (35% compared with 7%).

The findings therefore indicate that healthcare difficulties for disabled children extend beyond access to medical treatment alone and include emotional wellbeing, participation, education, development and quality of life more broadly.

Figure 7: Have any of the following applied to your child(ren) as a result of delays or difficulties accessing health care, health services, treatment, or support?



* statistically significant

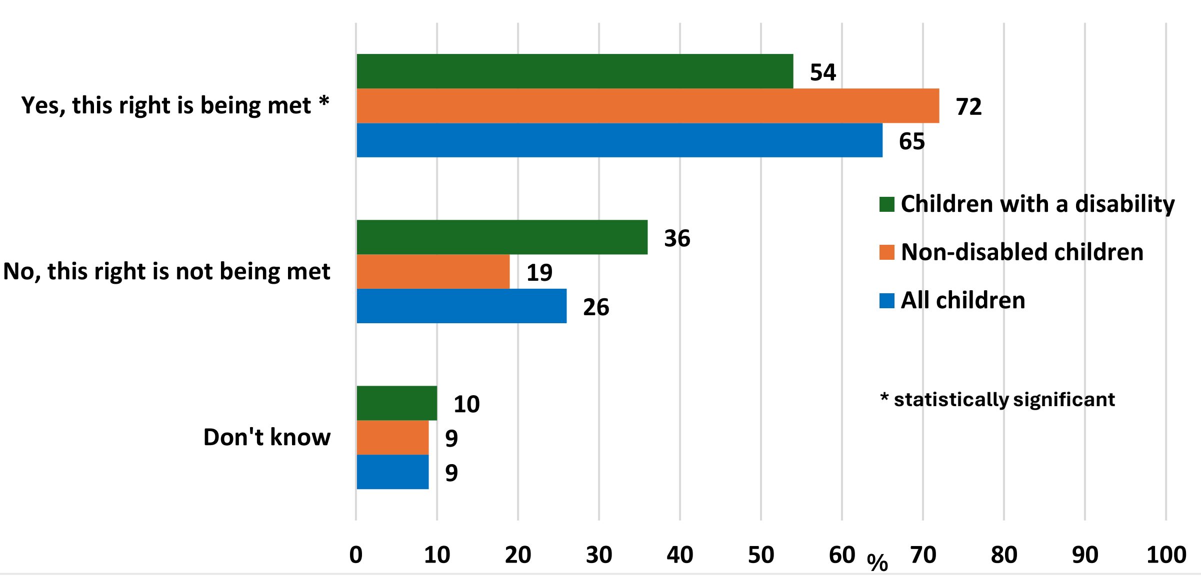
Parents and carers of disabled children consistently expressed concerns about delays and barriers within the healthcare system. Many describe children waiting years for autism, ADHD and other specialist assessments, often without meaningful support while waiting. Others highlight difficulties accessing mental health services, occupational therapy, speech and language therapy and specialist care.

A Child’s Right to the Highest Attainable Standard of Health

Article 24 of the UNCRC recognises every child’s right to the highest attainable standard of health, access to medical care and information that will help them stay well.

More than one-third (36%) of parents and carers of disabled children believed their child’s right to healthcare was not being met, compared with 19% of parents and carers of non-disabled children.

Figure 8: Children's right to the highest attainable standard of healthcare



The reasons provided by parents reveal the depth and complexity of the healthcare pressures many families face. A dominant theme was that current healthcare systems and support structures are not meeting the needs of disabled children. Parents describe:

- long waiting times for assessment, diagnosis and treatment;
- lack of access to appropriate services and specialist support;
- systemic underfunding and staffing shortages;
- poor communication and coordination between services;
- barriers created by rigid eligibility criteria;
- the need for persistent parental advocacy;
- inadequate or inconsistent support following diagnosis; and
- negative impacts on children’s and families’ mental health and wellbeing.

One parent explained:

> *"Awaiting 4 years for autism assessment; it's a disgrace."*

Many parents describe children being left without appropriate support even after diagnosis:

> *"Because although some services exist, the delays in assessments, long waiting lists for treatment, and limited availability of specialist support mean my child isn't getting the care they need when they need it."*

Families also describe frustration with fragmented and poorly coordinated healthcare systems:

> *"Often there is poor communication between different specialist teams."*

Others highlight the impact of underfunding and staffing shortages within health services:

> *"As the health service is massively underfunded."*

Some parents describe children falling between services because they do not meet strict eligibility criteria:

> *"Constantly denied services as not able enough for mainstream but too able for learning disability support so left in limbo..."*

Across responses, there was a strong sense that families often feel dismissed, unheard and unsupported within the healthcare system. Parents told us:

> *"Parents are ignored regarding concerns with children; we are just told it's an 'autism' issue. There is no regard for my child's quality of life or help to stop her from injuring herself."*

There was also a strong sense within some of the qualitative data that only families with the financial means to access private assessments or treatment are able to bypass delays and secure timely support for their children, creating inequalities in access to healthcare. One parent explained:

> *"I cannot go private for diagnosis as GPs don't do shared care for ADHD meds. So I would pay for private diagnosis but still need to wait for NHS diagnosis and then 2+ years for meds to be considered."*

The findings suggest that healthcare pressures are directly linked to disabled children's ability to participate fully in everyday life. Parents repeatedly described children experiencing worsening mental health, increased distress, missed developmental milestones, reduced participation in education and community life and declining quality of life because appropriate support was unavailable or delayed. For many families, barriers within healthcare settings negatively affected not only physical health outcomes, but also emotional wellbeing, inclusion, participation and family life.

We recognise that ongoing health service reform and strategic planning within Northern Ireland aim to improve access to care, early intervention and specialist support. However, the findings from this research demonstrate that many disabled children and their families continue to experience substantial delays, barriers and unmet healthcare needs which are significantly affecting wellbeing and participation.

The evidence highlights the need for policy responses that recognise the importance of timely, accessible and inclusive healthcare, as well as the cumulative pressures experienced by families caring for disabled children. This includes consideration of:

- reducing waiting times for assessment, diagnosis and treatment;
- improving access to specialist therapies and mental health support;
- increasing investment in early intervention and community services;
- strengthening communication and coordination between healthcare providers and professionals;
- developing more flexible and inclusive eligibility criteria; and
- improving support for families navigating healthcare systems.

Education

The publication of the SEN Reform Agenda and five-year Delivery Plan reflects growing recognition within Northern Ireland of the need to improve educational experiences and outcomes for children with special educational needs and disabilities. The reforms aim to deliver, 'the right support, from the right people, at the right time and in the right place,' and acknowledge longstanding concerns regarding access, inclusion and consistency of provision. Existing research in Northern Ireland has highlighted persistent barriers experienced by disabled children and young people within the education system, including delays in assessment and statementing, inadequate support provision, poor coordination between education and health services and significant impacts on children's wellbeing and educational outcomes. A rights-based review by the Northern Ireland Commissioner for Children and Young People (NICCY) found that many children with special educational needs experience unmet need, exclusion and prolonged delays accessing appropriate support and provision.[31]

The findings from this research suggest that many disabled children and their families experience significant barriers within the education system in Northern Ireland. Across every area examined, parents and carers of disabled children reported poorer experiences and outcomes than other families, including greater difficulty accessing educational support, higher levels of school-related anxiety and exclusion and lower confidence that the education system is meeting their child's needs.

The evidence points to a system that many families perceive as insufficiently resourced, difficult to navigate, slow to respond and unable to consistently provide inclusive and appropriate support for disabled children.

Many parents describe feeling that they must continually advocate or "fight" for support for their children. Others highlight the emotional impact on children whose needs are not recognised or appropriately supported within school environments. Several responses also reflect frustration with what parents perceived to be a, "one-size-fits-all," education system that does not sufficiently accommodate individual needs, learning styles or neurodiversity.

Access to educational support emerged as a major concern within the research. **More than half (53%) of parents and carers of disabled children report that it is difficult for their child to access the educational services they**

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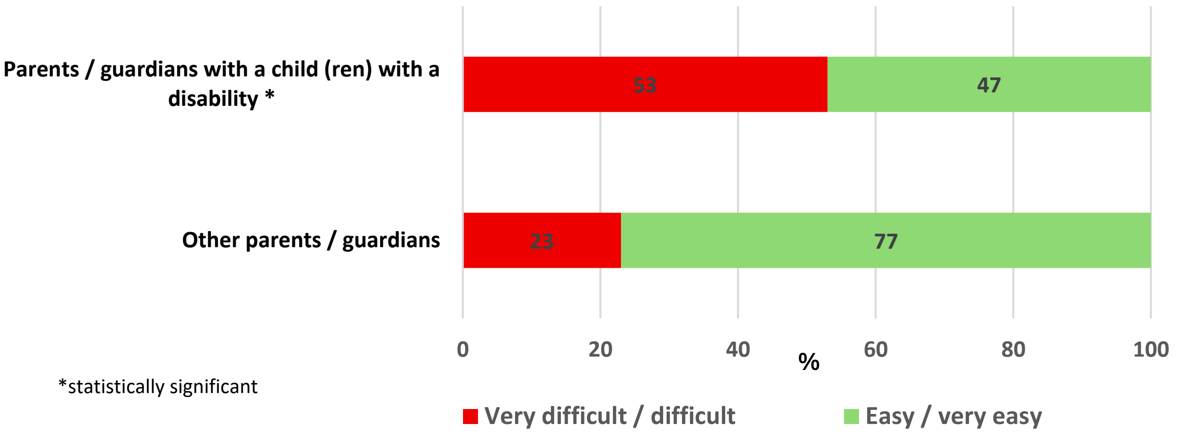
[31] NICCY (2020) Too Little, Too Late: A Rights-Based Review of Special Educational Needs Provision in Mainstream Schools in Northern Ireland: https://www.niccy.org/media/3883/too-little-too-late-report.pdf

need, compared with less than one-quarter (23%) of parents and carers of non-disabled children.

Figure 9: How easy or difficult is it for your child(ren) to access the education services they need?

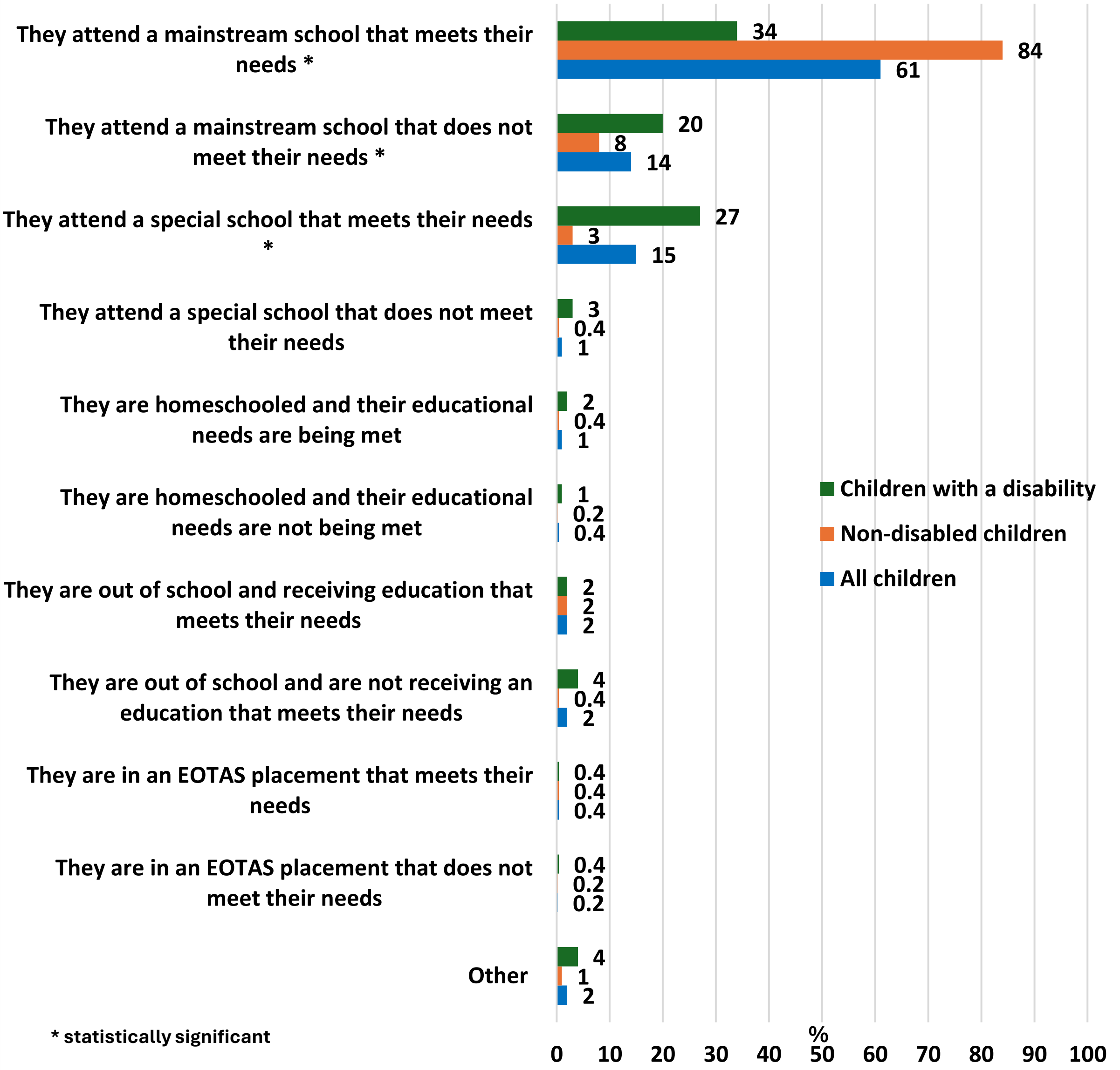


The research also highlights concerns regarding the suitability and inclusiveness of educational provision. While most non-disabled children were reported to attend mainstream schools that meet their needs (84%), this fell substantially among disabled children, with one-third (34%) of parents and carers reporting that their child attends a mainstream school that meets their child's needs. **One in five (20%) parents and carers of disabled children stated that their child attended a mainstream school that did not meet their needs**, while over one-quarter (27%) reported that their child attended a special school that meets their needs. These findings suggest that many families continue to experience challenges securing appropriate educational placements and support.

The findings also suggest that many disabled children experience difficulties participating fully and positively within school environments. Parents and carers of disabled children were significantly more likely to report that their children:

- experience anxiety or stress related to school;
- avoid attending school;
- fall behind educationally;
- experience bullying or intimidation; and
- experience exclusion from aspects of school life.

Figure 10: Thinking about your child(ren), please say which of following applies to them.

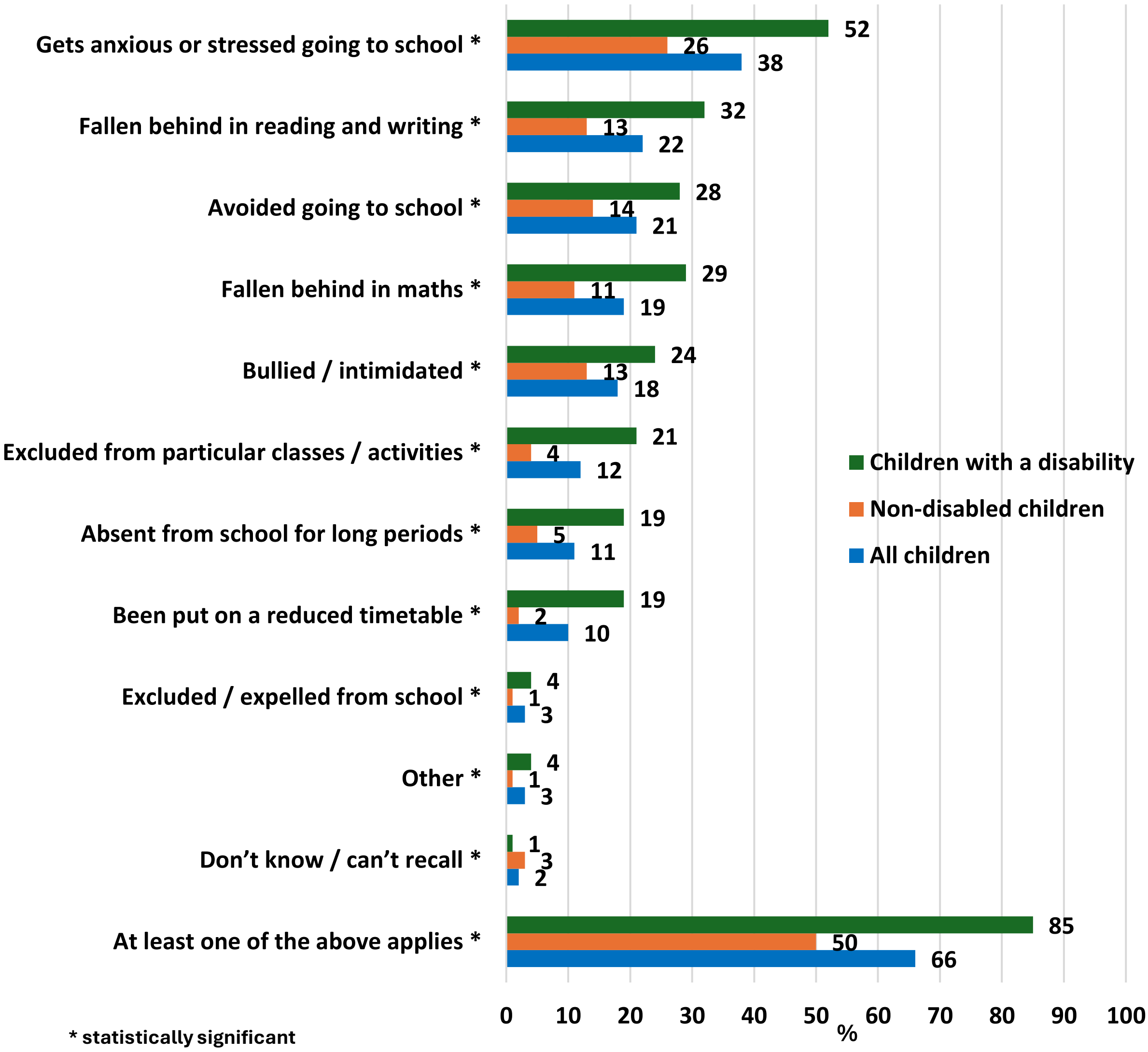


* statistically significant

Overall, 85% of parents and carers of disabled children report that their child had experienced at least one significant school-related issue, compared with half (50%) of non-disabled children.

According to the parents we surveyed, **1 in 4 disabled children (24%) had been bullied or intimidated in school**; **1 in 5 (21%) had been excluded from particular classes or activities, absent for long periods (19%) and been put on a reduced timetable (19%)**.

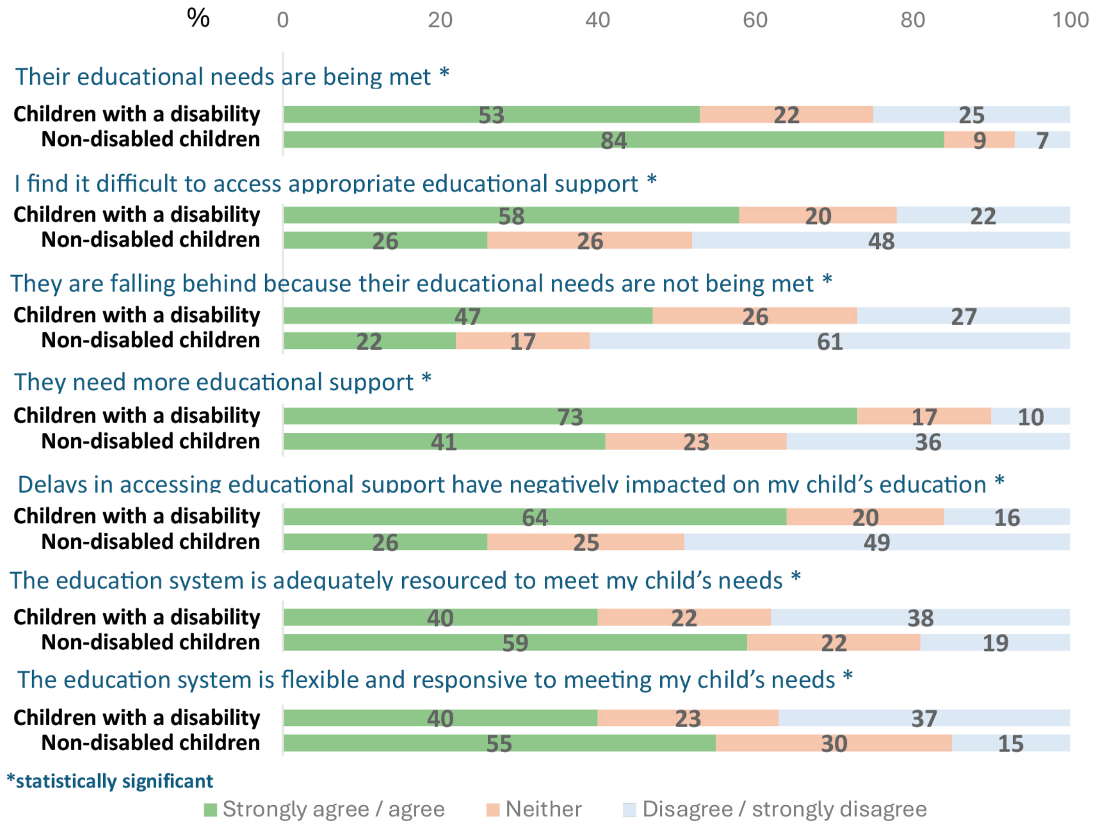
Figure 11: Please say if any of the following applies to your child(ren)?



* statistically significant

The stark findings therefore indicate that educational difficulties for disabled children extend beyond academic attainment alone and include emotional wellbeing, inclusion, participation and school experience more broadly. They also raise very serious questions around disability discrimination, unlawful practices and a failure to protect the most vulnerable children.

Figure 12: Please say to what extent you agree or disagree with each of the following statements about your child(ren)



Parents and carers of disabled children consistently express concerns about delays and barriers within the education system. While most parents report that their child's educational needs are being met, this fell significantly among parents and carers of disabled children, with just over half (53%) agreeing that their child's needs are being met, compared with 84% of parents and carers of non-disabled children.

Similarly, almost **three-quarters (73%) of parents and carers of disabled children believe their child needs more educational support, compared with 41% of parents and carers of non-disabled children.**

Fifty-eight percent of parents and carers of disabled children said they find it difficult to access appropriate educational support, more than double the proportion among parents and carers of non-disabled children (26%).

Nearly half (47%) of parents and carers of disabled children, compared with 22% of parents and carers of non-disabled children, also believe their child is falling behind because their educational needs are not being met.

Almost two-thirds (64%) of parents and carers of disabled children agree that delays in accessing educational support have negatively impacted their child's education, compared with 26% of parents and carers of non-disabled children.

Only 40% of parents and carers of disabled children agree that the education system is adequately resourced to meet their child's needs and that the system is flexible and responsive in meeting those needs. This compares with 59% and 55% respectively among parents and carers of non-disabled children. The findings suggest that many families experience compounded educational disadvantage due to multiple pressures occurring simultaneously.

A Child's Right to an Effective Education

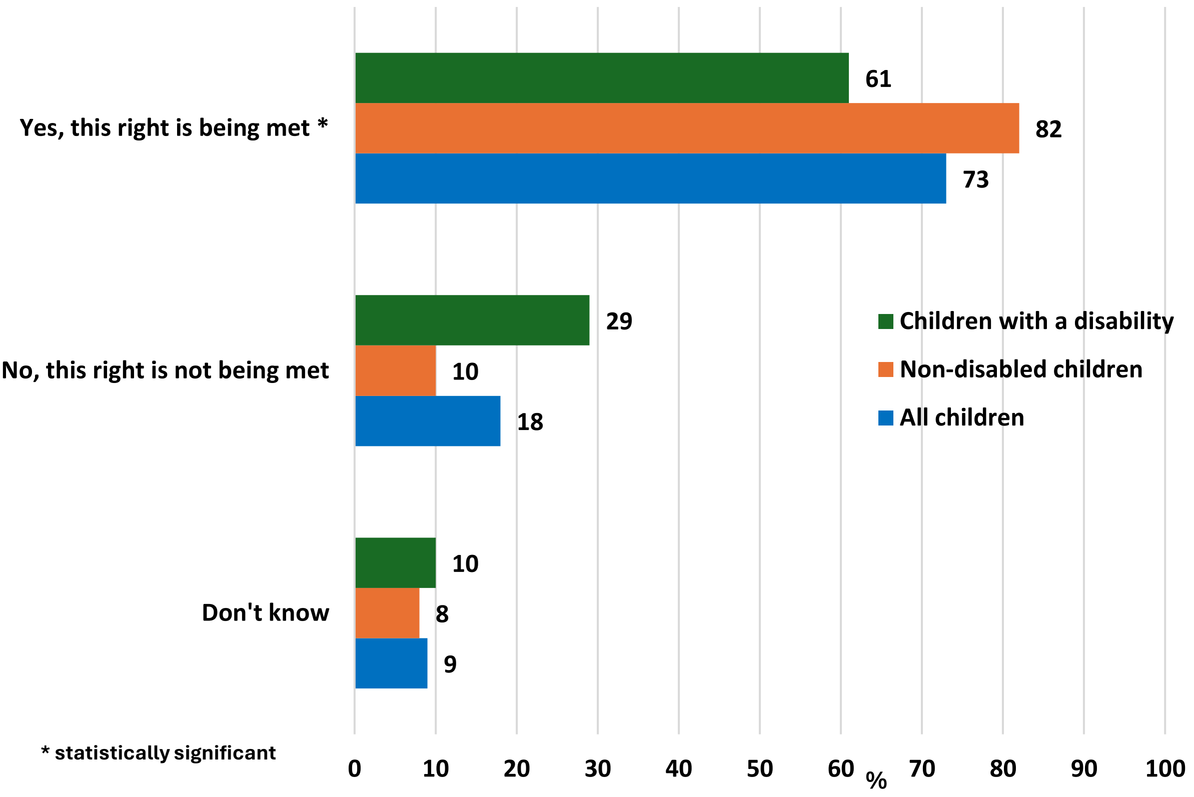
Article 28 of the UNCRC recognises every child's right to education. It states that governments must make primary education compulsory and freely available to all children, encourage access to secondary and higher education and take steps to reduce barriers to attendance. Article 29 of the UNCRC outlines the purpose of an effective education and states that education should help children develop their personality, talents and abilities to their fullest potential.

Almost three in ten (29%) parents and carers of disabled children believed their child's right to an effective education was not being met compared with 10% of parents and guardians of non-disabled children.

The reasons provided by parents reveal the depth and complexity of the educational pressures many families face. A dominant theme was that current education systems and support structures are not meeting the needs of disabled children. Parents described:

- difficulties accessing appropriate school placements;
- lack of classroom support and specialist provision;
- delays in assessment, statementing and interventions;
- negative impacts on children's mental health and wellbeing;
- bullying and exclusion;
- inadequate understanding of disability within schools, including insufficient teacher training and awareness; and
- the emotional and practical strain of having to constantly advocate for their child.

Figure 13: Children's right to an effective education



One parent explained:

> *"My child's needs are not being met in school and I feel like I have to fight for every bit of support."*

Many parents describe schools being unable or unwilling to provide appropriate support, resulting in children struggling to participate fully in education:

> *"My child is constantly overwhelmed in school because there isn't enough support in place."*

Families also describe the stress and exhaustion associated with navigating complex educational systems and securing assessments or specialist provision:

> *"You spend all your time chasing referrals, reports and support, but nobody seems to take responsibility."*

Others highlight the lack of available specialist services and the need to seek private assessments or support in order to secure help for their child:

"We had to pay privately just to get the assessments needed so school would listen."

Across responses, there is a strong sense that families often feel unheard and unsupported within the education system. Parents told us:

"We are left to figure everything out ourselves."

"I feel like I have to constantly prove my child's needs over and over again."

"The process is draining and nobody explains what support is actually available."

There was also a strong sense within some of the qualitative data that only families with the financial means, confidence, or knowledge to challenge decisions and access private support are able to secure appropriate educational provision for their children, undermining equality of opportunity. Some parents of disabled children attributed their struggles to systemic failings within education systems that do not adequately recognise or respond to disability-related needs. Many also expressed concerns about the long-term impact this was having on their child's wellbeing, confidence and future opportunities.

The findings suggest that educational pressures directly contribute to disabled children being unable to participate fully in school and everyday life. **Parents repeatedly describe children missing out on learning, struggling socially, experiencing emotional distress and becoming isolated because appropriate support is unavailable or delayed.** For many families, barriers within education negatively affected not only academic outcomes, but also wellbeing, inclusion, confidence and family life.

We recognise that the SEN Reform Agenda, the Education Authority's SEND Transformation work and wider emotional health and wellbeing initiatives provide an important opportunity to strengthen inclusion, early intervention and support within education settings. However, the findings from this research suggest that many disabled children and their families continue to experience significant barriers in accessing timely, appropriate and inclusive educational support.

The evidence highlights the need for policy responses that recognise the importance of an inclusive and accessible education, as well as the cumulative pressures experienced by families caring for disabled children. This includes consideration of:

- improving access to specialist educational support;
- strengthening early identification and intervention;
- reducing waiting times for assessments and services;

- improving training and awareness for school staff; and
- strengthening collaboration with families to ensure children's needs are understood and met.

Participation and Advocacy

The Northern Ireland Executive's Draft Disability Strategy and wider equality and inclusion commitments recognise the importance of participation, inclusion and ensuring disabled people's voices are reflected within decision-making processes.[32] Existing research has consistently highlighted that right to participation under Article 12 of the UNCRC is not being fully realised for disabled children, with children often excluded from decisions affecting their education, healthcare and everyday lives and their views not routinely given due weight.[33] International human rights frameworks, including the UNCRC and UNCRPD, further emphasise the right of disabled children to participate fully in society and in decisions impacting on their lives.

The findings from this research suggest that many disabled children and their families experience significant barriers to participation and inclusion within society in Northern Ireland. Across a range of measures, parents and carers of disabled children report poorer experiences and lower levels of inclusion than other families, including greater social isolation, fewer opportunities to participate in decisions affecting their lives and lower confidence that society values or listens to the views of disabled children.

The evidence points to a society that many families perceive as insufficiently inclusive and unresponsive to the needs and rights of disabled children. Many parents describe feeling that their children are excluded from community life, decision-making processes and activities routinely available to other children. Others highlight the emotional impact of children feeling unheard, isolated and unable to fully participate because appropriate support and inclusive opportunities are unavailable.

Participation in society emerged as a major concern within the research. Among all parents and carers surveyed, almost half (47%) report that it is difficult for their child to take part in society. However, **parents and carers of disabled children were significantly more likely to report difficulties, with more than four in five (81%) stating that participation is difficult for their child, compared with 21% of parents and carers of non-disabled children.**

The findings also suggest that many disabled children experience barriers not only to participation itself, but also to having their voices heard and their rights upheld. **Parents and carers of disabled children were significantly more likely**

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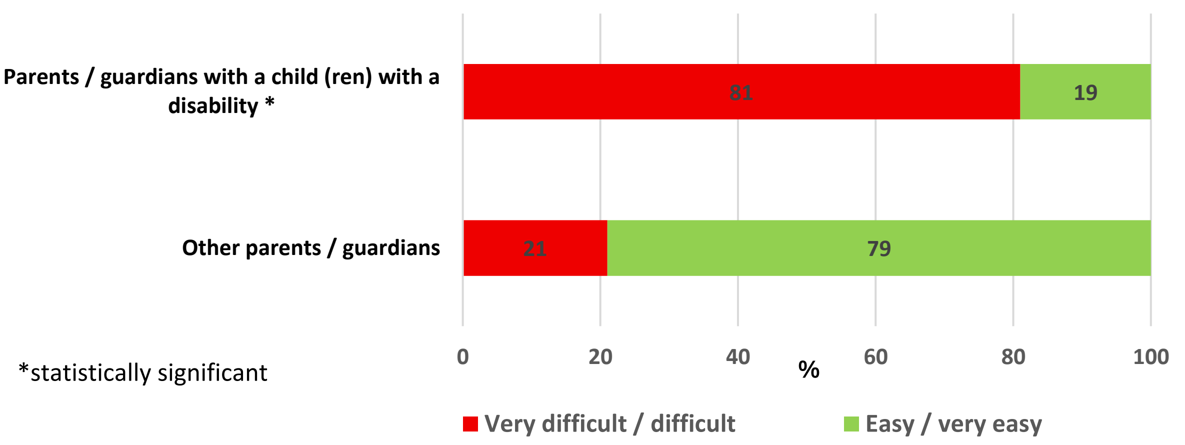
[32] Department for Communities (2025) Consultation of the NI Executive Draft Disability Strategy 2025-2035: https://www.communities-ni.gov.uk/consultations/consultation-ni-executive-disability-strategy-2025-2035

[33] Andersen, C.S. (2022) Recognition and Capability – Prerequisites for Empowerment for Children with Disabilities? *Child Ind Res* 15, 1363–1378: https://doi.org/10.1007/s12187-022-09925-5

to express concern about social isolation, with 80% reporting concerns compared with 37% of parents and carers of non-disabled children.

Figure 14: How easy or difficult is it for your child(ren) to take part in society?



Similarly, parents and carers of disabled children were less likely to agree that:

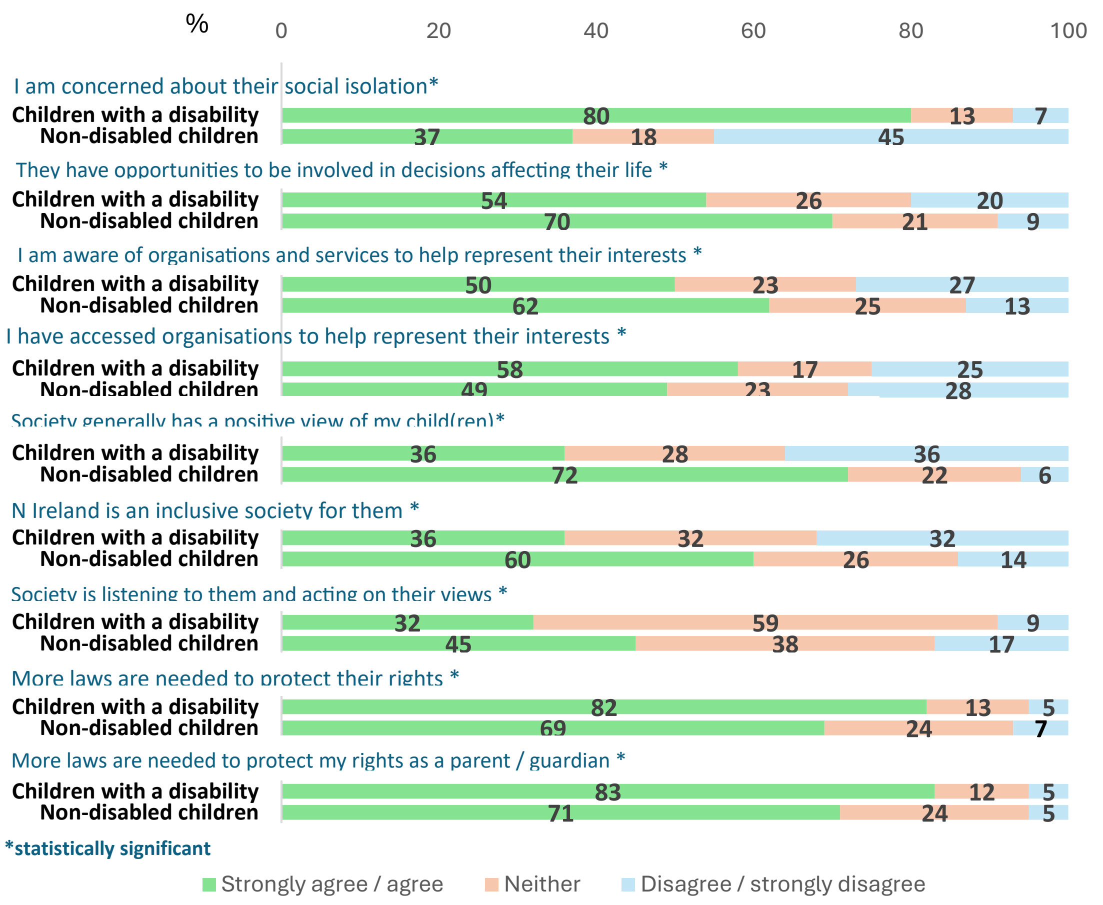
- their child has opportunities to be involved in decisions affecting their life;
- society generally has a positive view of their child;
- Northern Ireland is an inclusive society for their child; and
- society listens to disabled children and acts on their views.

Just over half (54%) of parents and carers of disabled children agree that their child has opportunities to be involved in decisions affecting their life, compared with 70% of parents and carers of non-disabled children. Similarly, **only a third (36%) believe society generally has a positive view of their child, compared with nearly three quarters (72%) of parents and carers of non-disabled children.**

The research also highlights the extent to which many families feel unsupported in advocating for their child's rights and participation. While parents and carers of disabled children were more likely to have accessed organisations to help represent their child's interests (58% compared with 49% of other parents), they were less likely to report awareness of available organisations and services.

There is also strong support among parents and carers for strengthened legal protections. **More than four in five (82%) parents and carers of disabled children agree that more laws are needed to protect their child's rights, while 83% agree that more laws are needed to protect their own rights as parents and carers.**

Figure 15: Please say to what extent you agree or disagree with each of the following statements about your child(ren)



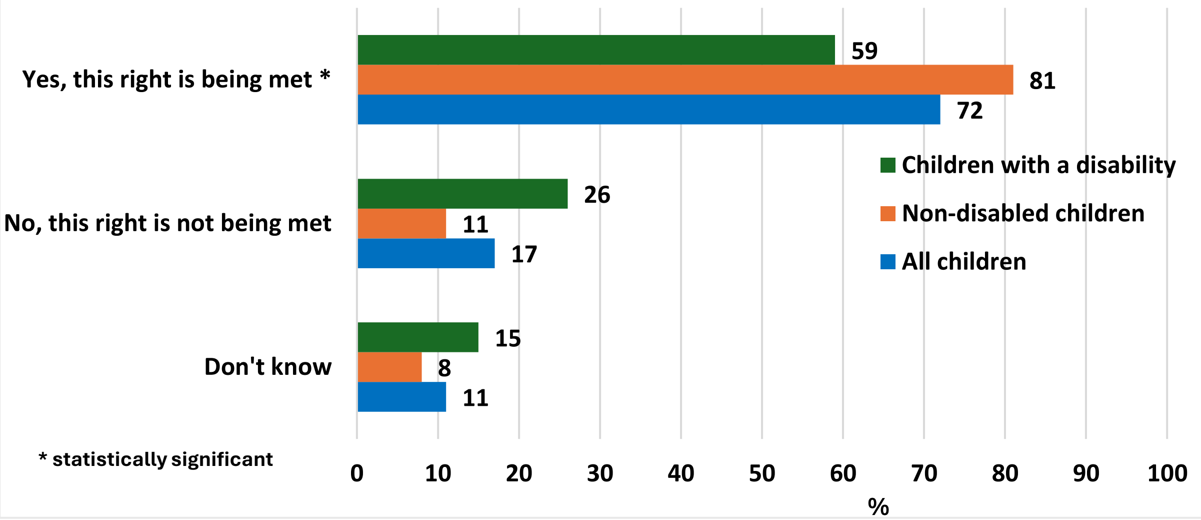
The findings suggest that many families experience compounded disadvantage across multiple aspects of participation and inclusion simultaneously. Difficulties accessing services, negative societal attitudes, social isolation and limited opportunities to influence decisions were frequently described as interconnected experiences.

A Child’s Right to Participate in Decisions Affecting Their Lives

Article 12 of the UNCRC states that children have the right to express their views freely in matters affecting them and to have those views taken into account, according to their age and maturity. Children should also receive support to participate meaningfully in decisions affecting their lives.

More than one-quarter (26%) of parents and carers of disabled children believed their child’s right to participate in society was not being met, compared with 17% of parents and carers of non-disabled children.

Figure 16: Children's right to participate in decisions impacting on their lives



The qualitative evidence provides further insight into parents' experiences of participation, inclusion and advocacy. The most prominent themes identified by parents and carers of disabled children included:

- lack of voice and meaningful participation for disabled children;
- insufficient or inaccessible services and support;
- systemic barriers and institutional inaction;
- long waiting times and delays;
- negative school experiences and lack of educational support;
- emotional and social impacts of exclusion; and
- the burden placed on parents to advocate for their child.

Parents and carers consistently describe concerns that disabled children are not listened to or meaningfully included in decisions affecting their lives. One parent explained:

"They do not have a voice in society."

Families also express frustration with what they perceive as systemic failures to prioritise disabled children's needs:

"The government do not give one toot about children with disabilities unless it makes them look good on social media."

Long waiting times for diagnosis and support were also highlighted as significant barriers to participation and inclusion:

> *"Waiting lists for diagnosis are so long that for many years children are in limbo with no support, or voice."*

Some parents describe negative experiences within educational settings, where children felt unheard or unsupported:

> *"When dealing with school in particular, my child is often subject of having consequences and sanctions put on him with minimal to no discussion with or from staff."*

Others highlight the emotional toll associated with exclusion and the pressure many disabled children feel to "mask" in order to participate socially:

> *"They find they have to mask to exist outside their home/their safe space, and they don't want to do that as school is so exhausting when the[y're] masking."*

Across responses, there was a strong sense that parents are often required to become the primary advocates for their child, navigating complex systems with limited guidance or support. Parents told us:

> *"Most parents of children with disabilities in Northern Ireland have to unfortunately exhaust every avenue to have their children included in society, whether that be leisure or education."*

There was a strong sense within some of the qualitative data that participation and inclusion are often dependent on parental persistence, financial resources and the ability to navigate complex systems, rather than being consistently guaranteed through accessible and inclusive services. Many parents describe feeling that disabled children remain marginalised within society and that their voices are inadequately reflected in decision-making processes and policy development.

The findings suggest that barriers to participation are directly linked to disabled children's wellbeing, confidence and opportunities for inclusion within everyday life. **Parents repeatedly describe children becoming socially isolated, withdrawing from activities and feeling excluded from opportunities available to their peers.** For many families, these barriers negatively affected not only participation itself, but also emotional wellbeing, confidence, belonging and overall quality of life.

We recognise that the development of the Draft Disability Strategy provides an opportunity to strengthen participation, inclusion and advocacy for disabled children and their families. However, the findings from this research suggest that many families continue to experience exclusion, limited opportunities to influence decisions and insufficient recognition of disabled children's voices and rights in practice.

The evidence highlights the need for policy responses that recognise disabled children's right to participate fully in society and the pressures experienced by families seeking inclusion and advocacy support. This includes consideration of:

- greater involvement of disabled children in decisions affecting their lives;
- reduced waiting times for diagnosis and support services;
- improved awareness of advocacy organisations and supports;
- stronger legal protections for disabled children and their families; and
- greater investment in inclusive and accessible environments across education, leisure and community settings.

Play and Leisure

Current disability and inclusion policy discussions in Northern Ireland increasingly recognise the importance of accessibility, participation and community inclusion for disabled children and young people. The Draft Disability Strategy highlights the need to reduce barriers to participation and improve inclusion across community and public life.[34] The Northern Ireland Executive's Children and Young People's Strategy 2020-2030 recognises that the enjoyment of play and leisure as a key outcome to improve the wellbeing of children and young people.[35] The Strategy commits to collaborative working to improve services for disabled children and young people and their families and carers, including promoting greater awareness of the need for suitable play and leisure facilities and activities.

The Department of Education has responsibility for play and leisure policy in Northern Ireland. It commits to giving further consideration as to how new play and leisure opportunities could be promoted. It states that,

> *"Providing all children, including those with a disability… with safe, accessible, inclusive spaces for play and socialisation has many benefits in terms of physical and mental health, education, skills development and the increasing of social confidence as well as contributing to wider community cohesion."*[36]

Research in Northern Ireland has identified persistent barriers preventing disabled children from fully accessing play and leisure opportunities, including inaccessible facilities, limited inclusive provision and inadequate support within community and recreational settings.[37]

The research findings show that many disabled children and their families experience significant barriers in accessing play and leisure opportunities in Northern Ireland. Across every area examined, parents and carers of disabled children reported poorer experiences and outcomes than other families, including greater difficulty accessing play and leisure services, lower levels of inclusion within recreational activities and higher levels of social isolation and exclusion.

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[34] Department for Communities (2025) Consultation of the NI Executive Draft Disability Strategy 2025-2035: https://www.communities-ni.gov.uk/consultations/consultation-ni-executive-disability-strategy-2025-2035

[35] NI Executive (2020) Children and Young People's Strategy 2020-2030: final-execuitve-children-and-young-people's-strategy-2020-2030

[36] Department of Education Play Matters: Play Matters | Department of Education

[37] PlayBoard NI (2020) A Right to Play for Children with Disabilities in Northern Ireland: https://www.playboard.org/wp-content/uploads/2020/11/A-Right-to-Play-for-Children-with-Disabilities.pdf

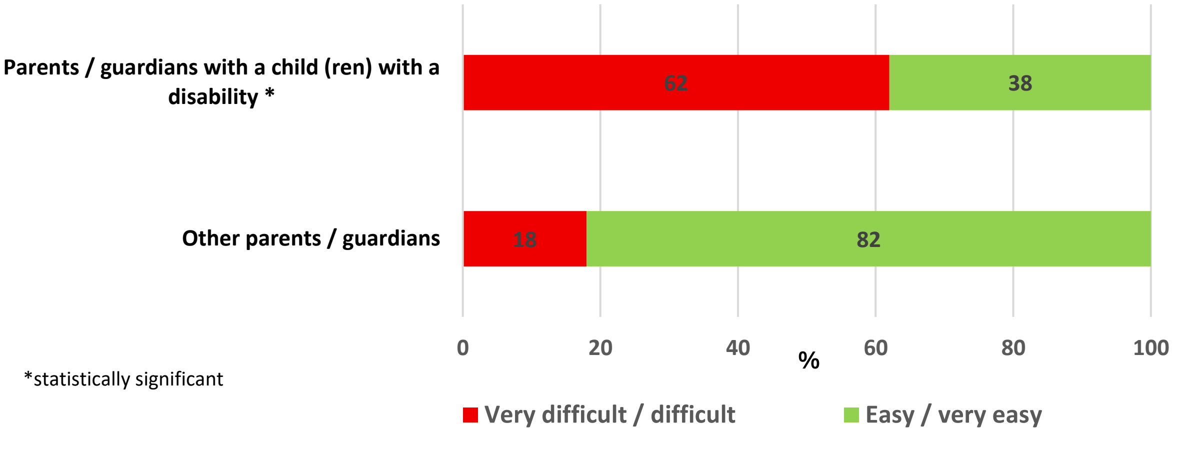
The evidence points to a system that many families perceive as discriminatory, inaccessible and inadequately equipped to support disabled children's participation in play and leisure. Parents described barriers including inaccessible facilities, a lack of appropriately trained staff, limited inclusive opportunities, financial pressures and environments that do not adequately recognise or respond to the needs of disabled children.

Access to play and leisure services emerged as a major concern within the research. **Almost two-thirds (62%) of parents and carers of disabled children report that it is difficult for their child to access play and leisure services, compared with fewer than one-fifth (18%) of parents and carers of non-disabled children.**

The research also highlights concerns regarding the accessibility and inclusiveness of recreational opportunities for disabled children. Parents and carers of disabled children were consistently less likely than other parents to agree that:

- public play areas are accessible for their child;
- community and recreational services are well equipped to meet their child's needs;
- staff are appropriately trained to support disabled children;
- their child can easily participate in social activities with other children;
- there are enough inclusive recreational opportunities available; and
- their child has equal access to sports, arts, music and cultural activities.

Figure 17: How easy or difficult is it for your child(ren) to access play and leisure services?



Only around one-third (34%) of parents and carers of disabled children agree that their child finds it easy to participate in social activities, clubs, or informal play with other children, compared with almost three-quarters (74%) of

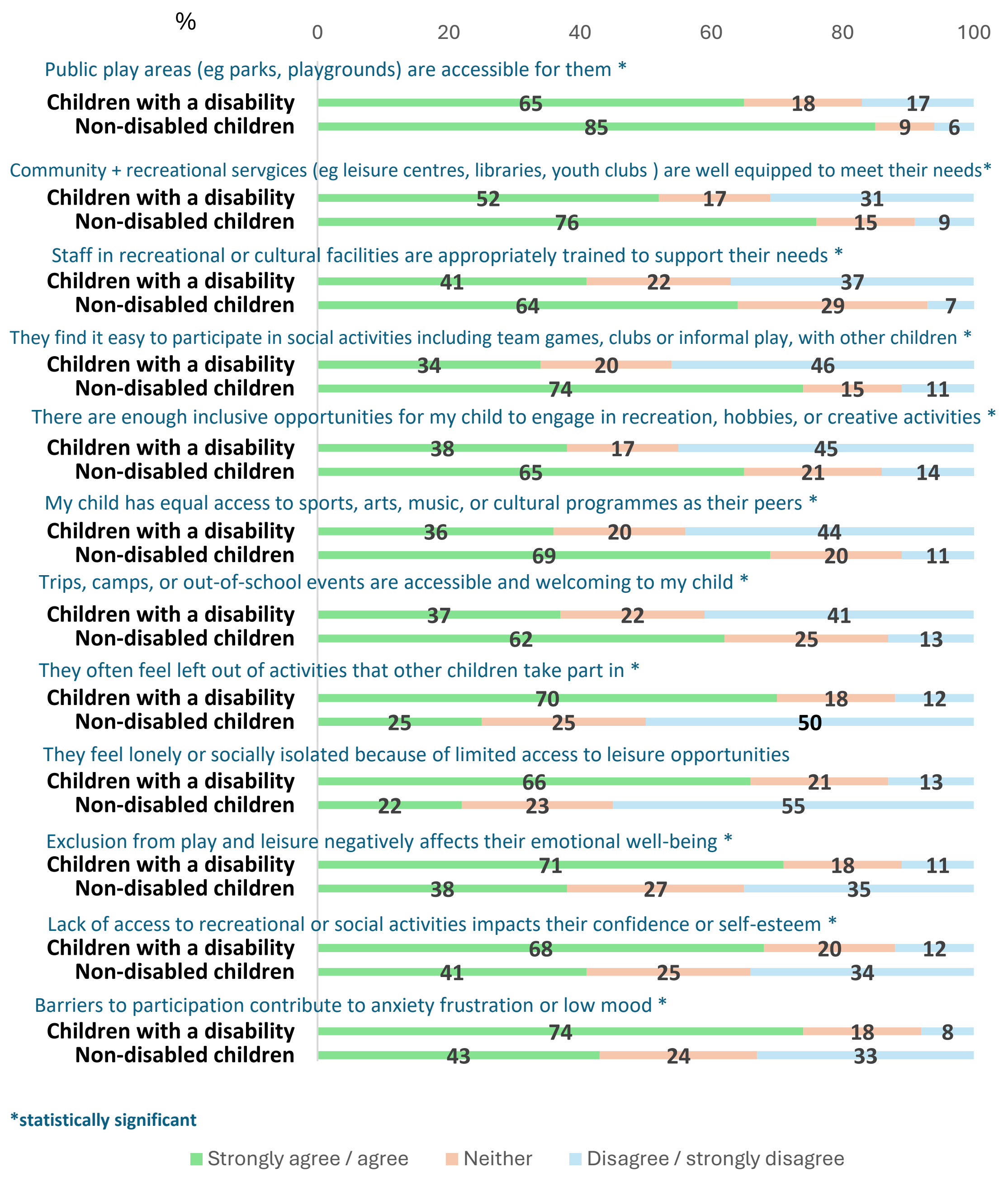
parents and carers of non-disabled children. Similarly, only 36% agree that their child has equal access to sports, arts, music, or cultural programmes, compared with 69% of parents of non-disabled children.

Parents and carers of disabled children were also significantly more likely to report negative social and emotional impacts associated with exclusion from play and leisure opportunities. Compared with other parents and carers, they were substantially more likely to agree that their children:

- often feel left out of activities other children participate in;
- feel lonely or socially isolated because of limited leisure opportunities;
- experience negative impacts on emotional wellbeing because of exclusion;
- experience reduced confidence or self-esteem; and
- experience anxiety, frustration, or low mood because of barriers to participation.

Overall, **70% of parents and carers of disabled children agree that their child often feels left out of activities that other children participate in, compared with 25% of parents and carers of non-disabled children**.

Figure 18: Please say to what extent you agree or disagree with each of the following statements about your child(ren)



***statistically significant**

Similarly, **two-thirds (66%) agree that their child feels lonely or socially isolated because of limited access to leisure opportunities, compared with 22% of other parents and carers.**

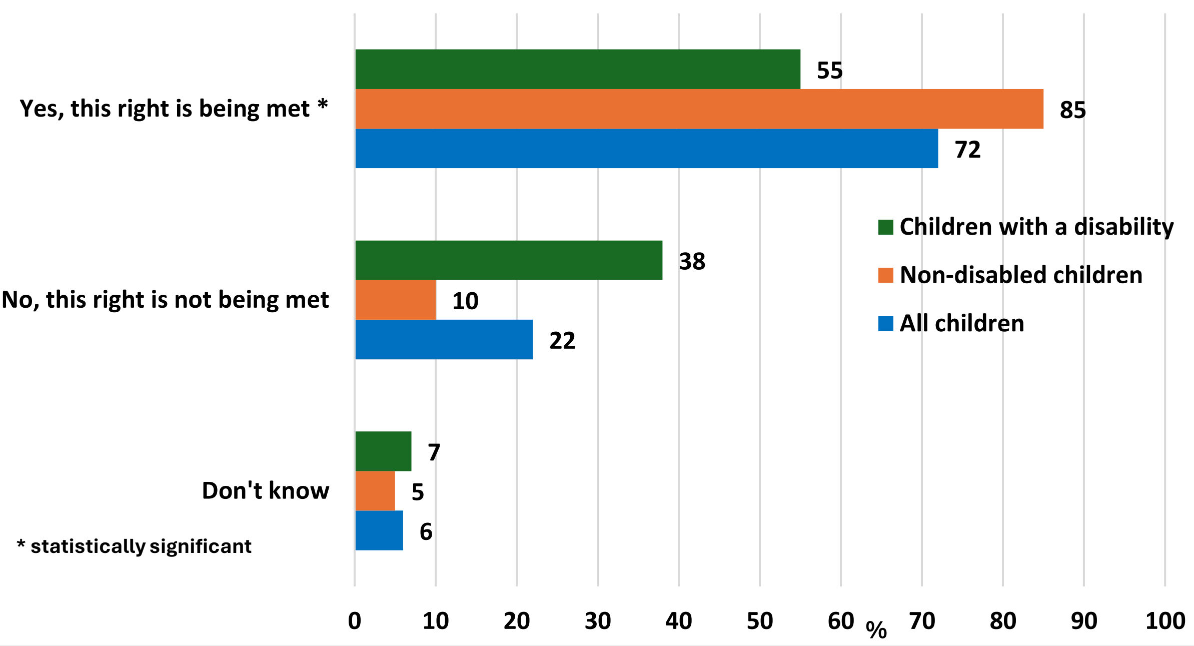
The findings indicate that barriers to play and leisure for disabled children extend beyond access to activities alone and include emotional wellbeing, confidence, social inclusion and participation more broadly.

A Child's Right to Play and Leisure

Article 31 of the UNCRC recognises every child's right to rest, relaxation, play, leisure and participation in cultural and recreational activities. It states that governments must ensure children have time, space and opportunities to participate safely in play, recreation, sport, arts and cultural life.

More than one-third (38%) of parents and carers of disabled children believed their child's right to access play and leisure services was not being met, compared with 10% of parents and carers of non-disabled children.

Figure 19: Children's right to access play and leisure services



The reasons provided by parents reveal the depth and complexity of the barriers many families face in accessing inclusive play and leisure opportunities. **A dominant theme was that existing recreational services, facilities and activities are not adequately designed or adapted to meet the needs of disabled children.**

Parents describe:

- lack of inclusive activities and facilities;
- insufficient staff training and understanding;
- social exclusion and isolation;
- financial and logistical barriers;
- government and policy failures;
- barriers associated with invisible disabilities;
- physical accessibility challenges; and
- negative impacts on children's mental health and wellbeing.

One parent explained:

> *"A lot of sports teams and hobbies do not offer teams or services for children with disabilities and quiet times are usually not quiet or inclusive – it's just a tick box."*

Many parents describe staff and volunteers lacking the training or understanding needed to support disabled children appropriately:

> *"Children with SEN feel excluded as others don't know or aren't trained in how to care or help them. Volunteers, especially in activities outside of school, are usually just local parents helping out and aren't trained in SEN needs."*

Families also describe the emotional impact of social exclusion and isolation:

> *"As an autistic child, other children have noticed the 'difference' and excluded them, while adults remain oblivious. Being highly perceptive, the child is acutely aware of their social isolation, with no means of addressing it."*

Others highlight the significant financial and logistical barriers associated with accessing suitable activities:

> *"I have to pay £100 for 4x 45-minute sessions a month for 'Sports for Autism', which is suitable for my daughter's needs and gives her the opportunity to be part of a small group session to learn new skills. Local youth centres, football clubs, Girls Brigade, Scouts, and dance clubs – none can meet her needs. I've tried them all."*

Parents also express frustration with what they perceive as inadequate policy and government support for disabled children's inclusion:

> *"Again, the fact that the government are clamping down on so much to do with disabled citizens – the ones who actually need the help and support to live are being punished."*

Some parents highlight how invisible disabilities are often overlooked or misunderstood within recreational environments:

> *"I do not feel that this right is being fully met for my child. Although he does not have a physical disability, his additional needs still affect how he participates in activities, games, and social situations. Unfortunately, I feel that these needs are often overlooked, and he misses out on many opportunities as a result."*

Across responses, there was a strong sense that families often feel unsupported and excluded from community life. Parents repeatedly described children experiencing loneliness, reduced confidence, anxiety and frustration because appropriate opportunities and supports were unavailable.

There was also a strong sense within some of the qualitative data that only families with sufficient financial resources, transport and knowledge of specialist provision are able to secure appropriate recreational opportunities for their children, creating inequalities in access and ability to participate.

The findings suggest that barriers to play and leisure are directly impacting on disabled children's emotional wellbeing and confidence. Parents repeatedly describe children feeling excluded from peer relationships, missing out on social and recreational experiences and experiencing negative mental health impacts due to inaccessible environments and a lack of inclusive opportunities. **For many families, barriers within play and leisure settings negatively affect not only participation itself, but also their child's sense of belonging, self-esteem, wellbeing and family life.**

We recognise that the Draft Disability Strategy and wider inclusion commitments present an opportunity to strengthen access to inclusive play, leisure and recreational opportunities for disabled children. However, the findings from this research demonstrate that many disabled children and their families continue to face substantial social, physical and financial barriers to participation within community life.

The evidence highlights the need for policy responses that recognise the right of disabled children to inclusive play and leisure and the pressures experienced by families seeking accessible opportunities for their children. This includes consideration of:

- improving access to inclusive recreational and cultural activities;
- strengthening training and awareness for staff and volunteers;
- increasing investment in accessible facilities and infrastructure, including relevant policies that mandate, 'inclusivity by design';

- improving support for children with invisible disabilities;
- reducing financial and transport barriers to participation; and
- strengthening the inclusion of disabled children within mainstream community activities and services.

Cost of Living

Families caring for disabled children experience significantly greater financial pressures than other families in Northern Ireland. The findings from this research demonstrate a consistent pattern: **disabled children and their families are more likely to experience lower incomes, financial insecurity, reduced employment opportunities, debt, stress and exclusion from ordinary aspects of family and community life.** These findings reinforce what we know from contemporary academic research that families with disabled children and high unpaid care responsibilities experience significantly higher levels of poverty and deprivation than other families and that disabled households experience both lower income and higher unavoidable expenditure.[38] Indeed, our evidence suggests that levels of poverty among families of disabled children cannot be understood simply in terms of income alone. Rather, it reflects the combined impact of:

- additional disability-related costs;
- reduced parental earning capacity;
- inadequate financial support;
- barriers to accessing services; and
- wider pressures associated with navigating complex systems of support.

In the survey, families caring for disabled children report substantially greater financial strain than other families across every measure examined. Overall**, 91% of parents of disabled children report experiencing at least one significant financial or employment-related impact, compared with 57% of other parents.** Statistically significant differences were identified across all financial indicators, including reduced working hours, leaving paid employment, inability to access work, difficulties accessing benefits and struggling with debt.

Almost half (48%) of parents of disabled children report increased costs related to their child's needs, such as therapies, transport and specialist equipment. **More than one-third (38%) say they struggled financially to meet their child's needs, compared with one-fifth (21%) of other parents.**

The findings suggest that many families with disabled children experience sustained financial pressure not because of a single issue, but because multiple pressures occur simultaneously, including:

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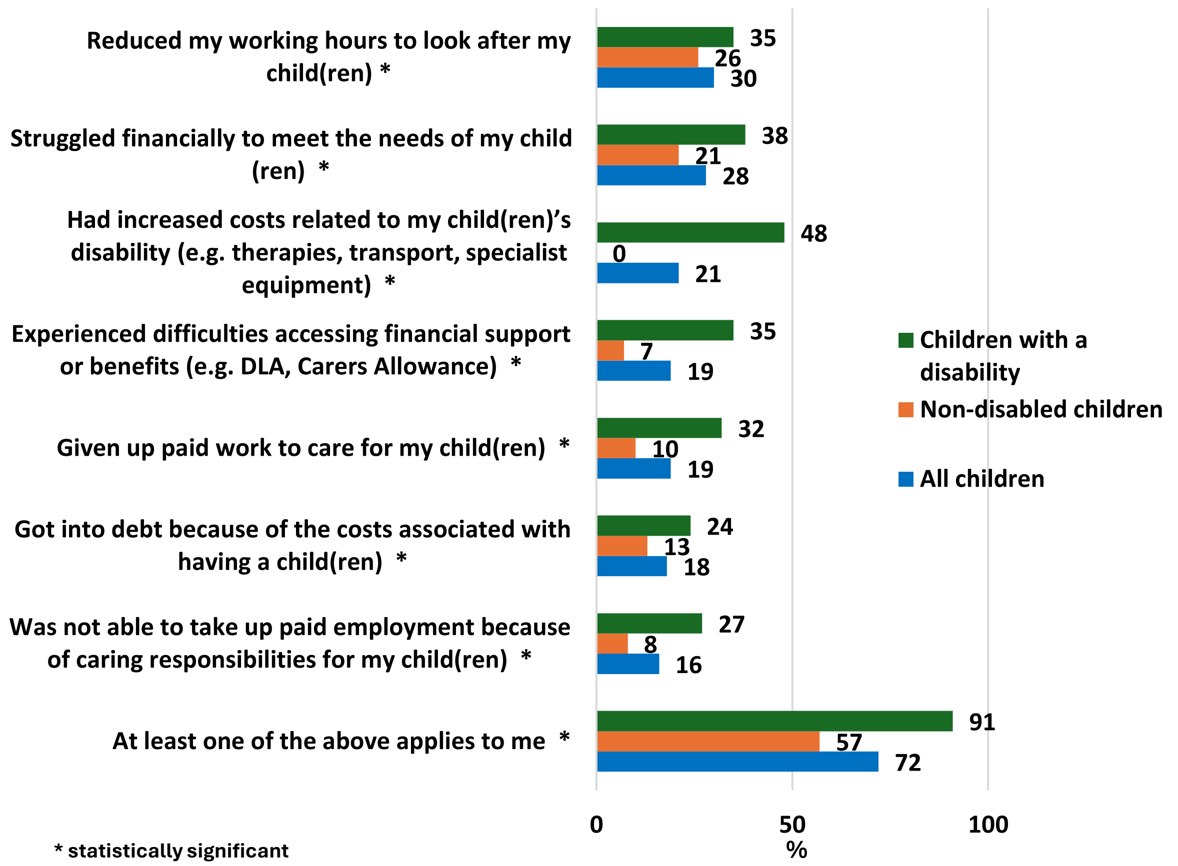
[38] Nicoriciu and Elliot (2023) Families of children with disabilities: income poverty, material deprivation, and unpaid care in the UK: https://doi.org/10.1057/s41599-023-01993-4; Doorley et al. (2025) *Adjusting estimates of poverty for the cost of disability*: https://doi.org/10.26504/JR8

- reduced earnings;
- increased costs;
- complex benefit systems;
- limited childcare and support; and
- barriers to employment.

Figure 20: As a parent or guardian which of the following applies to you?



* statistically significant

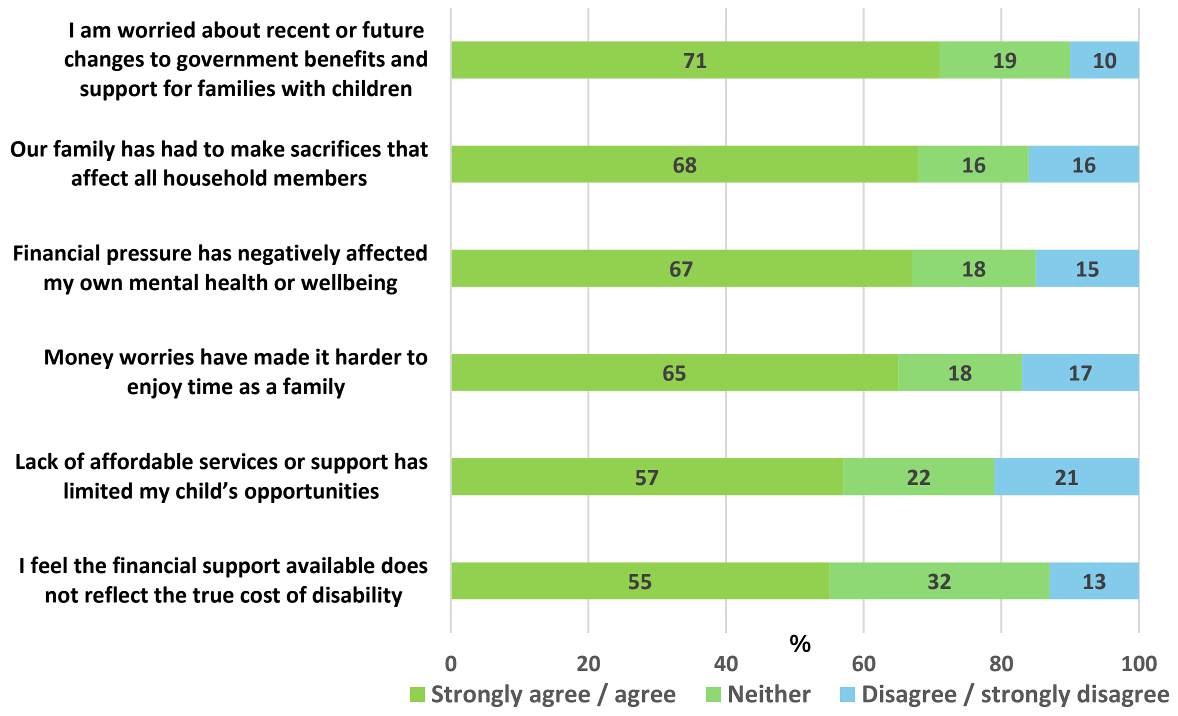
Analysis of demographic information captured within the survey also helps build a broader picture of the parents and carers who shared their views. **Families caring for disabled children were significantly more likely to:**

- **be on lower household incomes (47% earning £20,000 or less per annum);**
- be lone or single parents (50%, compared with 39% of other parents);
- have a disability themselves (62%);
- report poorer physical health (69% reporting bad or very bad health);
- **be in receipt of Universal Credit (57%)**; and

- **use food banks (64%).**

These findings reflect a strong association between childhood disability, financial insecurity and wider social inequality. The impact of financial pressure extends far beyond household income. Parents and carers of disabled children report high levels of stress, anxiety and emotional exhaustion associated with the financial realities of caring for their children.

Figure 21: Please say to what extent you agree or disagree with each of the following statements about your child(ren)?



When parents were presented with a range of statements reflecting broader impacts associated with financial pressures, **three-quarters (76%) of parents caring for disabled children said their situation had negatively affected their mental health and wellbeing**. Parents of disabled children were also more likely to say that:

- their family had to make sacrifices affecting all household members (78%, compared with 60% of other parents);
- money worries made it harder to enjoy time together as a family (71%, compared with 59%); and
- **a lack of affordable services and support had limited their child's opportunities (73%, compared with 44%).**

These findings suggest that financial pressure is not experienced in isolation, but shapes:

- family relationships;
- parental mental health;
- participation in social and community life; and
- children's opportunities.

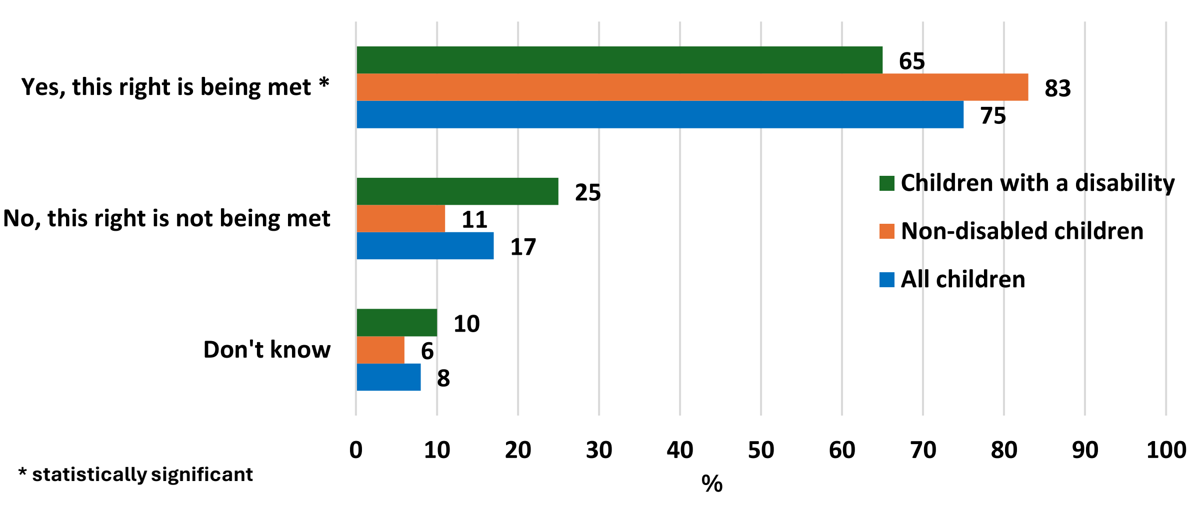
A Child's Right to an Adequate Standard of Living

Article 27 of the UNCRC recognises the right of every child to a standard of living adequate for their physical, mental, spiritual, moral and social development. It states that governments:

"shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall, in case of need, provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing."

One in four parents of disabled children (25%) said that their child's right to an adequate standard of living was not being met compared with 11% of parents and carers of non-disabled children.

Figure 22: Children's right to an adequate standard of living



* statistically significant

The reasons provided by parents reveal the complexity of the pressures many families face. **A dominant theme was that current financial support does not reflect the real cost of disability**. Parents described the combined pressures of:

- rising food and energy costs;
- private therapies;
- transport costs;

- specialist equipment; and
- reduced ability to work because of caring responsibilities.

One parent explained:

> *"The cost of living with a disability is not met by PIP or DLA and I cannot work to make up the difference because of my child's disability."*

Many parents describe being unable to work or increase working hours because of caring demands:

> *"I am unable to work due to caring and therefore have not enough funds to provide food."*

Families also describe the stress and complexity associated with accessing support:

> *"Accessing DLA… is a lottery… the forms are onerous… the wait for a decision is very stressful and takes a toll."*

Others highlight long waiting lists and lack of support, forcing families to pay privately for therapies and interventions:

> *"Extra cost in attending private treatment."*

Across responses, there was a strong sense that families often feel unsupported and left to navigate complex systems alone. Parents told us:

> *"Zero support so far has been received and no idea what to do or where to go ask due to conflicting information."*

> *"Universal Credit is hugely confusing and stressful to manage. It's awful."*

> *"I have been on the housing list for seven years waiting while my rent has doubled in price."*

There was also a strong sense within some of the qualitative data analysed that only families with higher incomes who can access private services are able to meet their child's needs, undermining equality of opportunity. Some parents of disabled children attributed their struggles to systemic neglect or political disregard for disabled children and their families, while the vast majority (83%) said they were worried about future changes to benefits and support. **Three-quarters (75%) of parents of disabled children said the financial support currently available does not reflect the true cost of living with a disability.**

The findings suggest that financial pressure is directly linked to disabled children's opportunities to participate fully in everyday life. **Parents repeatedly**

describe having to limit activities because of cost, being unable to afford therapies or services and facing reduced social opportunities, all of which negatively affect family wellbeing and participation. For many families, the additional costs associated with disability create barriers not only to financial security, but also to inclusion, participation and overall quality of life.

The evidence highlights the need for policy responses that recognise the additional unavoidable costs associated with disability, the relationship between poverty and participation and the cumulative pressures experienced by families caring for disabled children. This includes consideration of:

- targeted financial support;
- improved benefit uptake and advice services;
- accessible childcare and family support;
- reduced barriers to employment; and
- greater investment in early intervention and specialist therapies.

We recognise that the Northern Ireland Executive is taking forward some of this work through the Early Learning and Childcare Strategy, the Good Jobs Bill and the Make the Call service. However, this evidence points to the need to go further and faster. Recommendations from the Welfare Mitigations Review Independent Panel Report, such as the implementation of **the Disabled Child Winter Fuel Payment**, have not been progressed. There remains a lack of accessible childcare places for children with additional needs and parents continue to face barriers to employment due to inadequate employment rights and workplace protections. The gap between the specialist therapies and healthcare available in other jurisdictions and what is currently provided through the health and social care system in Northern Ireland is widening. Without action from the Northern Ireland Executive, many disabled children and their families are likely to continue experiencing poorer outcomes, increased financial pressure and reduced opportunities compared with their peers.

Family Life

The research also highlights the complexity of navigating support for families of disabled children and the significant impact this can have on family life. Parents and carers frequently describe a system that is difficult to understand, fragmented across services and challenging to access in a timely and coordinated way. Many report uncertainty about the support available, how to access it and which services are responsible for meeting their child's needs.

Impacts on Parents and Carers

The findings suggest that caring responsibilities have significant and far-reaching impacts on the health, wellbeing, finances and family lives of many parents and carers in Northern Ireland. **Across every area examined, parents and carers of disabled children report substantially higher levels of stress, exhaustion, financial pressure, social isolation and difficulty navigating support systems than families with non-disabled children**.

The evidence points to the cumulative pressures experienced by many families caring for disabled children, with emotional, practical and financial challenges often occurring simultaneously. **Parents repeatedly describe feeling overwhelmed, unsupported and exhausted by the demands of caring responsibilities while attempting to navigate complex systems and secure appropriate support for their children**.

Impacts on Health and Wellbeing

Parents and carers of disabled children were significantly more likely than parents and carers of non-disabled children to report negative impacts on their own health and wellbeing because of their caring responsibilities.

Almost seven in ten (67%) parents and carers of disabled children report experiencing high levels of stress or anxiety because of caring responsibilities, compared with 41% of parents and carers of non-disabled children.

One-third (33%) report having been diagnosed by a GP with anxiety, stress, or depression, compared with 18% of parents and of non-disabled children.

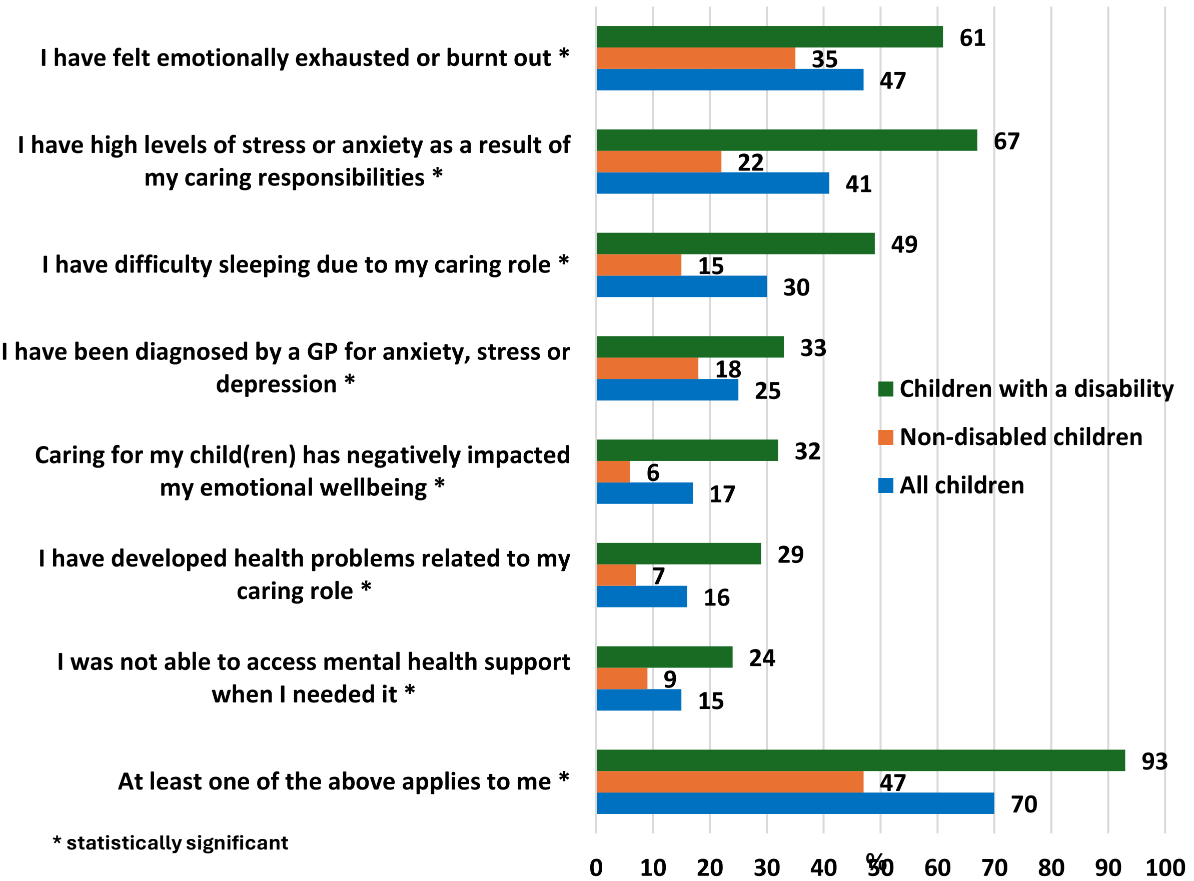
The findings also show high levels of emotional exhaustion and burnout among parents and carers. **Almost half (47%) of all respondents reported**

feeling emotionally exhausted or burnt out, while 30% reported difficulties sleeping because of their caring role.

Parents and carers of disabled children were significantly more likely to report every health and wellbeing impact measured in the survey.

Overall, 93% of parents and carers of disabled children report experiencing at least one negative impact on their health and wellbeing because of their caring responsibilities, compared with 47% of parents and carers of non-disabled children.

Figure 23: As a parent or guardian which of the following applies to you?



* statistically significant

The findings suggest that caring responsibilities have substantial impacts on parents' mental health, physical wellbeing and emotional resilience, particularly for families of disabled children.

Impacts on Families

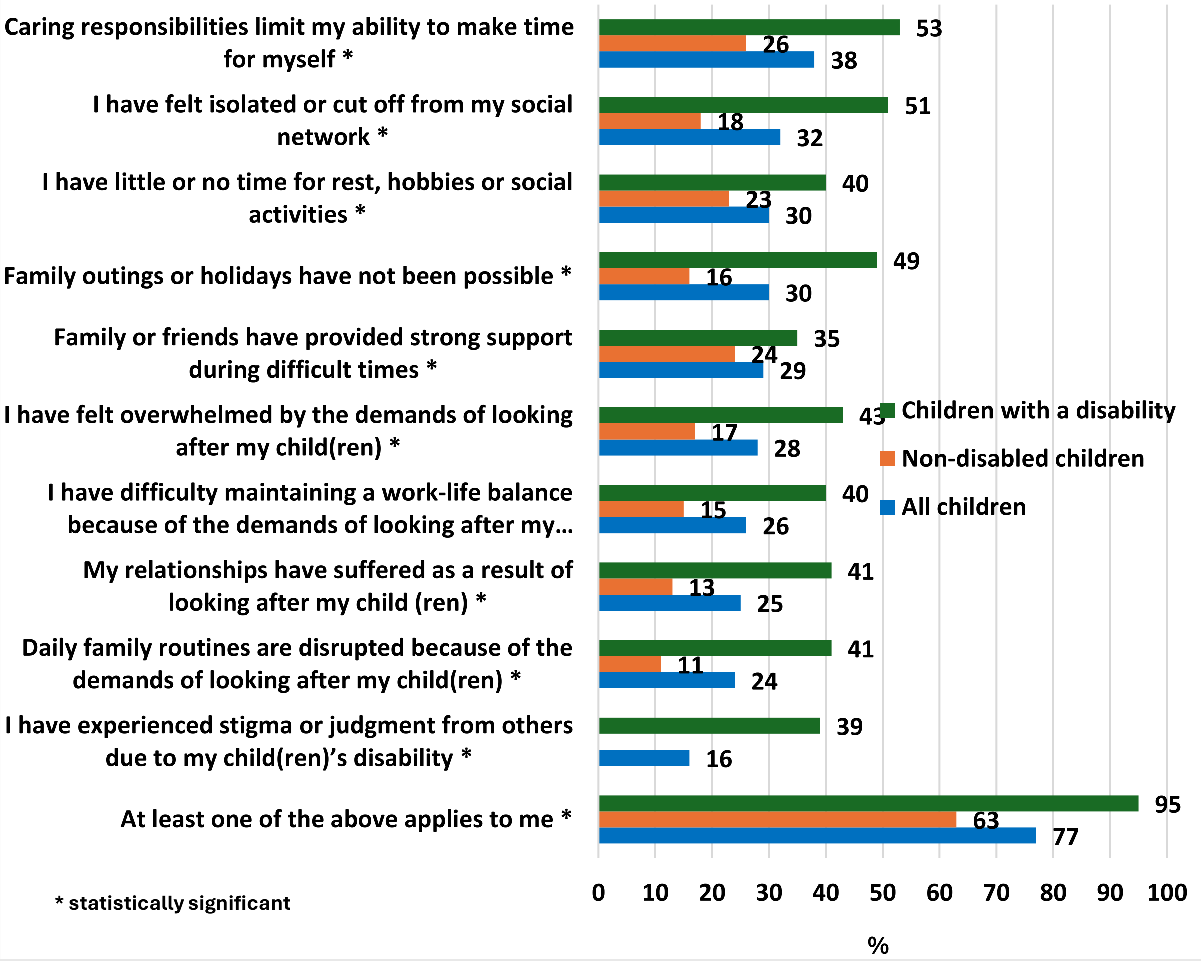
The research highlights the broader impacts caring responsibilities can have on family life and relationships. **Parents and carers of disabled children were significantly more likely to report experiencing social isolation, difficulties maintaining work-life balance, disruption to family routines and reduced opportunities for rest, social activities and family time.**

More than half (53%) of parents and carers of disabled children report that caring responsibilities limit their ability to make time for themselves, compared with 26% of parents and carers of non-disabled children. Similarly, **over half (51%) report feeling isolated or cut off from their social network, compared with 18% of parents of non-disabled children.**

The findings also suggest that many families experience restrictions on social participation and quality of life because of caring responsibilities. Parents describe difficulties taking family outings or holidays, a lack of time for hobbies or rest and feeling overwhelmed by the constant demands of caring for their children.

Overall, **95% of parents and carers of disabled children report experiencing at least one significant impact on family life, compared with 63% of parents and carers of non-disabled children.**

Figure 24: As a parent or guardian which of the following applies to you?

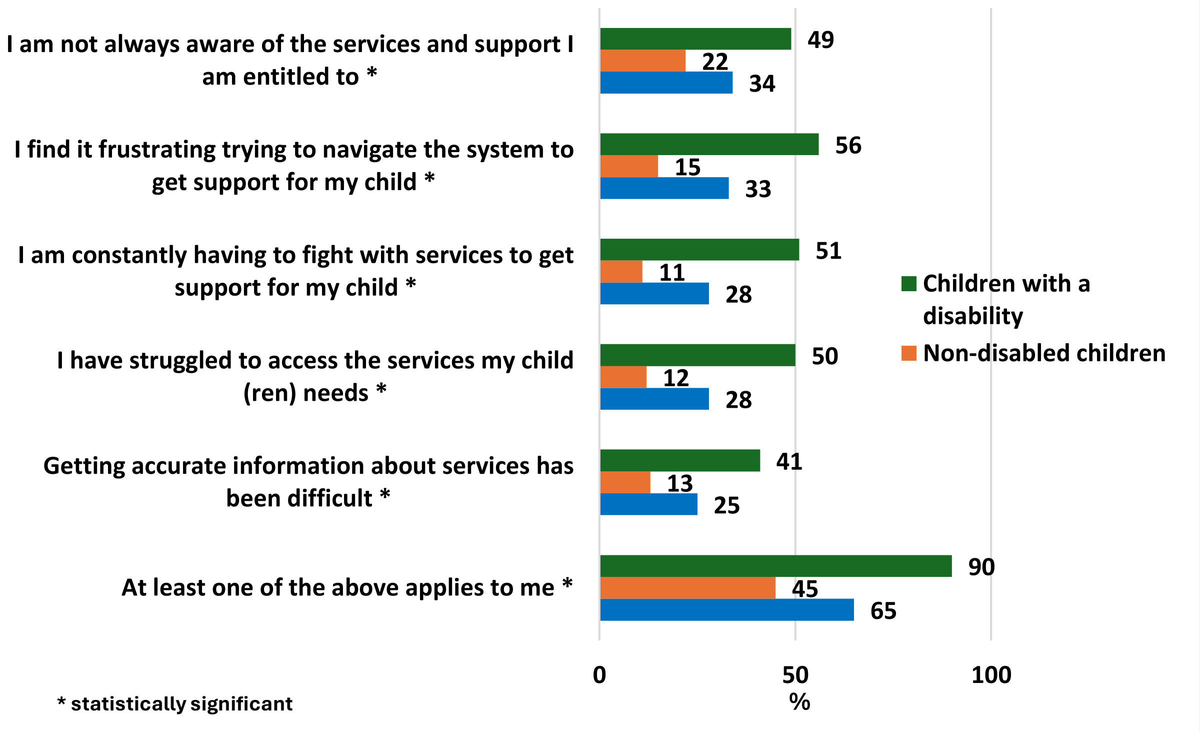


Navigating the System

The findings show that many parents and carers experience substantial difficulties navigating systems and accessing support for their children. Parents and carers of disabled children were significantly more likely than other parents to report:

- not being aware of the services and supports they are entitled to;
- finding systems frustrating and difficult to navigate;
- having to constantly "fight" with services to secure support; and
- difficulties obtaining accurate information about available services.

Figure 25: As a parent or guardian which of the following applies to you?



More than half (56%) of parents and carers of disabled children report finding it frustrating trying to navigate systems to obtain support for their child, compared with just 15% of parents and carers of non-disabled children. Almost half (49%) also report not always being aware of the services and support they are entitled to, compared with 22% of parents and carers of non-disabled children.

Overall, 90% of parents and carers of disabled children report experiencing at least one difficulty navigating systems and accessing support, compared with 45% of parents and carers of non-disabled children.

The findings suggest that many families caring for disabled children experience considerable emotional and practical burdens associated with navigating fragmented and complex support systems.

The evidence points towards interconnected pressures experienced by many families caring for disabled children. **Parents repeatedly described balancing emotional exhaustion, financial hardship, social isolation, difficulties navigating systems and reduced opportunities for family life.**

The findings suggest that the impacts of caring responsibilities reflect wider structural challenges relating to disability support, access to services, financial assistance and inclusion. For many families, these pressures negatively affect not only parents' wellbeing, but also children's participation, opportunities and overall quality of life.

The evidence highlights the need for policy responses that recognise the significant emotional and practical pressures experienced by families caring for disabled children. This includes consideration of:

- improving access to family and respite support services;
- strengthening mental health support for parents and carers;
- improving information, advice and navigation support;
- increasing investment in accessible and affordable services; and
- strengthening recognition of the needs and experiences of parent carers within policy and service planning.

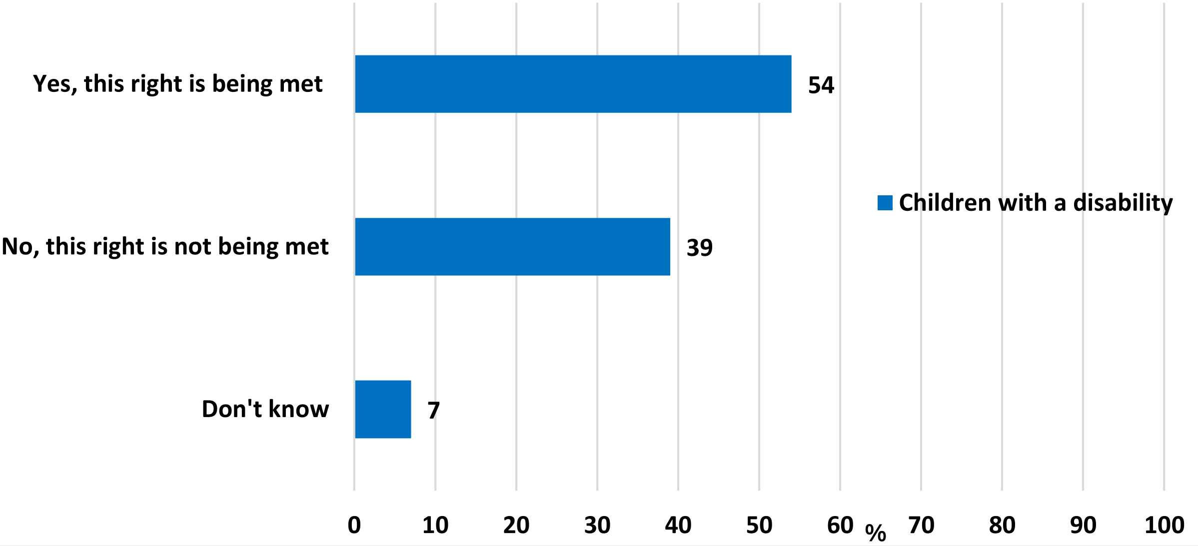
Disabled Children Reaching Their Full Potential

Existing research in Northern Ireland has highlighted that disabled children and young people continue to experience poorer outcomes across education, health, participation, wellbeing and social inclusion, limiting opportunities to reach their full potential. NICCY has previously identified persistent systemic barriers affecting disabled children's rights, participation and life opportunities, particularly in relation to access to support and inclusion within everyday life.[39]

Article 23 of the UNCRC states that disabled children should be supported to reach their full potential and be provided with opportunities to participate actively within their communities, including access to education, healthcare, recreation and support services.

Almost four in ten (39%) parents and carers of disabled children believed this right was not being met.

Figure 26: The right of children with a disability to reach their full potential



The findings also suggest that experiences of support and inclusion vary considerably across different groups of families. Parents and carers who were less likely to believe their child's right to reach their full potential was being met included:

- female parents and carers;

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[39] Northern Ireland Commissioner for Children and Young People (2021) Neither Seen Nor Heard: Rights-Based Review of Disabled Children and Young People in Northern Ireland: https://www.niccy.org/media/4290/neither-seen-nor-heard.pdf

- older parents and carers;
- those living in rural areas;
- families experiencing debt or financial hardship;
- those in lower income households;
- those in poorer health; and
- those in receipt of Universal Credit.

Only 34% of parents and carers living in rural areas believe their child's right to reach their full potential is being met, compared with 61% of those living in urban areas.

Similarly, **only 41% of parents and carers currently in debt believe this right is being met, compared with 63% of those not in debt.**

The findings therefore suggest that disabled children's opportunities to reach their full potential are shaped not only by disability-related barriers, but also by wider inequalities linked to poverty, health, geography and access to support.

The qualitative evidence provides further insight into parents' experiences of seeking support for their children. The most prominent themes identified by parents and carers of disabled children included:

- lack of services and support;
- educational needs not being met;
- social isolation and lack of accessible activities;
- healthcare delays and poor coordination between services;
- government neglect and systemic failures; and
- financial pressures on families.

Families highlight fragmented and under-resourced services that are unable to meet the needs of disabled children. Parents describe being left to navigate complex systems alone while attempting to access appropriate support across a range of services.

The reasons provided by parents illustrate the extent of the barriers families face in supporting their disabled children to reach their full potential. Parents described coping with the pressures of:

- inadequate statutory support and specialist services;
- unmet educational needs;

- lack of inclusive social and recreational opportunities;
- delays in healthcare assessment, diagnosis and treatment;
- financial pressures associated with disability; and
- the emotional and practical strain of having to constantly advocate for their child.

One parent explained:

> *"Statutory services are not meeting his needs… some voluntary services are taking up the slack but they are few and far between."*

Many parents describe educational systems being unable to adequately support disabled children:

> *"My child is not getting adequate educational support."*

Families also describe the lack of inclusive clubs, activities and opportunities for disabled children to participate socially and recreationally:

> *"There are very few activities or clubs etc for our children, or too limited places."*

Others highlight how delays within healthcare systems negatively affect every aspect of children's lives:

> *"If you can't access the healthcare to get your child the diagnosis they need… this negatively impacts every single aspect of their life."*

Parents also express frustration with what they perceive as government inaction and systemic neglect of disabled children and their families:

> *"Because government in NI DO NOT CARE."*

The findings suggest that barriers across education, healthcare, play, leisure and community support are interconnected and collectively impact disabled children's ability to reach their full potential. Parents repeatedly describe children experiencing exclusion, reduced opportunities, worsening mental health, limited independence and social isolation because appropriate support was unavailable or delayed.

We recognise that current policy reforms, including the Draft Disability Strategy and SEN Reform Agenda, provide an important opportunity to improve outcomes and opportunities for disabled children in Northern Ireland. However, the findings from this research demonstrate that many disabled children and their families continue to experience interconnected barriers that limit participation, inclusion and opportunities to reach their full potential.

The evidence highlights the need for policy responses that recognise the cumulative and interconnected pressures experienced by disabled children and their families. This includes consideration of:

- improving access to specialist and community support services;
- increasing investment in inclusive education, healthcare and leisure provision;
- reducing waiting times for assessments and interventions;
- strengthening coordination between statutory services;
- improving support for families experiencing financial hardship; and
- strengthening recognition of disabled children's rights to inclusion, participation and equality of opportunity.

Recommendations

Taken together, the findings throughout this research reveal a number of consistent themes and key priority issues requiring urgent action. Across every area examined, families of disabled children report significant inequalities, barriers to support and cumulative pressures affecting children's rights, wellbeing, inclusion and quality of life. The following recommendations are intended to support a more coordinated, rights-based and inclusive approach across government and public services to improve outcomes for disabled children and their families in Northern Ireland.

1. Legislative Reform

Prioritise the urgent review of Northern Ireland's disability legislative framework, as committed to within the Northern Ireland Executive's Draft Disability Strategy, with a view to strengthening legal protections for disabled people and addressing the persistent inequalities experienced by disabled children and their families.

The Northern Ireland Executive should also take steps to incorporate the UNCRC into domestic law to strengthen accountability for children's rights across government and public services and ensure that children's rights are systematically considered within legislation, policy development, budgeting and service delivery. This should include specific consideration of the rights and experiences of disabled children, alongside mechanisms to monitor implementation, reduce inequalities and improve outcomes.

Public authorities should also be required to carry out robust Children's Rights Impact Assessments on all draft legislation, policies and strategic decisions affecting children to ensure that potential impacts on children's rights are identified and addressed at the earliest possible stage.

Throughout this research, parents and carers of disabled children consistently reported poorer experiences across access to services and support, education, healthcare, play and leisure, participation and advocacy, standard of living and family life. Parents and carers of disabled children were also significantly more likely to report that their children's rights under the UNCRC are not being upheld across every area examined. The findings suggest that the current legal framework is not adequately protecting disabled children from unequal treatment or ensuring that their rights are fully realised in practice.

Disability legislation and children's rights protections in Northern Ireland should be strengthened without delay to address significant gaps in legal protection, provide robust safeguards for disabled people in line with the Equality

Commission for Northern Ireland's recommendations,[40] and improve outcomes for disabled children and young people.

2. Establish a Single Point of Contact for Families

Introduce a dedicated key worker or family navigator model to help families access and coordinate services across health, education, social care and community support. Families should not be left to navigate complex systems alone or repeatedly, "fight," for support.

3. Improve the Timeliness of Public Services

Introduce a single, comprehensive statutory waiting time target framework across children's services, with clear targets and legally enforceable accountability mechanisms, particularly for disabled children accessing assessments, therapies and support services. The findings demonstrate widespread concern regarding delays and poor responsiveness.

4. Provide Sufficient Financial Assistance to Families with Disabled Children

Address the financial pressures faced by families caring for disabled children through the introduction of a Disabled Child Winter Fuel Payment, as recommended by the Welfare Mitigations Review, alongside enhanced disability cost supplements to recognise the additional ongoing costs associated with disability.

Improve benefit uptake and access to financial support by embedding welfare advice within health, education and community settings and by funding targeted advice services delivered by the voluntary sector.

5. Reduce Barriers to Employment for Parents and Carers of Disabled Children

Take targeted action to reduce barriers to employment for parents and carers of disabled children, including improving access to inclusive childcare, respite and family support services, promoting flexible working arrangements and strengthening employment support for parent carers. Reducing barriers to employment would help improve financial security, reduce poverty and support the wellbeing and participation of disabled children and their families.

6. Increase Investment in Early Intervention Services

Expand early intervention and preventative support services for disabled children and their families to ensure support is available before needs escalate. Families

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[40] Equality Commission for Northern Ireland (2024) Submission to the Committee for the Executive Office Inquiry into Gaps in Equality Legislation: Submission to the Committee for the... | Equality Commission NI

should be able to access support when needs are identified, rather than only after a formal diagnosis.

7. Improve Awareness and Signposting of Available Support

Develop a centralised, accessible information and advice service for parents and carers, including:

- clear guidance on available supports and entitlements;
- referral pathways;
- information in accessible formats; and
- improved signposting following diagnosis or contact with services.

The research found that many parents, particularly parents of disabled children, are unaware of available support or how to access it.

8. Strengthen Coordination Between Services

Public services should adopt a more joined-up and integrated approach to supporting children and families, in line with their legal obligations under the Children's Services Co-operation Act (Northern Ireland) 2015.

Greater coordination is needed between health, education, social care and community services to reduce duplication, address gaps in provision and transform the fragmented nature of support.

9. Increase Funding for Disability Support Services

Increase investment in disability support services, including therapies, respite care, specialist support and community-based provision. The research demonstrates substantial unmet need among families caring for disabled children.

10. Deliver a Child-Centred and Inclusive SEN System

The current SEN Reform Agenda is an opportunity to deliver a genuinely child-centred and inclusive SEND system that provides the right support, from the right people, at the right time and in the right place.

Reform should prioritise:

- earlier intervention and improved access to specialist services;
- reduced waiting times for assessment and support;
- improved coordination between education and health services; and
- greater consistency of provision across Northern Ireland.

It should also ensure that the voices of children, young people and families are embedded throughout decision-making, service planning and review processes, alongside sustained investment in workforce capacity, inclusive practice and specialist support services.

11. Reduce Delays in Assessment, Statementing and Educational Support

Strengthen the statutory, legally enforceable waiting times for SEN assessments, statementing processes and access to educational provision. Delays in support are having serious impacts on children's learning, wellbeing and long-term outcomes.

12. Strengthen Inclusive Education in Mainstream Schools

Provide sufficient support to ensure mainstream schools can appropriately support disabled children and children with additional needs. This should include:

- increased staffing and specialist support;
- adapted learning environments;
- flexible approaches to learning; and
- improved access to therapeutic and behavioural supports.

13. Develop a Whole-School Approach to Mental Health and Wellbeing

Schools should implement comprehensive wellbeing strategies to address anxiety, school non-attendance, bullying and emotional distress. This should include:

- increased access to educational psychology, counselling and emotional wellbeing services;
- trauma-informed training and whole-school approaches;
- early intervention mental health support; and
- reduced reliance on punitive disciplinary approaches.

14. Sustain and Expand Voluntary and Community Sector Provision

Provide long-term, sustainable funding for voluntary and community organisations delivering essential support to children and families. Many families rely heavily on these organisations where statutory services are insufficient or inaccessible.

15. Introduce Mandatory Disability Awareness and Inclusion Training

Ensure frontline staff across public services receive training on disability awareness, the social model, neurodiversity, communication needs and family-centred practice to improve understanding and reduce negative experiences for families.

16. Improve Mental Health and Emotional Support for Parents and Carers

Develop dedicated emotional wellbeing and mental health supports for parents and carers of disabled children, including access to counselling, peer support networks and respite provision. The findings demonstrate high levels of stress, exhaustion and emotional strain among families.

17. Inclusive Childcare, Play and Leisure

Increase access to, and investment in, inclusive childcare and play and leisure provision that is responsive to the needs of disabled children in order to address the isolation and exclusion identified throughout the research.

Childcare and leisure providers should be supported to ensure staff are appropriately trained and buildings are adapted to meet the needs of disabled children.

Any additional costs incurred by families of disabled children in accessing childcare or activities should be compensated by government and not passed on to families. Families should not have to pay a premium to access services routinely available to non-disabled children.

18. Embed Co-Production and Family Voice in Service Design

Public authorities should actively involve disabled children, parents and carers in the design, delivery and evaluation of services to ensure support reflects lived experience and family need.

19. Monitor and Improve the Wellbeing of Disabled Children and Their Families

There is currently insufficient data available on the lives of disabled children and their families in Northern Ireland. This research highlights the significant cumulative pressures faced by families caring for disabled children across all areas of their lives.

It is imperative that this is addressed comprehensively and urgently, and that improving the wellbeing of disabled children and their families becomes a cross-government priority supported by measurable actions across all government departments.

In some respects, this research provides a baseline and the overall findings are stark. In order to track progress, measure the impact of investment and policy changes, the government should develop a dedicated data dashboard with a suite of indicators to ensure a dedicated focus on disabled children's outcomes. This work should be progressed through the Northern Ireland Executive's Disability Strategy.

20. Strengthen Accountability for Delivery of the Disability Strategy

The Northern Ireland Executive's Disability Strategy provides an important opportunity to improve outcomes for disabled children and their families. However, the findings throughout this research demonstrate that existing legal duties, policy responsibilities and service reforms have not consistently translated into improved experiences and outcomes in practice. The success of the Disability Strategy will therefore depend not only on its ambitions, but on effective implementation, accountability and delivery.

The Northern Ireland Executive should establish clear accountability arrangements for the delivery of the Disability Strategy, ensuring that ministers, government departments and public bodies are held responsible for implementing commitments and improving outcomes for disabled children and their families.

This should include:

- clearly defined departmental responsibilities and delivery commitments;
- measurable targets and implementation timescales;
- regular public reporting on progress;
- scrutiny by the Northern Ireland Assembly and relevant oversight bodies;
- independent evaluation of implementation and impact; and
- meaningful involvement of disabled children, young people and families in monitoring progress.

The findings throughout this report demonstrate that many of the inequalities experienced by disabled children persist despite existing legal protections, strategies and policy commitments. Stronger accountability for the delivery of the Disability Strategy is therefore essential to ensure that commitments result in meaningful improvements in the lives of disabled children and their families, rather than remaining aspirations on paper.

Conclusion

This report presents a clear and consistent picture of inequality in the lives of disabled children in Northern Ireland. Across access to services and support, education, healthcare, participation, play and leisure, financial wellbeing and family life disabled children are significantly less likely than their non-disabled peers to experience the conditions necessary for a full, inclusive and equal childhood.

The findings demonstrate that these inequalities are not isolated or incidental. Rather, they reflect a pattern of structural disadvantage experienced across multiple areas of children's lives simultaneously. Families repeatedly describe difficulties accessing support, long waiting times, fragmented systems, financial pressures, exclusion from everyday opportunities and the emotional exhaustion associated with continually advocating for their children. The evidence throughout this report suggests that these challenges are cumulative and interconnected, with barriers in one area often intensifying difficulties in others.

Importantly, the findings highlight the extent to which disabled children and their families continue to experience a gap between legal rights and lived reality. While Northern Ireland has a range of legal protections and policy commitments designed to promote equality, inclusion and participation, many families report experiences that suggest these rights are not being consistently realised in practice. Parents and carers of disabled children consistently report poorer experiences across every area examined, including lower confidence that systems are meeting their child's needs and greater concern about their child's future opportunities and wellbeing.

The research also demonstrates the resilience and persistence of families caring for disabled children. Despite significant pressures, parents and carers repeatedly described continuing to advocate for support, inclusion and opportunities for their children. However, the findings suggest that too often families are being required to compensate for gaps within systems that should be designed to support them. Access to timely support, participation in education and community life and opportunities to reach their full potential should not depend upon parental persistence, financial means or the ability to navigate complex systems.

The evidence presented throughout this report points clearly towards the need for coordinated and sustained action across government and public services. Improving outcomes for disabled children requires more than isolated service improvements. It requires a joined-up, cross-government approach that recognises the interconnected nature of the barriers families face and addresses the wider structural inequalities impacting disabled children's lives.

This includes improving access to healthcare, education and support services; reducing waiting times; addressing the additional financial costs associated with disability; strengthening inclusive practice across schools and community settings; improving support for parents and carers and ensuring disabled children and their families are actively involved in shaping the policies and services that affect them.

The development of the Northern Ireland Executive's Disability Strategy, alongside wider reforms in education, childcare and children's social care, provides an important opportunity to take this work forward. However, the findings from this research demonstrate the need for urgent and meaningful action. To be effective, policy commitments must be accompanied by clear implementation plans, measurable targets, adequate resourcing and accountability mechanisms capable of improving outcomes in practice.

Disabled children are rights holders under the UNCRC and the UNCRPD. They are entitled to participate fully in society, access appropriate support and enjoy the same opportunities as their peers. This report provides robust evidence demonstrating where these rights are not currently being realised and where change is urgently needed.

Ultimately, the findings present a clear challenge to policymakers, public authorities and wider society. Disabled children and their families should not continue to face disproportionate barriers to participation, support and inclusion. The evidence within this report provides both a compelling account of lived experience and a strong foundation for action to ensure disabled children in Northern Ireland are able to thrive, participate equally and reach their full potential.

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