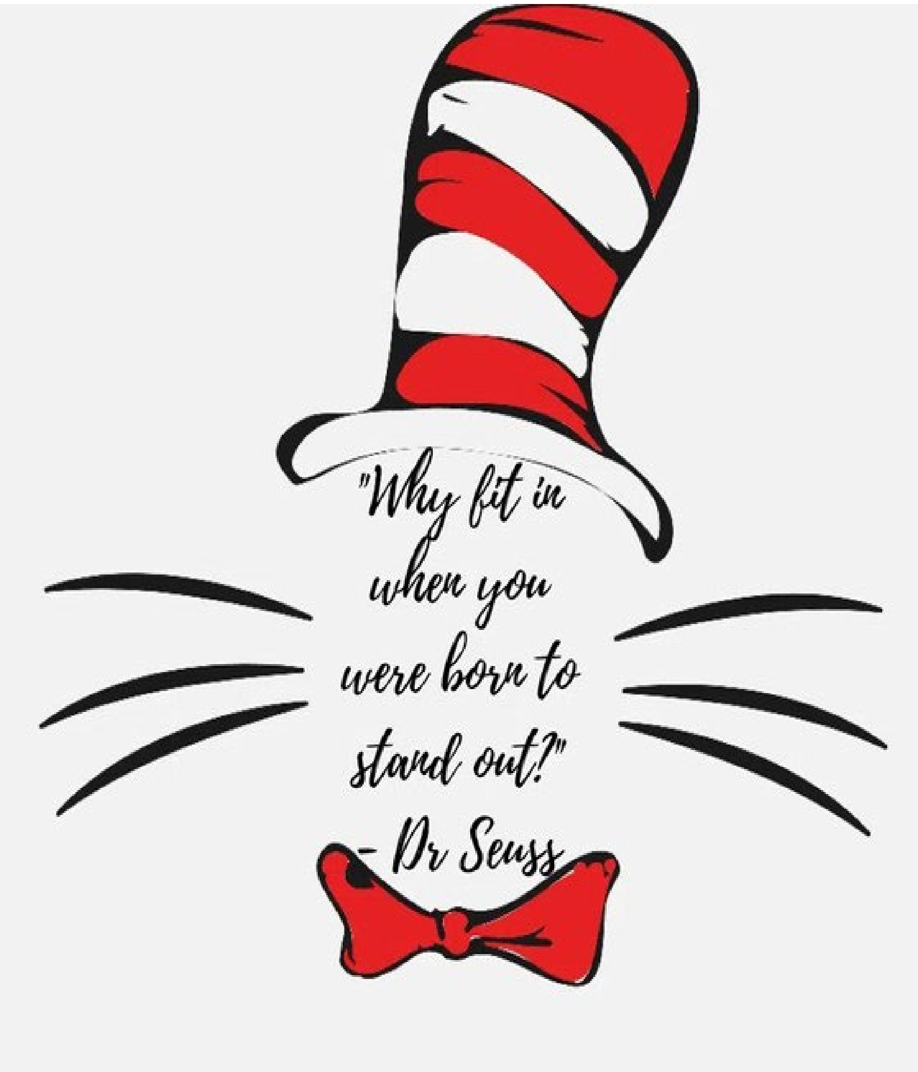
Survey Findings

Experiences of Parents of Children with Autism & Additional Needs in the North East Inner City

ICON

F.A.A.C.T

Contents



Acknowledgments

We would like to thank all those who were involved in the production of this report.

We would especially like to thank the interviewees who were willing to share their lived and living experience and for being so generous with their time.

The breath of this work would not have been captured without our peer researchers who worked tirelessly to capture the experience of service users.

Who we are

Inner City Organisations Network (ICON)

ICON is a forum where issues affecting the north east inner city are discussed and agreed and joint action is planned. It is made up of residents' associations, community/voluntary organisations and individuals living and working in the north east inner city. The broad functions of ICON include:

- Acting as a source of information
- Provision of information & advocacy services
- Campaigning and lobbying around issues identified within the community
- Encouraging local policy making through debated and discussion forums
- Promoting partnership approach between community, voluntary, statutory and business sectors

ICON has its roots in thirty years of community organisation. It was formed to bring together local projects to fight against increasing local disadvantage and long-term unemployment and to make sure that local voices were heard. ICON has played a key role in the development of initiatives in an effort to combat poverty and disadvantage. ICON established the first Drugs Task Force which later became the model for the Local Drugs Task Forces throughout the country. ICON also set up the first Community Policing Forum, the Young People at Risk Initiative (YPAR) and Citywide Drugs Crisis Campaign. More recently ICON played a major role in the establishment of the Dublin City Community Co-operative and the North Inner City Community Coalition.

More information can be found at www.iconnetwork.ie

ICON FAACT Group

In 2022, ICON organised a series of housing forums in the north east inner city. Local authority tenants, private rented & housing body tenants and home owners came together to discuss the challenges around the housing issue in the area. Consequently, the ICON Women's Housing Forum was established in an effort to create a collective action group to work to address some of the issues. Members engaged in peer-led research where they designed and implemented a housing survey across the NEIC. One of the key emerging themes was housing and autism and the lack of support for parents, a lack of information about schools, services, recreational spaces, after-school activities, and the absence of sensory activities and dedicated spaces for young people with autism and additional needs. This led to the formation of the Women's Housing Autism and Additional Needs Awareness Training Together (WHAATT) Group.

In 2023 in order to foster inclusivity, the group adjusted the name to ICON F.A.A.C.T. (Families of Autistic and Additional Needs Children Together) Group. Presently, the group consists of parents and guardians of children with autism and additional needs. They meet every week to address relevant parental challenges encountered in their daily lives. This platform is essential in facilitating the exchange of personal experiences and information among parents and guardians to help them in their everyday lives with their children with autism and/or additional needs. They host two youth clubs per week, targeting a younger and older cohort and organise a range of activities to meet the needs of both parents/ carers and the children.

> *'The ICON CDP Autism Awareness Group has sparked social change by bringing together parents and guardians of autistic children. They empower each other by participating in training sessions to address the challenges faced by autistic children who are being denied the services they require. The parents and guardians have demonstrated strong leadership within their collective group. Through active engagement and collaborative decision-making, they have successfully orchestrated developmental initiatives that harness the skills and knowledge acquired through community development programmes and training. Notably, this has resulted in the provision of tailored resources to meet the unique needs of children with autism, particularly within the 6-14 age range. Specifically, they have established swimming classes and recreational spaces explicitly designed for children with autism. They have actively engaged in fundraising efforts to procure the equipment for their proposed new facility.*
>
> ***Value Labs -Evaluation of the Pilot Community Development Funding***

Dublin North East Inner City

Historically the area defined as the north east inner city of Dublin (NEIC) is from Dublin Bay to the east and Drumcondra Road/ Dorset Street/Bolton Street and Arran Street East to the west. To the south, the area is defined by the river Liffey, while to the north the border is a wide arc made up of the Tolka River to the west and all of East Wall to the east. This area is inclusive of all of Dublin 1 and parts of Dublin 3.

This is the wider NEIC area, within that, there are smaller distinct communities, such as the communities of Sean McDermott Street, Summerhill, Ballybough, East Wall, North Wall, North Strand, the Five Lamps and Mountjoy Square. There are also new community strongholds such as Parnell Street, the communities of Dominick Street, the NCR, and the shopping and commercial districts including the IFSC and Henry Street/ Mary Street/ North Earl Street/Talbot Street as well as the historically significant O'Connell Street and Moore Street.

This is not a homogenous community, but it is a community that has experienced and continues to experience disadvantage and marginalisation, more saliently a series of communities that experience relatively higher levels of disadvantage than Dublin City and nationally. Key to understanding inner city communities is to be aware that the overall statistics and information on the city masks the deprivation therein and that macro average figures tell us nothing about the true experiences of the most disadvantaged.

The Pobal HP Deprivation Index[1], in simple terms, is a method of measuring the relative affluence or disadvantage of a particular geographical area using data compiled from various censuses. A scoring is given to the area based on a national average of zero and ranging from approximately -35 (being the most disadvantaged) to +35 (being the most affluent). In addition to this, percentage data for the area is given under the following categories:

Relative Index Score	Standard Deviation	Label	Colour Scheme
over 30	**> 3**	**extremely affluent**	dark blue
20 to 30	**2 to 3**	**very affluent**	medium blue
10 to 20	**1 to 2**	**Affluent**	Light blue
0 to 10	**0 to 1**	**marginally above average**	light green
0 to -10	**0 to -1**	**marginally below average**	light yellow
-10 to -20	**-1 to -2**	**Disadvantaged**	medium yellow
-20 to -30	**-2 to -3**	**very disadvantaged**	orange
below -30	**< -3**	**extremely disadvantaged**	red

The small area map below shows there are areas of the north east inner city that are still classified as very disadvantaged, surrounded by pockets of very affluent communities.[2]

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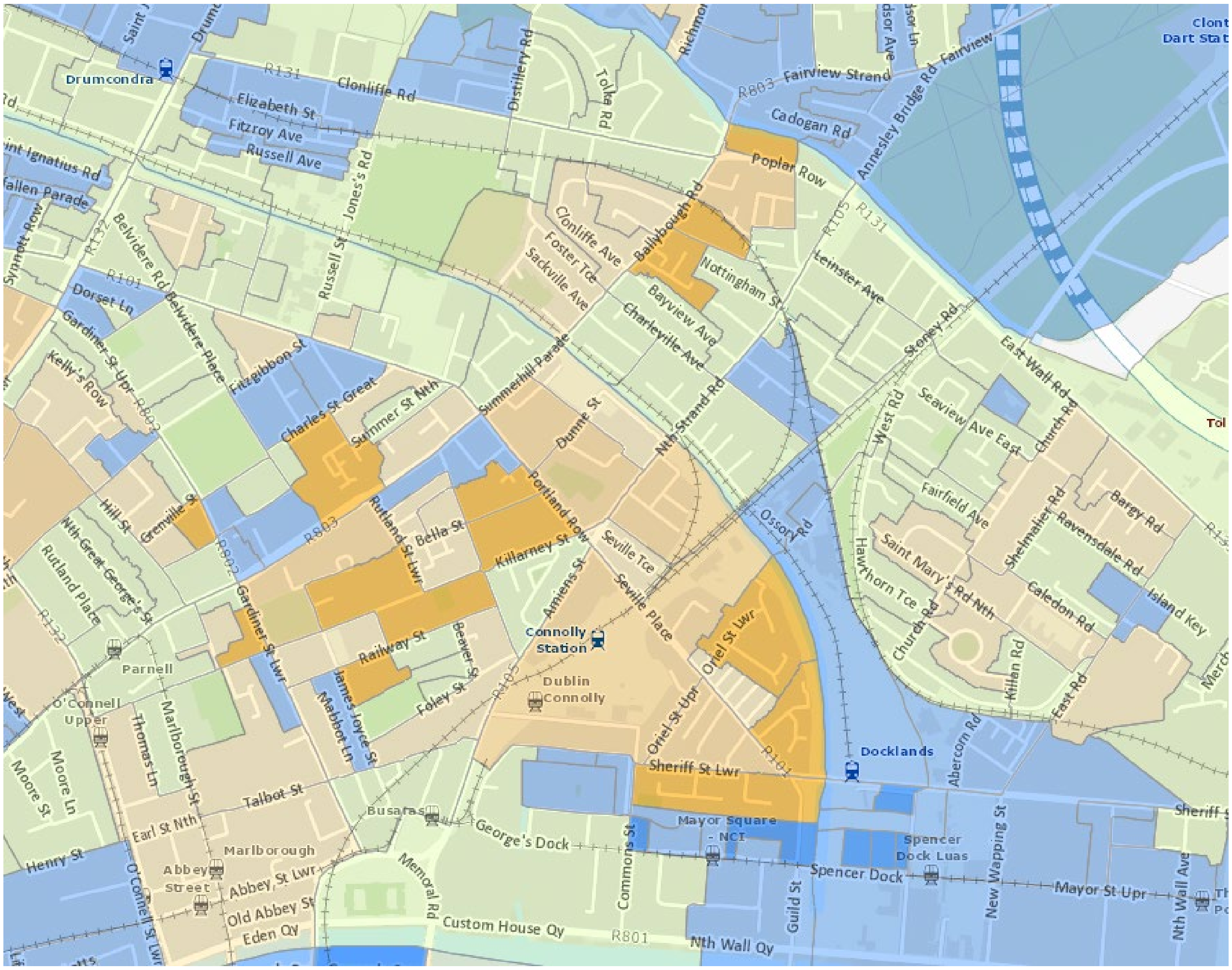
[1] https://data.pobal.ie/portal/apps/sites/#/pobal-maps

[2] https://www.pobal.ie/pobal-hp-deprivation-index/



The most recent Pobal maps also show that disadvantaged areas are further from the average in Ireland than they were in 2016 and disadvantage remains a spatially entrenched phenomenon in parts of Dublin's inner city.[3]

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[3] /https://www.pobal.ie/app/uploads/2023/11/Pobal-HP-Deprivation-Index-Launch-Presentation.pdf

Autism Definitions

When the ICON FAACT Group reviewed various definitions of autism, each member resonated with different characteristics, highlighting the reality that no two children experience autism in the same way. Consequently, it was decided to reflect this by leaving a number of different definitions from a range of sources.

Autism is a kind of brain difference that some people are born with. It means their brain works a little differently than most peoples' brains. This can sometimes make certain things harder for an autistic person but also might mean they are incredibly good at other things. Autistic people see, hear and feel the world in unique ways.

AsIAm

Autism – also referred to as autism spectrum disorder -constitutes a diverse group of conditions related to development of the brain. The abilities and needs of autistic people vary and can evolve over time. While some people with autism can live independently, others have severe disabilities and require life-long care and support. Evidence-based psychosocial interventions can improve communication and social skills, with a positive impact on the well-being and quality of life of both autistic people and their caregivers. Care for people with autism needs to be accompanied by actions at community and societal levels for greater accessibility, inclusivity and support.

World Health Organisation

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses.

National Autistic Society

Autism is a unique way of being. Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people. If you're autistic, you're autistic your whole life. Autism is not a medical condition with treatments or a "cure". But some autistic people need support to help them with certain things.

Health Service Executive (HSE)

The ICON FAACT Group said the following when asked 'what is Autism?'

Autism causes sensory, social & communication differences.

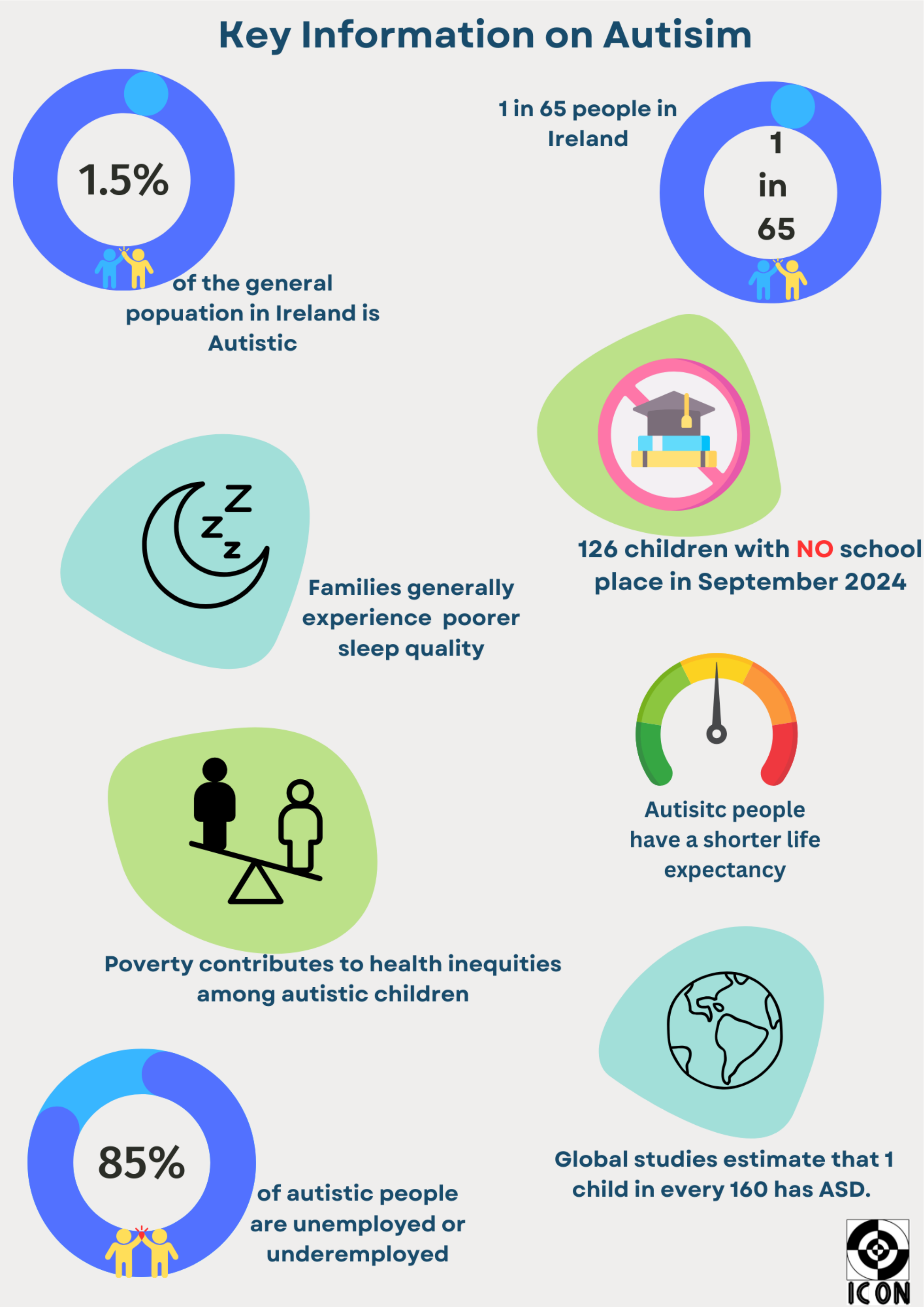
All depends on which way it's used personally I prefer a child with autism but each to their own, my child is starting to use the word neurodivergent a lot she prefers this but she's 15.

In our house we use autistic and everyone is different and unique in their own special way.

Autism causes differences in every person. Some persons will have sensory or social or communications, all depends on the person. They may have all 3 or 2 or 1 of these things.

Key Information on Autism

Autism is a lifelong neurodevelopmental difference which relates to how a person interacts with others and how they experience the world around them.



Key Information on Autisim

1.5%

of the general popuation in Ireland is Autistic

1 in 65 people in Ireland

1 in 65

126 children with NO school place in September 2024

Families generally experience poorer sleep quality

Autisitc people have a shorter life expectancy

Poverty contributes to health inequities among autistic children

Global studies estimate that 1 child in every 160 has ASD.

85%

of autistic people are unemployed or underemployed

ICON

- The prevalence of ASD in the general population in Ireland is estimated at 1% - 1.5%.[4] Autism affects approximately 1 in 65 people in Ireland, according to the Autism Spectrum Disorder (ASD) Prevalence Report.[5]
- 126 children with special educational needs unable to access a school place in September 2024[6]
- The average cost to families of autistic children was €28,464.89 (including accessing private services, loss of income and informal care). The study [7]conducted by Roddy & O'Neill (2018) found that the average family spends €28,464.89 per year, whereas the state spends €14,192 per child a year. According to the study's findings, Irish families with autistic children are more financially responsible for meeting their autistic children's needs. The average figure for debt incurred by the families of autistic children was €3,259
- 85% of autistic people are either unemployed or underemployed.[8]
- Autistic people have a shorter life expectancy than their neurotypical peers.
- Families with an autistic child have poorer sleep quality. Some 85% of parents of autistic children in the sample were 'poor sleepers' compared to 71% of parents of typically developing children. [9]
- Research indicates that around 30% of typically developing children experience sleep difficulties throughout their childhood but these difficulties become 'near ubiquitous among those with a diagnosis of autism with up to 80% of autistic children experiencing difficulties with sleep.

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[4] Sweeney, Staines & Boilson, 2016

[5] https://www.cognitivesupport.ie/

[6] Report card Children's Rights Alliance 2025 page 15

[7] (Roddy & O'Neill, 2018, P1106)

[8] Final Report of the Joint Committee on Autism (June 2023) page 13

[9] Smyth, Sinead Dr (2023) School of Psychology – Sleep Medicine

Recommendations

The Joint Committee on Autism published its Final Report of the Joint Committee on Autism (June 2023). The ICON FAACT Group have reviewed these recommendations and chosen to accept them where they relate to the outcome of the research. They have also added their own recommendations based on this research and on their own lived experience.

General

1.	Ensure that the needs of autistic people are considered when designing all public services and include the autistic community when designing autism specific services. The ICON FAACT group also supports the involvement of parent and carers in these consultations.
2.	Ensure that all government parties develop an autism policy.
3.	Ensure that all state agencies have an autism policy that is accessible and available.

Services

1.	Recognise the work of community groups who support autistic people by establishing a direct funding stream to develop their work and to facilitate the establishment of new autism community groups across the country.
2.	Develop and enforce guidelines to ensure that interventions provided to autistic people and disabled people are evidence based, and rights based.
3.	Ensure that all state agencies have an autism policy that is accessible and available.
4.	Provide adequate financial support to families who access assessments and support privately due to their unavailability in the public health system until such time as vacant positions within CDNTs have been filled.
5.	Increase the capacity of respite care across all Community Health Organisations.
6.	Reduce excessive paperwork needed to access services.
7.	Provide structured and timely post diagnosis information and care pathways.
8.	Provide a tailored approach to services and a not a ‘one size fits all’ approach.

Education

1.	Provide funding and guidelines to all schools building new premises to ensure that they are built with the principles of universal design.
2.	Provide funding and guidelines to all schools to undertake an audit of their buildings and make them autism friendly.
3.	Work to reduce class sizes to allow teachers the opportunity to better observe the development of pupils and to reduce distraction and distress for autistic children in overcrowded classrooms.
4.	Ensure that children in special classes, autism classes and special schools can participate in mainstream education classes to end the practice of segregation based on neurotype.
5.	Update Continuing Professional Development (CPD) to ensure that education professionals, including teachers and SNAs. Received suitable autism training.

Accommodation & Public Relam

1.	Ensure that autism is regarded as a sensory disability by all Local Authorities for the purpose of accessing prioritise social housing.
2.	Provide adequate grants to allow for sensory rooms to be added to homes and the sensory proofing of homes for autistic people.
3.	Ensure that local Authorities engage with schools to assist in developing suitable sensory provision for autistic children.
4.	Provide designated funding to Local Authorities to add sensory areas and communication boards to all playgrounds, play areas, parks and public recreational spaces and ensure they are accessible to individuals with disabilities. Designate 'sensory hours' each day in these spaces.
5.	Provide autism training to staff in Local Authorities and ensure that autism is accepted as a condition which qualifies housing support.
6.	Recruit a designated Disability Officer in every Local Authority to advise autistic

	people and their families on accessing supports and assist them to complete the application
7.	Extend Blue Badge parking to extended to parents/carers of children with autism and additional needs.

Background

In 2022, a group of mothers came together to have a meeting in ICON. The mothers first made contact with ICON, either through the Housing Support and Information or by attending one of the ICON working groups or attended one of a series of Housing Forums held by ICON. Each of them had spoken about supports they needed as mothers of children with autism and additional needs. Using a community development approach, ICON brought the women together to explore how we could collectively work to meet their and their children's needs and work to improve and develop services. The ICON WHAAT Group was officially formed and met every Tuesday in Mud Island to provide peer support and to begin a programme of education and training which has led to the production of this peer led research.

Methodology

The project team chose peer led research as the main methodology. ICON has a long history of working in this way to ensure that the target group are active participants in the research being carried out about them. The development of the questionnaire was carried out by ICON staff and members of the FAACT Group over a number of weeks. The group participated in social research training as part of the process. The women were keen to see if their experience of being a parent/carer of child with autism and/or additional needs was similar to other parents/carers in the area. Concurrently, they also wanted to assess the standards of care and services being provided against human rights indicators, notably in the areas of health and education.

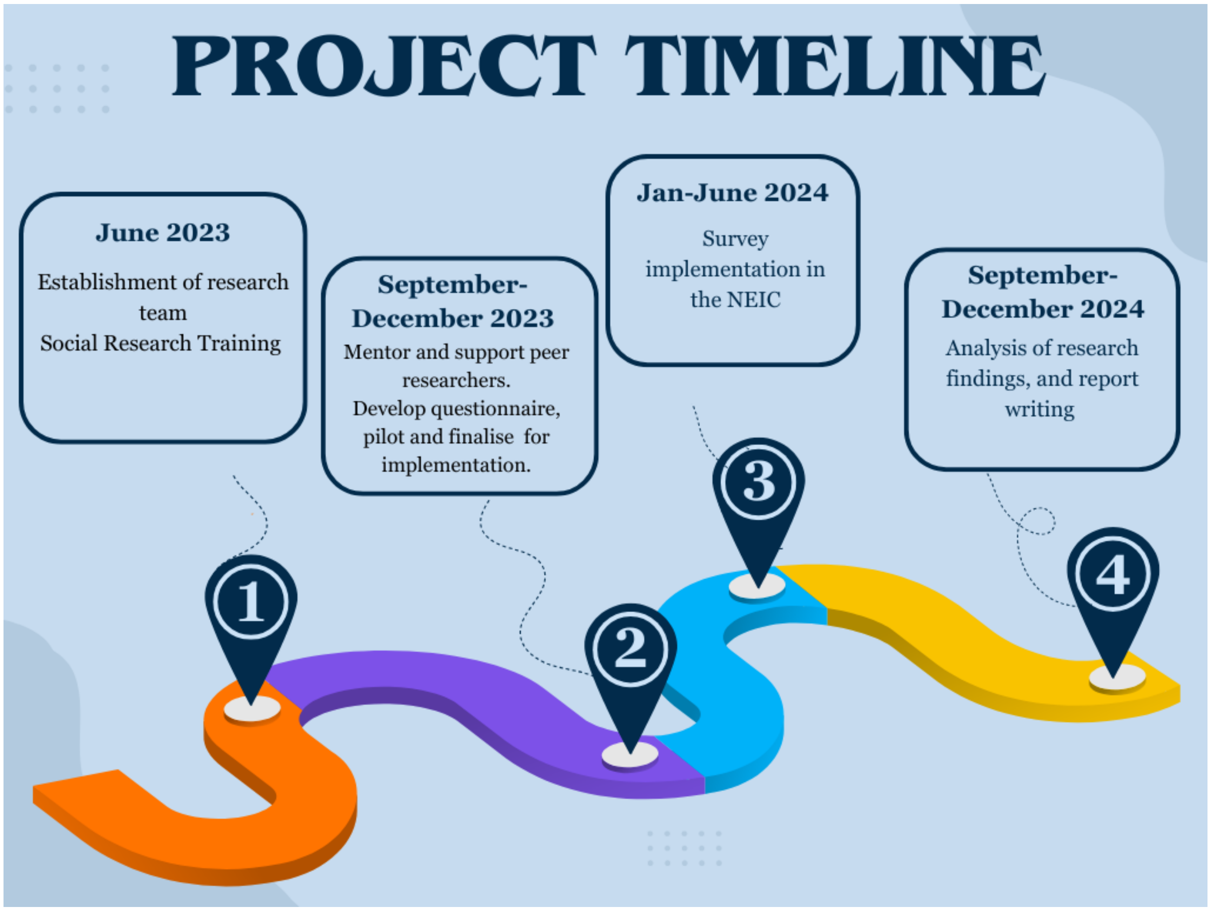
The questions covered the following areas:

- Demographics
- Family Life
- Accommodation
- Health
- Public realm & Safety
- Education

A copy of the questionnaire can be found in Appendix.

The peer researchers identified respondents through their group, their community, schools and the wider community. Respondents could self-complete the survey or the peer researchers would assist in the completion of the survey. A web link was also available to use alongside the paper version. The survey had 49 questions and was timely to complete and initial completion rates were slow. The peer researchers promoted the survey at a number of their events and this helped in getting parents/family members to complete the survey. In total 24 surveys were completed. We have chosen to report all the further comments made in the survey responses to reflect the lived experiences of these parents/family members whose voices are often not heard or ignored.

Project Timeline



PROJECT TIMELINE

June 2023
Establishment of research team
Social Research Training

September-December 2023
Mentor and support peer researchers.
Develop questionnaire, pilot and finalise for implementation.

Jan-June 2024
Survey implementation in the NEIC

September-December 2024
Analysis of research findings, and report writing

Ethics

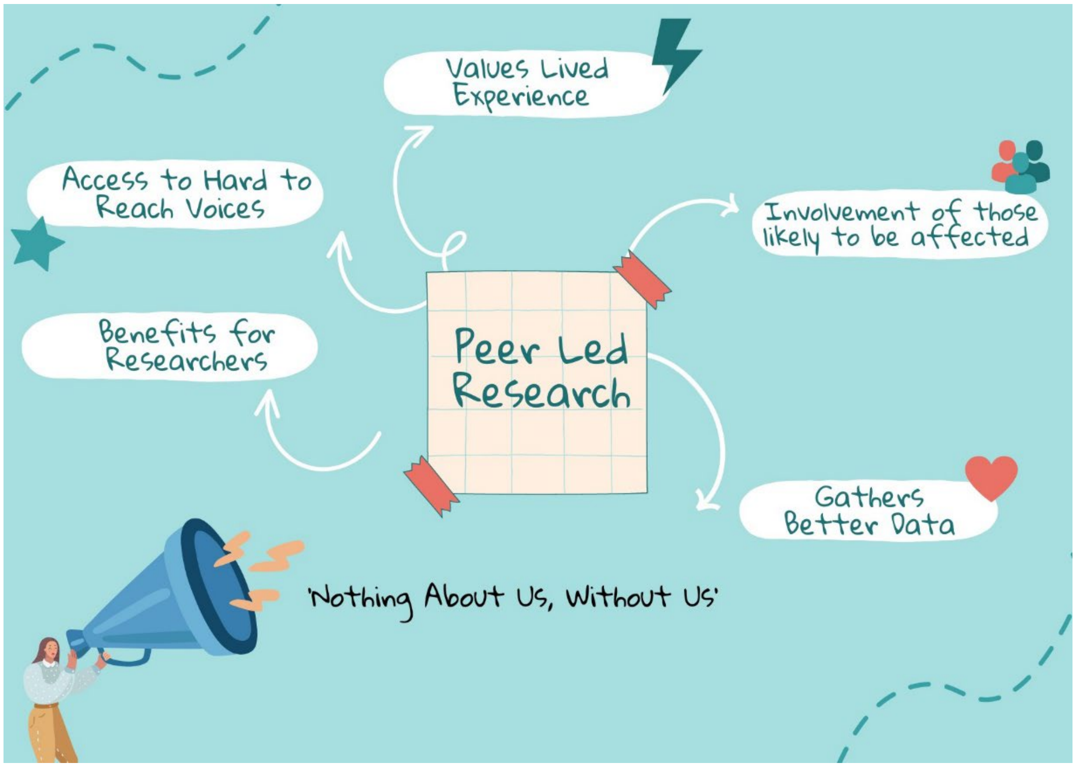
The project designed ethical, non-exploitative research that did not stigmatise or disempower. The research was based on informed consent of all participants and was carried out with consideration to the centrality of ethical and participatory research approaches. Interviews were carried out with respect for participants, and responses were confidential and based on consent. Participants' identities are protected.

The purpose of the research was explained in a meaningful way to participants. Participants were made aware of their right to refuse to participate and that they could withdraw from participation at any time in the process. All work is fully complaint with GDPR. All aspects of the research from start to publication of results have been conducted with honesty and integrity.

Why peer led?

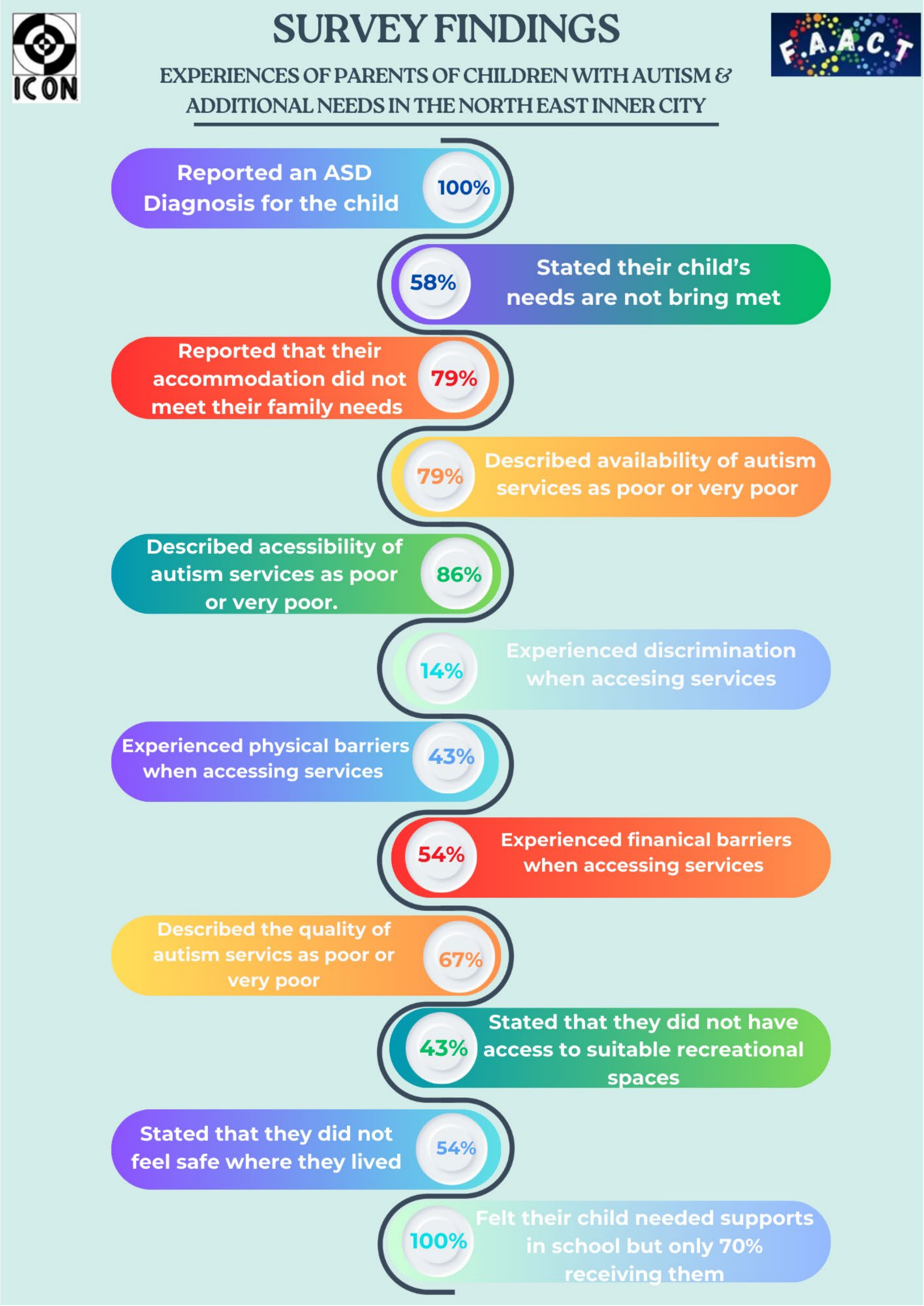
Peer led research is a form of research in which individuals with lived experience are central to the design and delivery of the research. It is part of a methodology known as Participatory Action Research (PAR). Essentially, this is a cyclical research methodology that is beneficial in research with marginalised and disempowered populations. It is a means of helping people to:

- Identify their issues and link them to human rights
- Come up with possible solutions
- Assess the solutions
- Create indicators for change
- Mobilise for action
- Monitor and evaluate progress over time



ICON has been used this methodology since the early 1990s and has been working directly with service users and tenants to identify their human rights and equality issues, to design, pilot, conduct peer to peer interviews, to analyse the findings, set indicators, engage with service providers, and monitor progress over time. This facilitates participants' voices to be heard and validated. In so doing, it recognises and values the unique knowledge of lived experience and the power it has to bring perspective and expertise to the design and delivery of services that are both appropriate and based on respect and rights.

Survey Findings



SURVEY FINDINGS

EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM & ADDITIONAL NEEDS IN THE NORTH EAST INNER CITY

Reported an ASD Diagnosis for the child **100%**

58% Stated their child’s needs are not bring met

Reported that their accommodation did not meet their family needs **79%**

79% Described availability of autism services as poor or very poor

Described acessibility of autism services as poor or very poor. **86%**

14% Experienced discrimination when accesing services

Experienced physical barriers when accessing services **43%**

54% Experienced finanical barriers when accessing services

Described the quality of autism servics as poor or very poor **67%**

43% Stated that they did not have access to suitable recreational spaces

Stated that they did not feel safe where they lived **54%**

100% Felt their child needed supports in school but only 70% receiving them

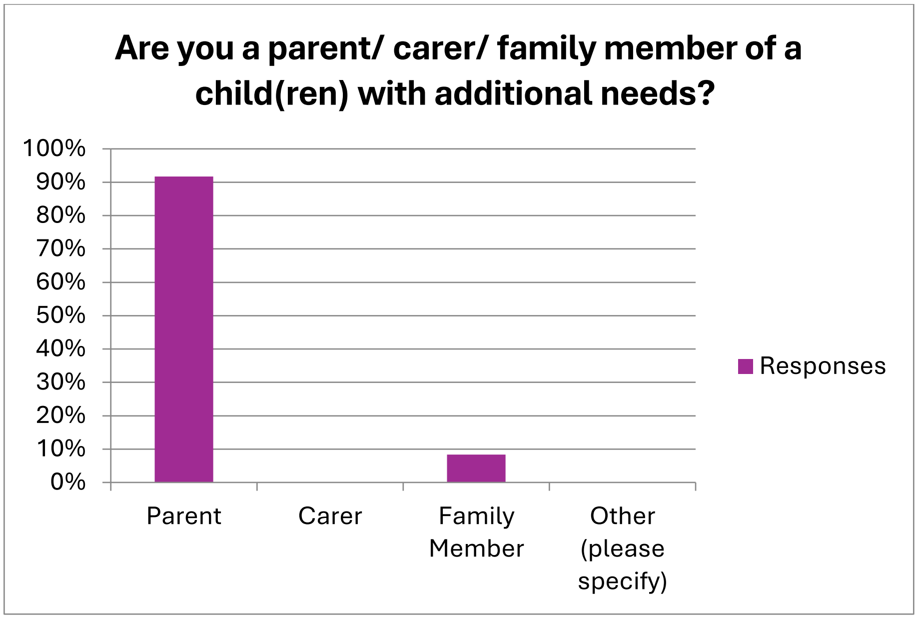
The survey focused on the following areas and the findings are presented under these headings.

- Demographics
- Impact of Family Life
- Accommodation
- Supports & Services
- Public Ream, Environment & Safety
- Education

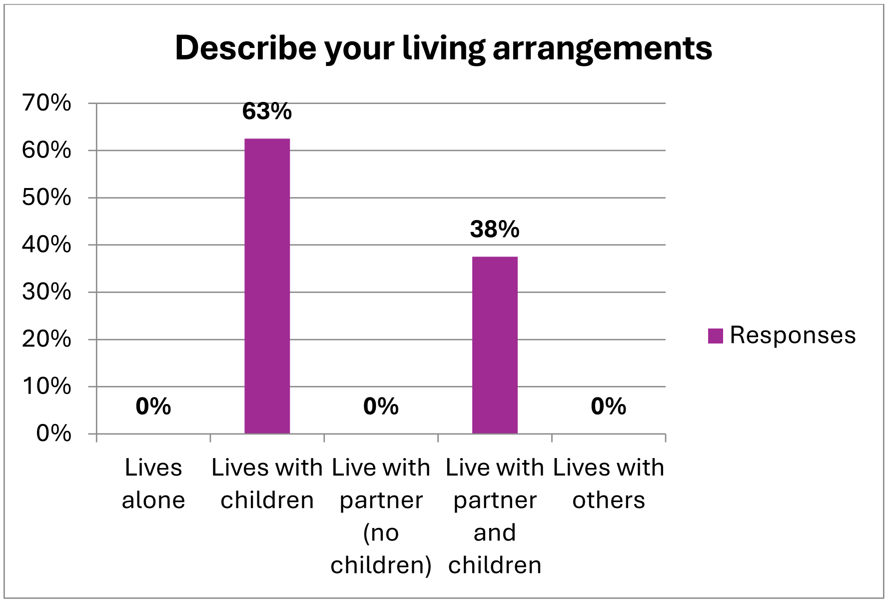
Demographic Profile of Survey Respondents

The main age range of respondents was between 25 and 55, there were no respondents under the age of 25 and no one over the age of 55. The majority of respondents were female at 92% with 8% male respondents. 74% of those responded were Irish with 26% stating they were of a different nationality, while 73% stated that they were White Irish, 14% were any other white background, 5% were Black African and 9% were any other Asian background.

The majority of respondents, 92%, were parents and 8% classified themselves as a family member.



- In total this survey covered the experience of 24 children whose ages ranged from 3 – 21 years old with the majority of responses centring in the 3-10 age group.
- Of the respondents, 63% live with their children and 37% live with a partner and children.



100% of responses showed a diagnosis of autism spectrum disorder (ASD) with a range of additional needs reported: 9 stated anxiety as a diagnosis; 6 stated ADHD and 3 stated bi-polar disorder.

Some respondents were still waiting on an assessment and other diagnoses were described as:

- Dyspraxia
- Asperger Syndrome
- Global Developmental Delay
- Sensory Processing Disorder
- ADHD

Impact on Family Life

Family life is affected in different ways, as raising a child with autism and/or additional needs can bring a range of emotional and behavioural challenges, which differ in both nature and severity. Parents and carers reported on the ways that family life was affected such as the limitations placed as they always needed to be mindful of the external environment or the range of emotions experienced when trying to parent or care for their child. There is a significant mental health burden placed on parents and carers as they try and cope with lack of sleep, juggling all the needs of the family and the associated stress as families seek to adapt and accommodate the child's needs and/or avoid meltdowns. There is no break with constant care, planning and routine. The potential for dangerous behaviour by their children was also a continual fear.

Limits what you can & can't do due to sensory seeking behaviour, we are always on alert with locking doors, keeping a calm environment can be stressful impacts on mental health.

Can be extremely tiring, sad, angry, secluded, embarrassing for siblings but also funny, happy, proud and fulfilling moments.

It's very hard. My children need more attention, they are two different characters and it is very difficult to reconcile it. Additionally, running from one school to another when there are problems, food pickiness, stress when visiting a doctor or dentist. Additionally, the younger one (4 years old) is just starting to speak, so I devote all my time and concentration to the children.

Sleepless nights take you off the A game.

Big changes day to day, things depend on how child is in the moment. Some days we can do every day things, other days can be full of triggers and meltdowns, missing out on family events, kids' parties etc cause it's too much for the child.

We are always on alert making sure our daughter has everything that she needs. We also as a family have to make sure she is safe e.g. crossing roads, strangers.

Very difficult, one day is never same as day before and go with them at their own pace.

Everything planned, strict routine, no parties or get togethers, no meals out, can be isolating at times.

To cater for my sons needs we run a tight ship.

Learning to be aware of the child's ways, if routine is changed it can cause tantrums in the house. If unaware of child's certain ways of living it can be extremely hard to understand what is happening and how to calm child down.

Whole life has changed, exhausting for parent.

High alert whole time.

I give my children 24 hour care and that's very hard work. Sometimes at home I can't control my emotions. I need support.

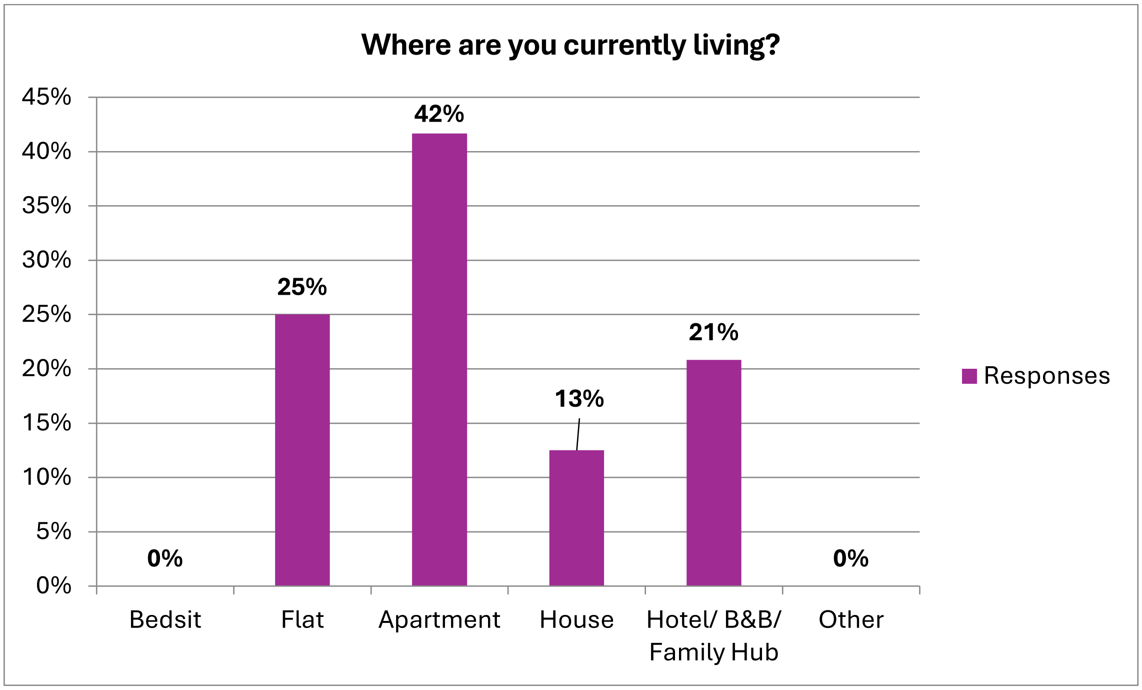
Mentally and physically, there is no space for xxxx to move. I can't open doors and windows. There is no lift so he is down the stairs before me and runs out the door.

My whole life has changed, it is exhausting for parents, must have a routine and know the cues to watch out for, I must be on high alert all the time.

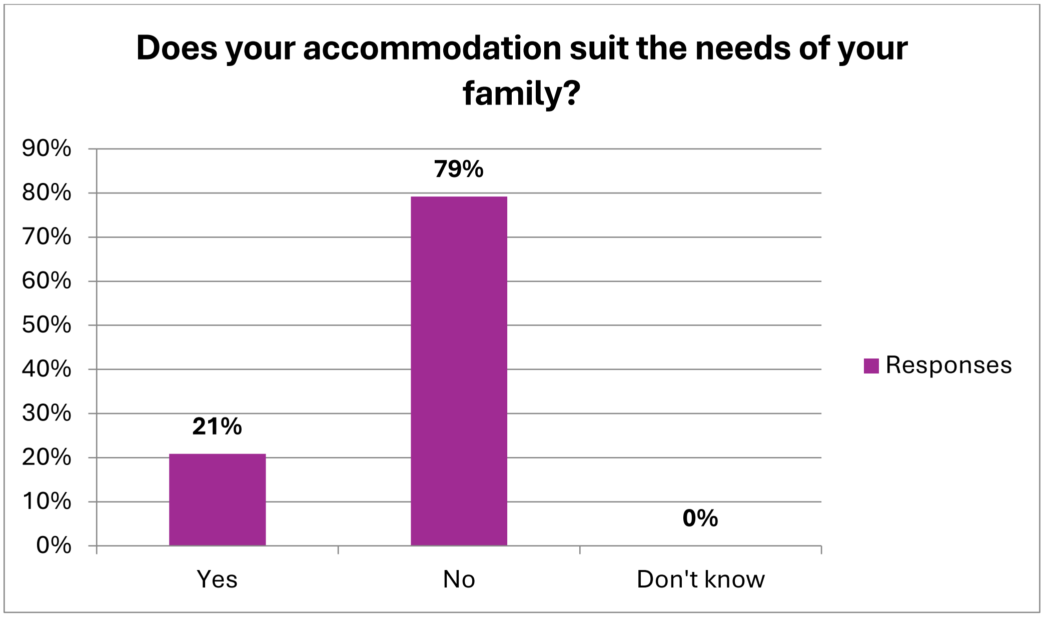
Accommodation

Accommodation varied for the respondents with the highest proportion being local authority tenants and living in apartments or flats.

- 42% stated that they were living in an apartment, 25% were living in a flat; 21% were living in a Hotel, B&B or a Family Hub and 12% were living in a house.
- 46% stated that they were local authority tenants, a further 21% were in private rented accommodation and 21% were in some form of homeless accommodation, 1 respondent classified themselves as a home owner and 1 respondent stated 'other' but provided no further details on what type of accommodation this was.



The survey clearly highlighted how the accommodation for the respondents who live in the NEIC was not suitable and did not meet the needs of their family with 79% stat that their accommodation did not suit their family needs and only 21% stating that it did.



Responses centred on the size of the accommodation as being inadequate with very tight living arrangements and overcrowding.

It is too small, it's very old, very wet in general.

One very small room, no space for child to regulate, no private space. Very noisy and scary for son, afraid of noise and constantly on high alert.

No garden or much space to play and burn off energy.

There is myself and my 3 children living in one room.

No room for anything, effecting the growth of the children with lack of space to move around.

Home is too small for people.

I have a very small and old house; we have 1 room for 2 adults and 2 kids.

I live with too many people and I share a room. My room is too small and is very noisy. My son has sensitive ears and sometimes he can't sleep because of the noise in the apartment. Some people don't understand my son is on the spectrum. There is bullying also.

My son with ASD gets angry and sharing one room is unsuitable.

For one family, the small space was an advantage:

Yes, it suits us because we are very close as a family. Our daughter could not sleep in a room on her own. We have a big park facing us which is brilliant for getting out and about.

There were many issues that presented significant challenges and real danger to their children such as unsafe environments:

Bikes joyriding and noise drives kid crazy. Kid jumps out window, which is on the canal, open drug dealing! Has to share room and wakes up numerous times.

Very unsafe as both kids have no safety awareness.

My housing and surrounding area adds more anxiety to my son as he wants to go out independently.

I live in 1 room that is very noisy and this scares my son, he is afraid of noise. I am constantly on high alert, it's very small and not very private, my son has no space to regulate his emotions.

In one bedroom because of son's sensory issues. I sleep on the couch. I have a c4 disk injury that I get pain injections for. This is tough. Anti-social behaviour, all single tenants, mould, rats in garden, mice in the house. No support from council, after many complaints put in. Waiting to be approved or not from medical and social grounds.

No space and windows can't be opened, must lock the door.

Parents and carers were able to clearly identify what type of improvements would help to improve their home which include more space, a better and safer home with sensory spaces and a garden.

I defo need to move and give him some indoor/outdoor space he can call his own.

Extra safety locks a little play area for children.

Extra bedroom, a garden.

We would love a sensory wall.

A new safe home with adequate space to cater for my son's needs, where he can have a decent sleep, very bad with noise as doors banging and parties etc. having such an effect on my sons day to day.
A garden with more room for toys that would help with sensory processing e.g. trampoline, swing etc.

Bigger place with garden and outdoor space, playground.

I would love a 3 bedroom house with a garden.

More space for the kids to grow and develop.

My son needs more space, he needs to stay careful. We need some peace and quiet at night.

I would like a bigger space where I have a garden, with outdoor space for water play and a small playground.

Supports & Services

The levels of support required by parents varies. There are significant challenges facing parents of children with ASD and additional needs when trying to access appropriate supports and services. The questions in the survey were framed from a rights based perspective looking at availability, access and discrimination and sought to ascertain their perceptions regarding the services they accessed and the impact that service provision had on their quality of life.

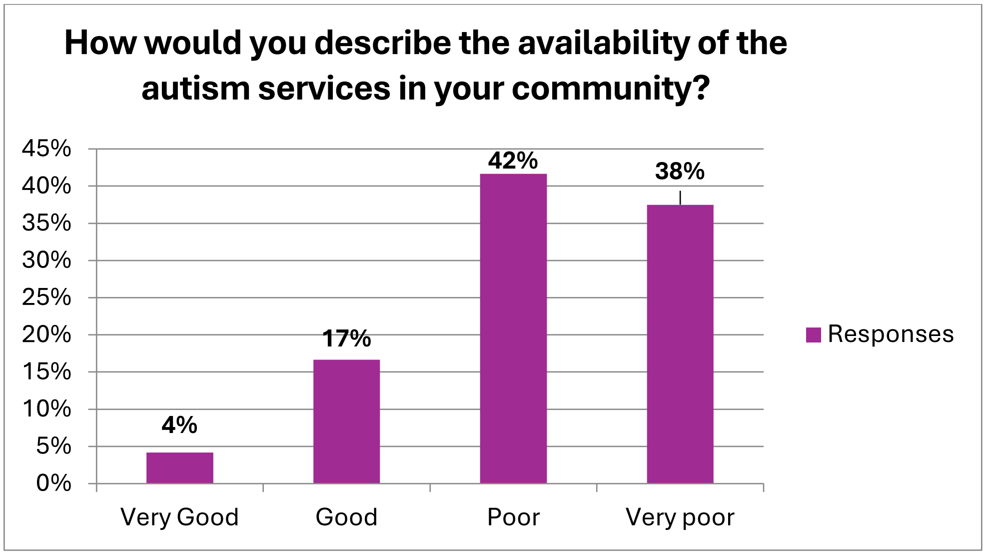
In 2021, the HSE reorganised their service provision under Progressing Disability Services Programme and children are allocated to a regional Children's Disability Network (CDNT). Children who have mild or moderate difficulties may be referred to one or more health professionals in their local primary care services. However, children who are displaying a range of significant difficulties may be referred to their local Children's Disability Network Team (CDNT).

The National Policy on Access to Services for Children & Young People with Disability & Developmental Delay outlines that Primary Care Services are providers of services for children with non-complex needs i.e. *"one or more impairments giving rise to functional difficulties which result in mild restrictions in participation in normal daily living"*. Children's Disability Network Teams are the providers of services for children with complex needs, i.e. *"one or more impairments which contribute to a range of significant functional difficulties that require the services and support of an interdisciplinary disability team"*.

The Children's Disability Network Teams (CDNTs) provide specialised support and services for children who have a disability and complex health needs associated with their disability. The CDNT includes health and social care professionals, each team member specialises in different areas of child development. Children who require a diagnostic assessment for ASD usually access these assessments through the CDNT.

There are three main types of public educational provision for autistic pupils in Ireland. There are mainstream classes, special classes in mainstream schools as well as special schools. Most special schools also provide autism classes and many special classes in mainstream schools are established to cater specifically to autistic pupils. There are no second-level special schools in Ireland, however some second-level schools provide special classes for autistic pupils or pupils with other types of SEN (Special Educational Needs).[10]

Systems are failing parents by lack of availability of services, 79% described the availability of autism services as poor or very poor with 21% stating that they were good or very good.



The negative responses referred to a one size fits all approach used by statutory services with little to no recognition of individual or family needs. Respondents talked about the lack of ASD units and how they were hard to access or had long waiting times. On the other there was praise for local people setting up groups to meet the needs.

Statutory services offer one size fits all approach with little understanding of presenting needs of children, no focus on supporting children to reach potential: little or no recognition of impact of families. Same group intervention offered to toddlers and teenagers, no insight into progression. It's a numbers game; this approach is endorsed by the government with no accountability.

Two sessions with speech and language therapist in 1.5 years. OT has been good apart from constantly arguing the point of a special needs pram being needed.

Not many schools in the area have ASD units.

Very hard to access the services.

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[10] Final Report of the Joint Committee on Autism (2024) pg.51

Very hard to get information and long lists for services.

My son was diagnosed in May after 26 months wait, active for service on the CDNT and no therapy. NIC Side by Side have been amazing and yourselves are the only supports in the area.

There isn't much support surrounding autism in my area.

Long waiting times, no appointments, no early intervention, no school place.

Waiting for everything a long time.

I am getting help but ASD services could improve a great deal to support parents with ASD children.

XXX has not received speech and language since he is 16 months old, he is now 7.

Never heard of any services in our community.

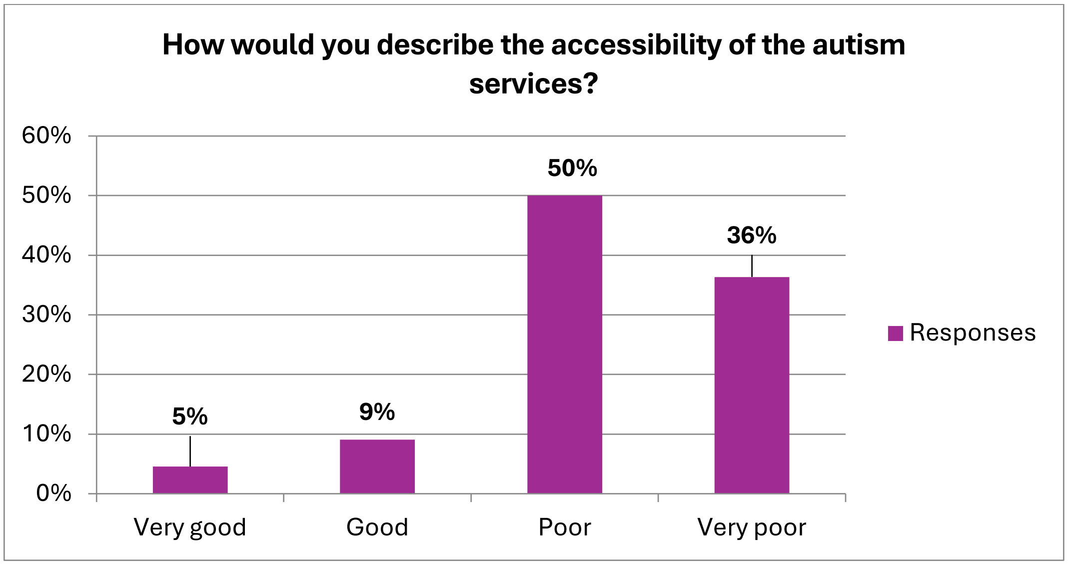
Positive Responses

Local people set up groups which are amazing.

There is a lot of care in the community around autism and they don't dismiss the condition.

Everyone has the right to equal healthcare without discrimination – not healthcare on the basis of wealth, class, gender, immigration status or race. We can all expect fairness, respect, equality, dignity and autonomy from our health service. That is what a rights-based approach to healthcare means.

For 86% the accessibility of autism services was classified as poor or very poor with only 5% stating they were very good and 9% stating they were good.



Respondents referred to long waiting times when waiting for a diagnosis and the lack of services available.

Services are gatekeeper by CDNT, this prevents families having choice or being able to make informed decisions about their children.

I cannot work with kid since his ASD diagnosis and have waitlisted him for CDNT, which is a 3 year wait.

It's a constant fight from having the assessment done to getting services for the child to then trying to find a school.

Waiting lists are so long that it's impossible to get the services we need.

Long waiting lists.

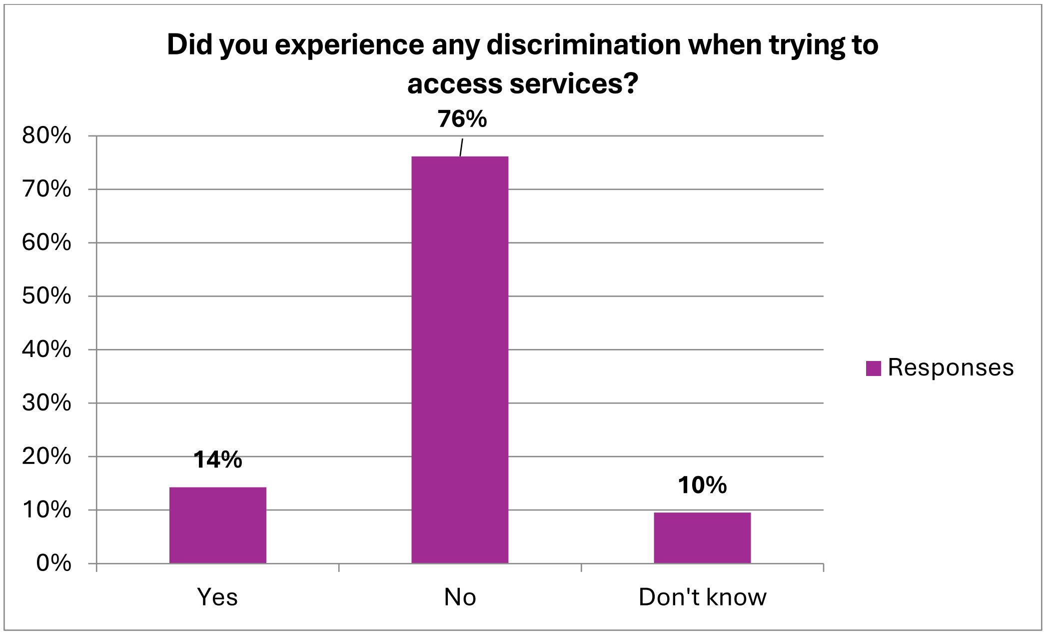
Lack of services or spaces available.

Being let down by CAMHS, saying there's nothing there when clearly there is.

Some more services could be of a great help to children and parents.

There is nothing for xxxxx to do, currently he is on waiting list in an autism group.

14% stated they had experienced discrimination when trying to access services.



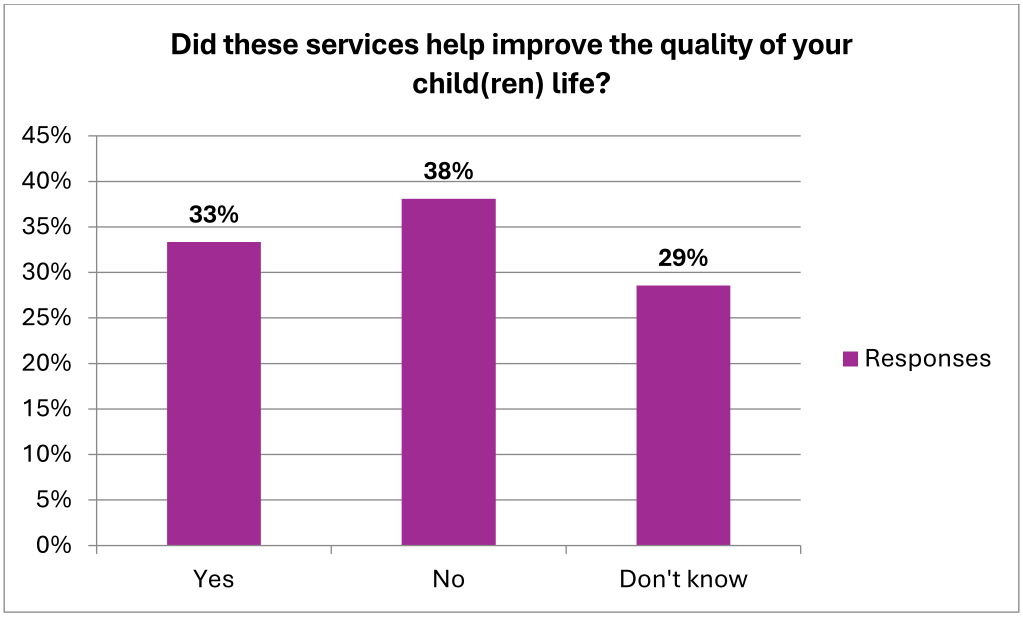
Things had reached crisis point & was asked by a senior HSE manager was I still able to work. They are trying to push families into private self-funded services. This is not appropriate for children with complex needs that require lifelong multi-disciplinary supports.

- **43%** stated that they had experienced physical barriers when trying to access services.
- **54%** felt that they had experienced financial barriers when trying to access services.
- **46%** stated that they were able to access appropriate information and 46% stated that they were unable to access appropriate information when trying to access services. 8% did not know.

How acceptable are the services in the following areas?

For your child's culture?	For your child's gender?	For your child's age?
Child's presenting behaviour caused by ASD. ADHD & moderate GLD attributable to stereotype beliefs that are held about children from the NEIC.	Services not suitable for sensory seeking boys.	Not relevant to his age interests size or strength.
Ok	Ok	Ok
Good	Good	Poor
Good	Good	Good
Good	Good	Ok
		Very poor
Very acceptable	Very acceptable	Very acceptable
Ok	Don't see a difference yet	Yes if not going private I have to wait a long time or be of a certain age to be diagnosed.
Good	Very acceptable	Very acceptable
polish child		
Mongolian child	Male	
Good	Good	Ok
Don't think they're good unless you pay privately	Autism most common in boys	He is 7 years old and we have to do it on our own.
Not aware of any services	Not aware	Not aware
Ok	Don't see a difference yet	Yes, have to wait for long to be diagnosed till over a certain age, if not going private

While it is evident that systems are failing parents by the lack of availability of services, only 33% stated that the services did improve their quality of life while 28% did not know.



Child has not benefited by multiple services who were unable to meet his need, the stress & impact on my mental health as a parent.

Still in limbo, still need help/resources/ therapy.

No, she barely sees anyone and they keep telling me what I'm doing wrong.

Has benefited from OT.

We were assessed but have yet received any services, just advice clinics no one to one or face to face, very impersonal.

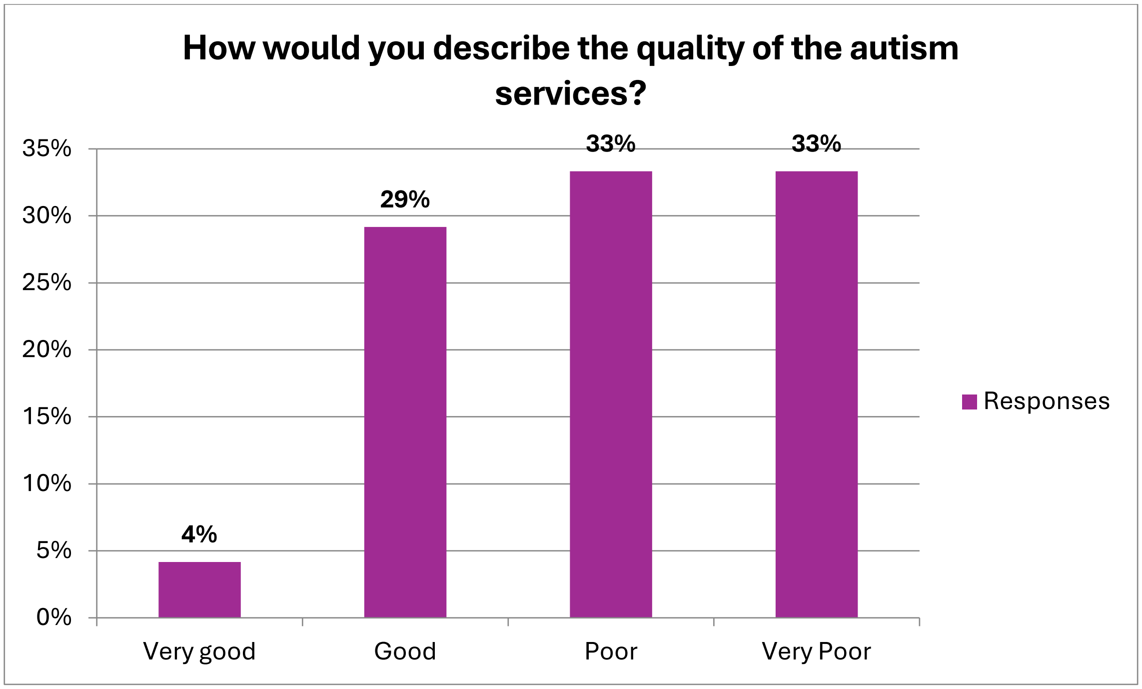
I have not yet linked in with anywhere as it is a recent diagnosis.

The private services that got paid for by parent made a big difference.

The child has tried to commit suicide because he doesn't get the help he needs.

School helping a lot.

67% stated that the quality of the autism services were either poor or very poor with 33% stating that they were good or very good.



- 30% said they did not think the services were medically appropriate and 17% said they were.
- 50% did not know if the services were of good quality, 18% said that they were and 32% said that they were not of good quality.

Paediatrician kept try to discharge child while issues had not been addressed.

I found Castleknock very good but there was a 2 year waiting list.

Aside from assessment no services to date.

Had to pay for private services, the public waiting list is huge.

Relatively new to the service.

Hospital sent letters to children's disability network.

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the right to enjoy 'the highest attainable standard of physical and mental health'. Article 11 of the European Social Convention (ESC) recognises the right to protection of health, while Article 13 enshrines the right to social and medical assistance. The right to health relies on the principle of progressive realisation – that states do what they can to fulfil their obligations with the resources they have available.

The ICESCR obliges states to:

- improve infant mortality rates and healthy child development
- improve environmental and industrial hygiene
- prevent, treat and control diseases

The ESC obliges them to:

- remove the causes of ill-health as far as possible
- promote health, including through health education at school
- prevent accidents and the spread of diseases, including through medical checks at school and screening
- provide healthcare to those without the resources to get it themselves

The UN Committee on Economic, Social and Cultural Rights (CESCR) has said that healthcare must:

- be available and accessible – this may require doctors travelling to patients who cannot leave their homes, or adaptations for cultural or religious needs
  - focus on prevention, cure and rehabilitation – through access to a wide range of health professionals, and vaccination and education programmes

United Nations

These wide-ranging obligations on states place broad duties on public authorities generally, not just health and caring authorities and medical treatment. The right to health could be claimed in relation to working conditions, the physical environment, in planning decisions, in the education system and housing.[11]

When asked if they considered that autism services have progressed, become worse or stayed the same over the last 5 years only 4.5% of respondents felt that autism services had progressed over the last 5 years with 23% stating that they have stayed the same and 32% felt that they had become worse.

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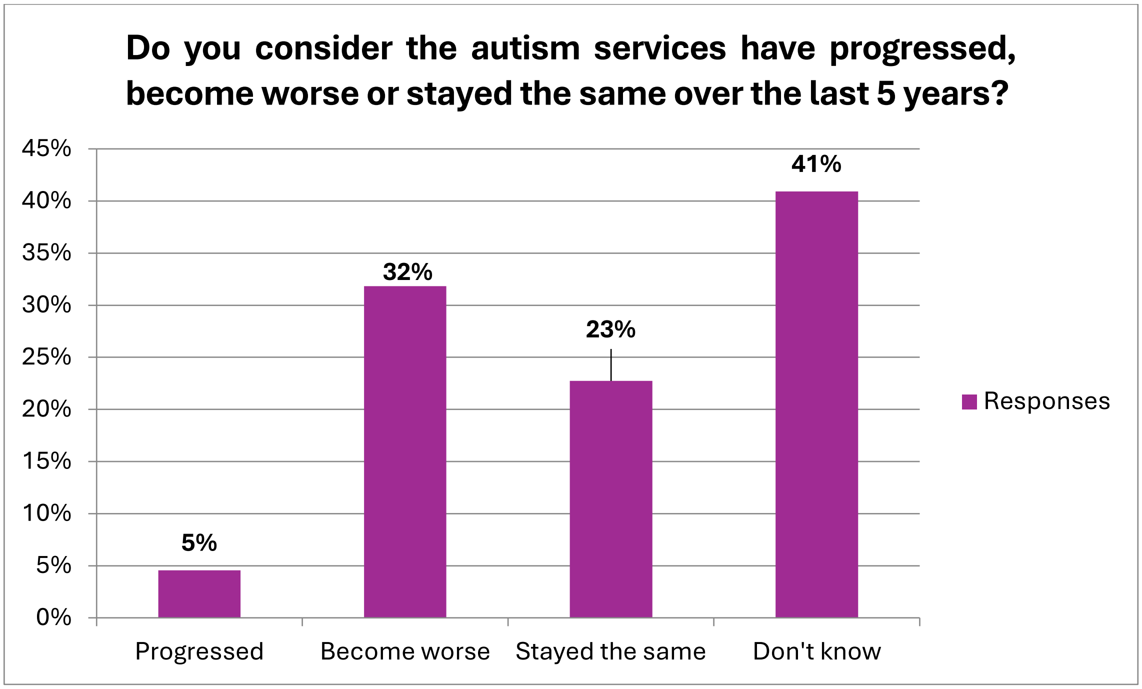
[11] https://www.equalityhumanrights.com/guidance/human-rights-and-complaints-ombudsman-schemes/right-health-ombudsman-schemes



46% stated that there were policies and practices that have a negative impact on the health of children with autism or additional needs.

Push parents into private services.

Focus on very vulnerable families such as refugees & who are often transition because it sounds good but they are often moved so they use that as an excuse why they couldn't follow through on services. Department of Education failure to provide enough special school placement.

MDT dropping kids when needed most.

The long list means your child regressed.

Early intervention is key but you can't access services as the wait lists are unbelievable, this needs to change. Promising services and assessments and school placements and then your left fighting for yourself.

Slow provision of services are delaying and affecting the growth and progress of children living with ASD.

Don't see or hear from anyone.

When asked what opportunities exist (if any) for participation in decision making in the autism services in your area?

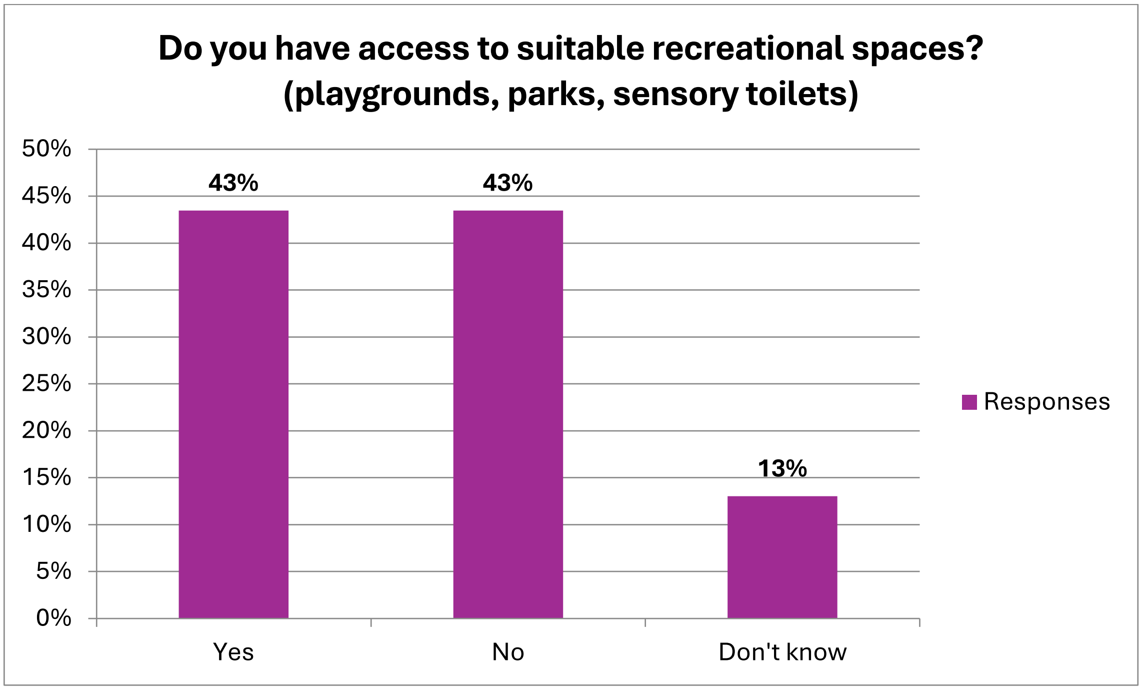
Family forums but questions asked & flow of information controlled by CDNT managers.

We can attend 3 family forums per year to discuss services, how to improve etc.

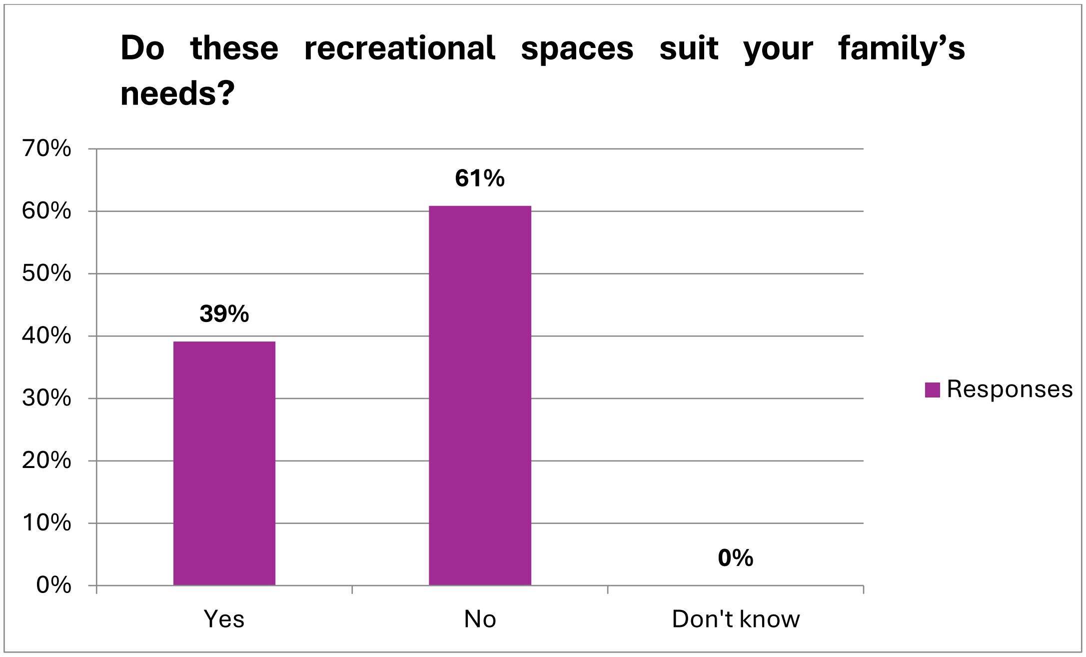
A letter or zoom meeting but you're not allowed to ask or give input. Was told there would be follow up meeting but there was none.

Public Realm & Environment

43% said they did have access to suitable recreational spaces (playgrounds, parks, sensory toilets) while 43% stated that they did not and 13% did not know.



61% said that the recreational spaces did not meet their family's needs and 39% said that they did.



Parents and carers are very clear on what they would like to see in recreational spaces.

Safe suitable staffed & furnished equipped spaces that can meet a whole spectrum of needs & ages of children with additional needs.

Textures… security to stop bikes inside.

Autism friendly play areas

More sensory areas

More visuals, there's no toilets, more gated areas my sone would run of needs constant watching. only playground down the road is usually full of dog poo, teens drinking at night, swings broken etc.

Sensory equipment.

A park for themselves to play without fear.

More space and garden space.

Free sensory rooms.

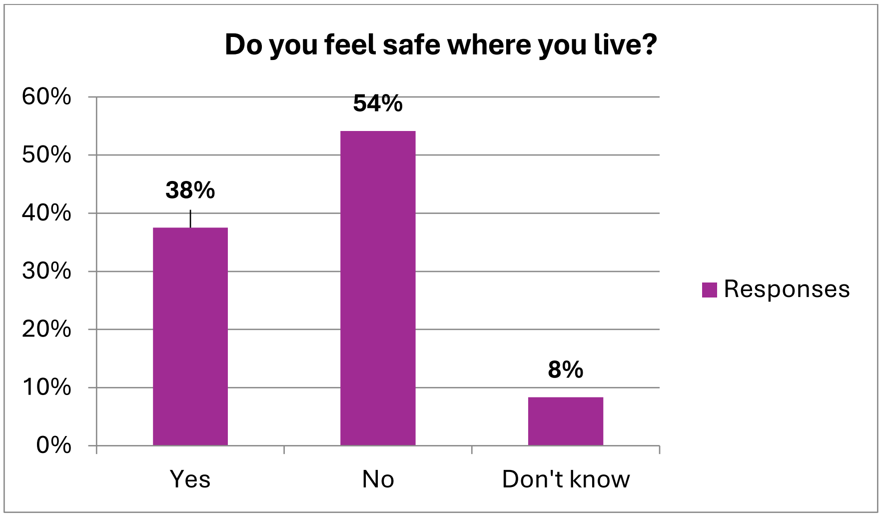
Sensory areas, playgrounds with ASD kids in mind parks with the same ASD spaces in mind. There's a park down the road but nothing to suit his sensory needs, this causes him to be overwhelmed.

Sensory areas with time slots because the areas can be mental with the volume of children. safeguarding so that parents can have some downtime, there is no time to myself in the hub.

Safety

There are a range of every day behaviours that parents/carers experience raising an autistic child and parents have expressed concern about the uncertainty of their child's behaviour and the potential for dangerous behaviours.

54% of respondent felt that they were not safe were they lived and 37% said that they did feel safe, 8% did not know.



55% stated that their children did not feel safe, 41% stated that they did feel safe and 5% did not know.

He is not aware of dangers but community not safe for him.

My daughter is 12 but she thinks everyone is her friend and wouldn't know if someone was going to take advantage of her.

The area I live in can be antisocial like most, I feel safe as I grew up here, would I say I feel it in my building where I live? No. Random people /men coming and going, parties, noise, doors banging at all hours.

My son won't go out due to anti-social behaviour.

Very scared child, fighting, high alert of child running off. Safety concerns, needs parental supervision 24/7.

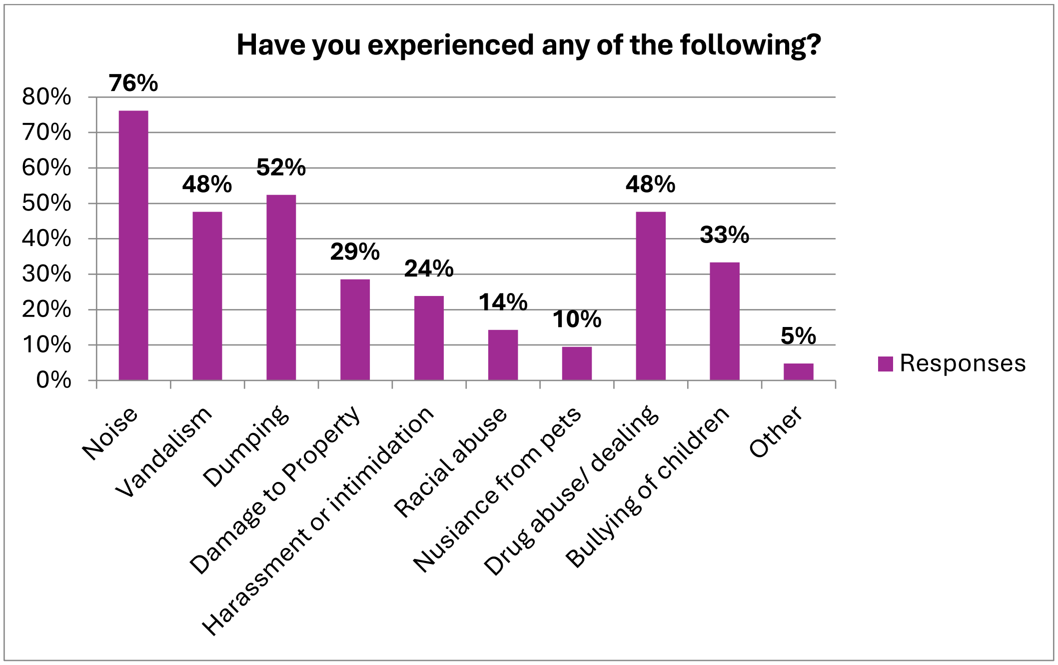
We are in the city centre where they are using vulnerable children like my son to groom them into all sorts of antisocial behaviour.

Very watchful and always have eyes on them.

He is very unaware of danger whether it is safe or not.

He is a very scared child, doesn't like fighting and I must be on high alert because he can run off, he needs parental supervision at all times.

Respondents experienced a wide range of issues with 76% stating noise, 52% stating dumping as an issue, 47% stated vandalism, 28% stated damage to property, 23% harassment or intimidation and 14% mentioned racial abuse. 71% stated that they experienced these issues frequently and 19% occasionally.



From a man who was supposed to do my floors.

I previously experienced racial abuse with my child.

Parents/carers outline a number of areas that would make them and their child(ren) feel safe.

More garda patrol, more speed ramps.

More garda visible on the streets.

By moving to suitable accommodation.

To live somewhere else, suitable to his needs not with single tenants.

Less antisocial behaviour. Less drugs.

Secure, safe, stable home.

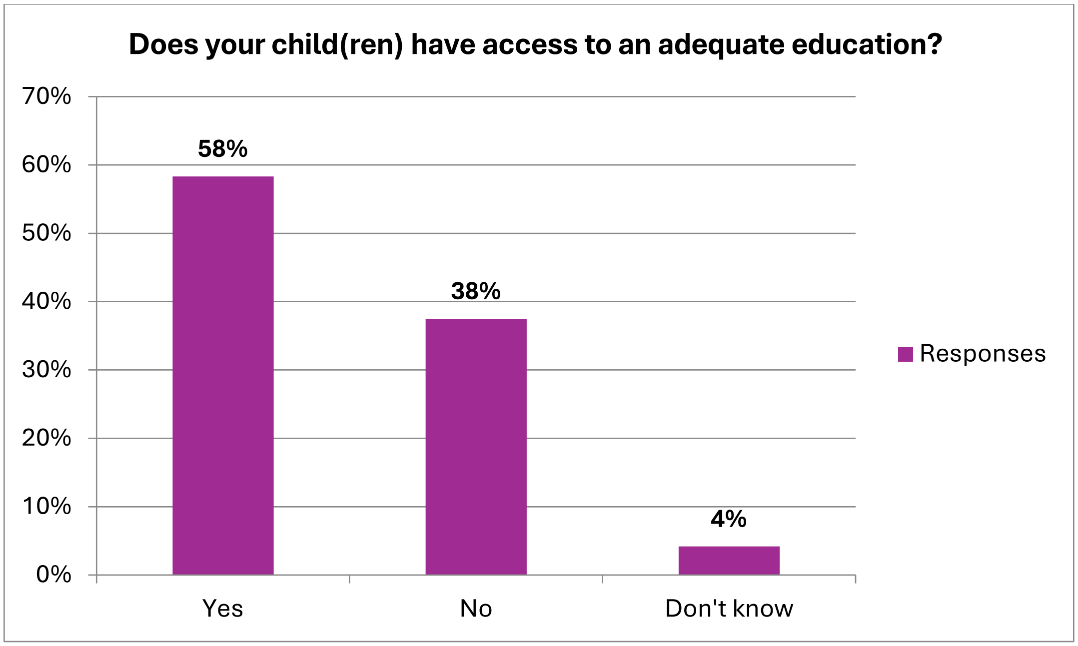
Just a bit more free space for them to feel safe.

Anti-social behaviour to be removed from complex.

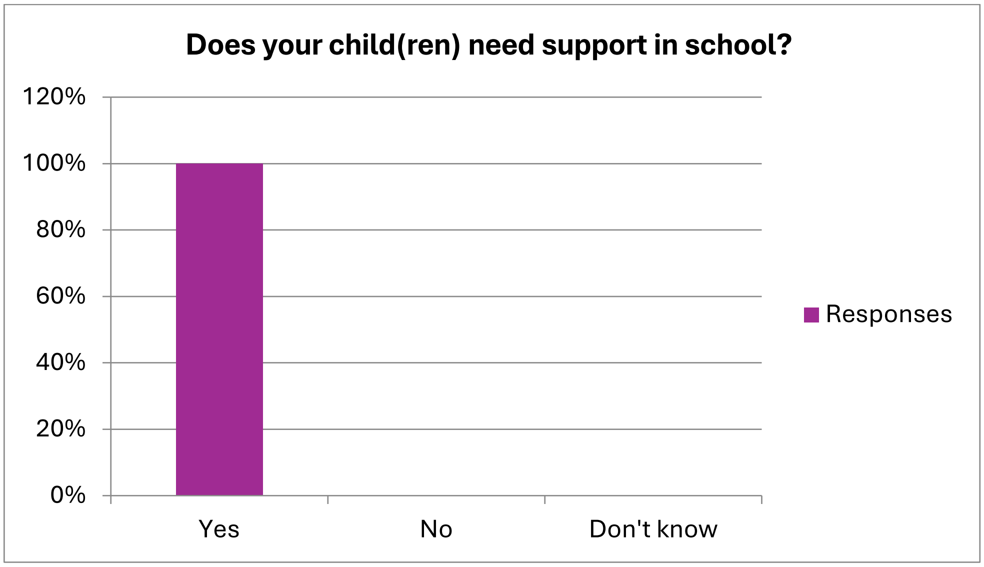
To live in a closed estate, not on a main road where there is constant traffic.

Education

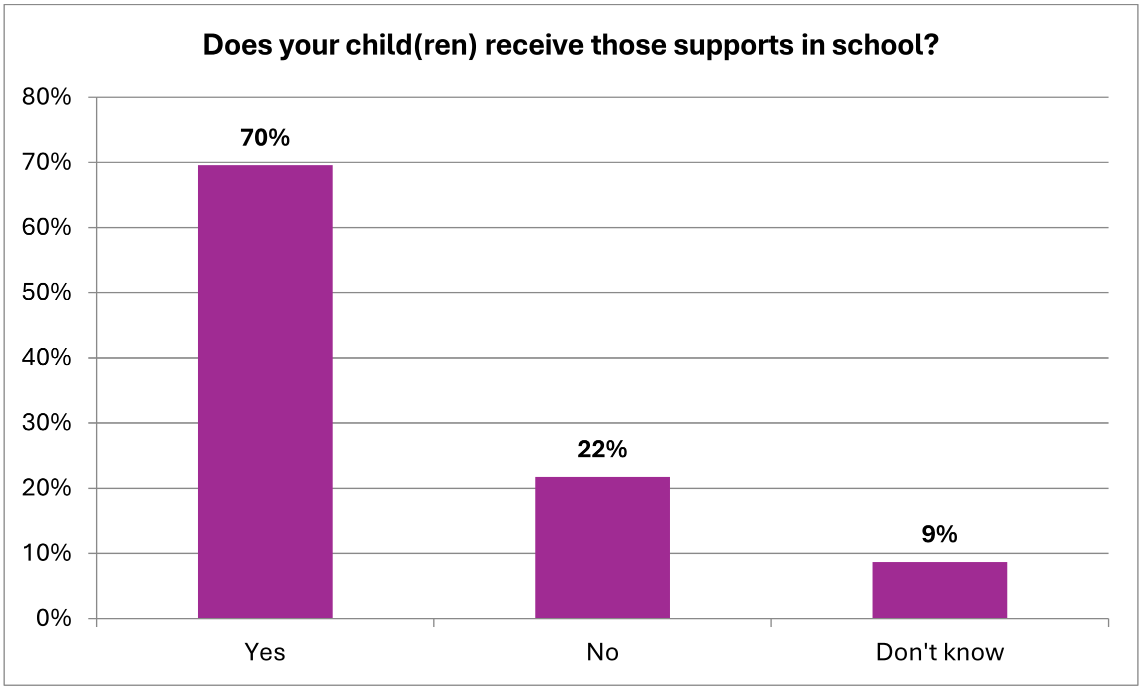
58% of responses stated that their child(ren) had access to an adequate education but 37% felt that their child did not have access to an adequate education.



100% of respondents said that their child(ren) needed support in school.



While 100% stated their child(ren) required support in school, only 70% were actually receiving supports for their child(ren). For many parents, their child was in an ASD unit or had access to an SNA with other extra supports being provided but for many children there are no school places available or are sent home due to the challenges they face in school.



He receives supports in autism class from teacher & SNAs, he requires a special school placement we have applied 2 years in a row he has no placement for September.

Depends on whether teachers are available for breaks etc.

She's in a special needs classroom.

Somewhat, has level 7 aim worker in pre-school.

Nurture room, SET, SNA support.

Help with reading, maths and attends a scoil group.

My son is currently in school for 2 hours. He is waiting on a space in the ASD unit within the school. He is currently in a class of 15 with no SNA or aims support. His teachers are amazing, he loves school but struggles at times.

Extra supports with maths. emotional support for anxiety

Place in ASD unit

He was never able for the curriculum in school so he was sent home a lot.

We need behaviour therapy , OT Support speech therapy.

Never able for the curriculum in school so was sent home a lot.

One getting assessments and the other has an SNA.

Parents and carers outline a range of supports that believe should be available in schools and that will help their children, there is a huge demand for additional ASD units in schools, earlier assessments and providing the supports that children need.

Classrooms equipped with appropriate equipment, SNA sensory room, appropriate safe space garden.

Trips to gardens, sensory breaks, movement breaks and whole class involvement at times too.
More SNA teachers, psychologist in all schools.

Speech & language.

OT, Physio, more SNAs

Every support a child needs.

More ASD units, floating staff and although you have an ASD unit you should be able to receive AIMS, children with all types of needs aside from autism. Schools can't avail of this if run by board of education.

Every support for both the parent and the child.

More people to help in schools more SNAs.

Son doesn't go to school so I don't know.

Second son, need support 1:1.

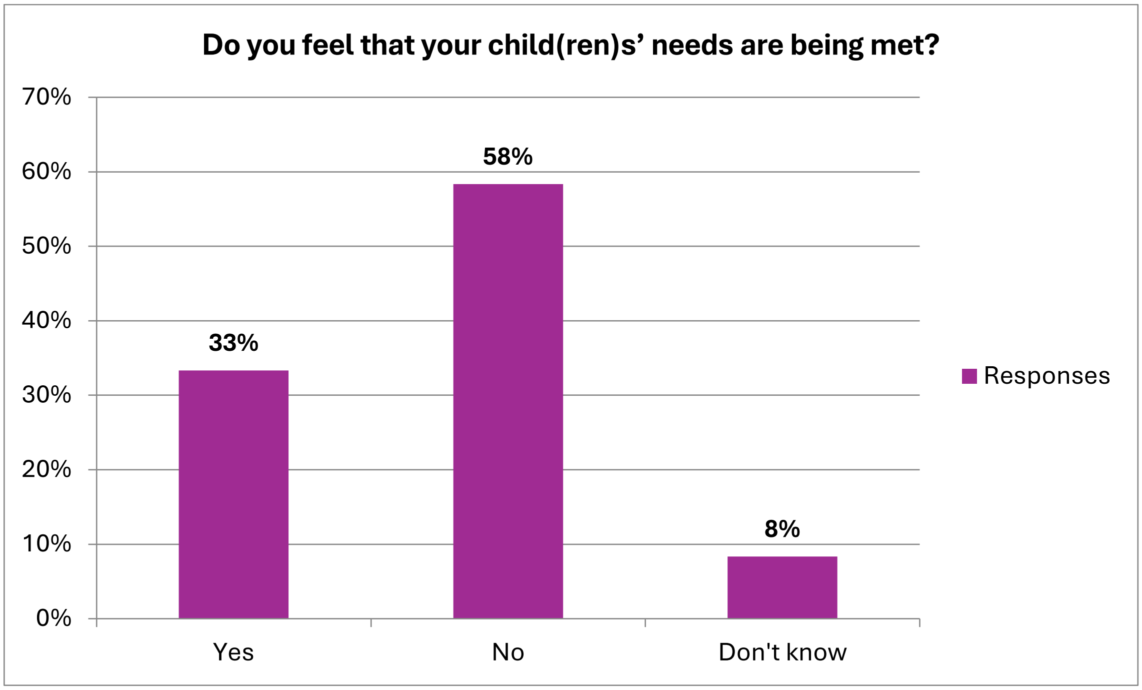
Every support for both the parent and the child.

All speech and language therapy needs to be in school, more moving breaks such as gross motor room and a sensory room needed supports for ASD.

More assessments from earlier.

More ASD units in schools.

58%% felt that their child’s needs were not being met and 33% felt that they were and 9% did not know. There are a lot of areas that can be improved in order to meet their needs.



For many parents dealing with a broken system is more challenging and more burdensome than the challenges faced as a parent/carer of a child with autism.

As a parent through our journey with my son, I can accept his diagnosis & what is required of me to care for him & I will gladly do that as his mother but experiences I have had with HSE & services they fund to provide services has been hell even when they are trying to do what's right they can't deliver. No one understands how bad things are unless you have been through disability services.

Change of culture and accountability in the HSE.

While parents reported that their experiences of schools were mainly positive there is a real need for a broader range of services to meet the needs of each child, tailoring supports, more school places and what is really critical is the need for early intervention and assessment and a reduction in waiting lists.

Time for breaks when suits kids, training around autism masking.

His behaviour requires 1-1 supports but there are 6 children in the class.

More ASD units, less waiting list to get supports they need.
To listen to mothers more regarding any issues that are happening with their children.

More understanding of the child, more help with school work.

More places in schools more hours for SNA.

More early interventions at preschool level. Build more ASD units every school.

Psychological assessment, rehabilitation and change of homeless situation.

More school places available for children with additional needs.

HSE, school and community involved.

More early intervention places must be available.

For many, information and help is provided by other parents of autistic children as they had to rely on their experiences and guidance.

Thank you for doing the survey to make more people aware of the struggles every parent goes through.

Thanks again for the Christmas day, my son enjoyed it nice to see organisations like yourselves think about our kids.

Conclusion

Parents, carers, and family members of children with autism and/or additional needs are being failed by inadequate systems of support. Public services are often insufficient, unavailable, or difficult to access, forcing many families—especially those on low incomes—into an impossible position. While some are able to turn to private services, this is not a viable option for many, reinforcing systemic inequalities and denying children and their families the right to equitable care and support.

Living with and caring for a child with autism or additional needs brings diverse emotional and behavioural challenges, which vary greatly in severity and impact. Families reported that their day-to-day lives are significantly affected. Parents must constantly manage their environment to accommodate their child's needs, often experiencing a wide range of intense emotions while trying to provide care. The mental health burden on parents and carers is substantial, as they cope with chronic sleep deprivation, overwhelming stress, and the constant pressure to meet the complex needs of the entire family. Many described the exhaustion of non-stop care, the need for structured routines, and the fear of potential harm caused by dangerous behaviours. For some, there is no reprieve—no break from the demands of caregiving.

The level of support required by families varies, yet many face serious barriers when trying to access appropriate services. These challenges represent more than just practical difficulties—they are human rights issues. A rights-based approach highlights failures in the availability, accessibility, and adequacy of support services, as well as instances of discrimination. The survey, framed through this perspective, sought to capture families' lived experiences and assess the extent to which current systems support or undermine their rights and quality of life.

The right to education is one of the most pressing areas where families encounter systemic failure. Under Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which Ireland is a State Party, every person with a disability has the right to inclusive, quality, and free education at all levels. However, families repeatedly report a lack of appropriate educational placements, insufficient special educational needs (SEN) resources, and under-resourced schools that are ill-equipped to meet their child's individual learning needs. The failure to ensure inclusive education not only undermines the child's right to learn in an appropriate setting but also places additional pressure on parents, who must advocate constantly for basic entitlements.

Irish legislation—such as the Education for Persons with Special Educational Needs (EPSEN) Act 2004—sets out clear commitments to support the inclusion of children with special educational needs in mainstream education wherever possible. However, nearly two decades after its enactment, key provisions of the EPSEN Act remain unimplemented. This legislative stagnation results in a mismatch between the legal rights of children and the services they receive in practice.

These shortcomings represent a violation of children's rights and a failure by the State to meet its obligations under both domestic and international law. The principle of equality enshrined in the Irish Constitution and supported by international human rights treaties obliges the State to take proactive steps to remove barriers to participation, ensure reasonable accommodations, and prevent discrimination on the basis of disability.
In this context, families are not merely asking for additional support—they are demanding that the rights of their children be respected, protected, and fulfilled. The current system forces parents into a constant cycle of advocacy, stress, and crisis management, all of which could be mitigated through a rights-based, adequately funded, and person-centred approach to disability and educational support.

Appendix 1 – Survey

ICON CDP Women’s Autism Awareness Training Together Group

Survey on Parent Experiences of Autism and Additional Needs

The ICON Women's Autism Awareness Training Together Group are carrying out a survey to understand the lived experiences of parents / guardians of a child / family member who has autism and / or additional needs. We aim to use the findings to advocate for better services.

Your answers will remain confidential and you are free to withdraw your participation at any time of the process. If you have any questions, please contact us, details below.

We appreciate your participation in our survey.

Section 1: Background Information

1. **Name:**

2. **Address:**

3. **What is your gender?** Male ☐ Female ☐ Other gender (e.g. nonbinary) ☐

4. **What is your age?** 18-24 ☐ 25-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 65+ ☐

5. **What is your nationality**?
   a. Irish ☐
   b. Other Nationality ☐
   Please detail: ______________________________

6. **What is your ethnic or cultural background? White**
   Irish ☐
   Irish Traveller ☐
   Any other White background ☐

   Black or Black Irish
   African ☐
   Any other Black background ☐

   Asian or Asian Irish
   Chinese ☐
   Any other Asian background ☐
   Other, including mixed background ☐ please explain:______________________________

Section 2: Identifying Autism

7. **Are you a parent / carer/ family member of a child(ren) with additional needs?**

   Parent ☐ Carer ☐ Family Member ☐

   Other ☐ Please explain: ______________________________

8. **How many child(ren) have additional needs?**

   Age of the child(ren) that has additional needs?

9. **Living Arrangements please tick the box that best applies to you**

   Lives alone ☐

   Lives with children ☐

   Live with partner (no children) ☐

   Live with partner and children ☐

Lives with others ☐

10. How does having a child(ren) with additional needs affect the family?

Section 3: Checklist

11. Has your child(ren) been diagnosed with any of the following?

		Yes	No
1.	**Autism spectrum disorder (ASD)**	☐	☐
2.	**Anxiety**	☐	☐
3.	**Attention Deficit Disorder (ADHD)**	☐	☐
4.	**Bi-polar Disorder**	☐	☐
5.	**Clinical Depression**	☐	☐
6.	**Down Syndrome**	☐	☐
7.	**Eating Disorders (e.g. anorexia, bulimia)**	☐	☐
8.	**Fragile X Syndrome**	☐	☐
9.	**Gastrointestinal Symptoms**	☐	☐
10.	**Intellectual Disability and Development Delays**	☐	☐
13.	**Other**	☐	☐
If other, please describe:			

Section 4: Housing & Accommodation

14. Where are you currently living?

Bedsit ☐ Flat ☐ Apartment ☐ House ☐

Hotel/B&B/ Family Hub☐ Other ☐

If other, please describe

15. What type of housing do you live in?

Local authority ☐ Private rented ☐

Approved Housing Body ☐ Homeless Accommodation☐

Traveller Accommodation ☐ Homeowner ☐ Other ☐

Please describe:

16. Does your accommodation suit the needs of your family? Yes ☐ No ☐ Don’t know ☐

17. Can you explain your answer?

18. What changes would you make to improve your home?

Section 5: Services and Supports

Answer the following questions with examples if possible.

19. How would you describe the availability of the autism services in your community?

Very Good	😍	☐
Good	🙂	☐
Poor	😟	☐
Very Poor	☹	☐

Please give some details

20. **How would you describe the accessibility of the autism services?**

Very Good	😍	☐
Good	🙂	☐
Poor	😟	☐
Very Poor	☹	☐

Please give some details

21. **Did you experience any discrimination when trying to access services?**
Yes ☐ No ☐ Don't know ☐

22. **Did you experience any physical barriers when trying to access services?**
Yes ☐ No ☐ Don't know ☐

23. **Did you experience any financial barriers when trying to access services?**
Yes ☐ No ☐ Don't know ☐

24. **Were you able to access appropriate information when trying to access services?**
Yes ☐ No ☐ Don't know ☐

25. **How acceptable are the services in the following areas?**

Culturally?

Gender?

Age?

25. **Did these services help improve the quality of your child(ren) life?**
Yes ☐ No ☐ Don't know ☐

Please provide further detail

26. **How would you describe the quality of the autism services?**

Very Good	😍	☐
Good	🙂	☐
Poor	😟	☐
Very Poor	☹	☐

27. **Were they medically appropriate (did they suit the needs of your child(ren)?**
Yes ☐ No ☐ Don’t know ☐

28. **Were they of good quality?** Yes ☐ No ☐ Don’t know ☐

Please provide further detail

29. **Do you consider the autism services have progressed, become worse or stayed the same over the last 5 years?**
Progressed ☐ Become worse ☐ Stayed the Same ☐ Don’t Know ☐

30. **Are you aware of any policies or practices that are having a negative impact on the health of children with autism or additional needs?** Yes ☐ No ☐ Don’t know ☐

Please provide further detail

31. **What opportunities exist (if any) for participation in decision making in the autism services in your area?**

Section 5: Recreational Spaces

32. **Do you have access to suitable recreational spaces? (playgrounds, parks, sensory toilets)** Yes ☐ No ☐ Don’t know ☐

33. **Do these recreational spaces suit your family’s needs?** Yes ☐ No ☐ Don’t know ☐

34. **What would you like to see in recreational spaces?**

Section 7: Safety in the Community

35. **Do you feel safe where you live?** Yes ☐ No ☐ Don’t know ☐

36. **Do your children feel safe in your community?** Yes ☐ No ☐ Don’t know ☐
Please give some details

37. Have you experienced any of the following?

Noise ☐ Racial Abuse
☐
Vandalism ☐ Nuisance from pets
☐
Dumping ☐ Drug Abuse/ Dealing
☐
Damage to Property ☐ Bullying of Children
☐
Harassment or intimidation ☐
Other, please describe:

38. How often do you experience this? Once off ☐Occasionally ☐Frequently ☐

39. What do you think would make you and your child(ren) feel safe?
Please give some details

Section 8: Education

40. Does your child(ren) have access to an adequate education? Yes ☐ No ☐ Don't know ☐

41. Does your child(ren) need support in school? Yes ☐ No ☐ Don't know ☐

42. Does your child receive those supports in school? Yes ☐ No ☐ Don't know ☐
If so, please outline supports receiving.

43. What supports do you think should be available in schools?

Section 9: Rights and Responsibilities

44. Do you feel that your child(ren)s' needs are being met? Yes ☐ No ☐ Don't know ☐

45. What do you think needs to be put in place to meet their needs? Please give some details

46. Do you have any further comments you would like to make?

47. If you would like to get involved in the work of this group, please leave your email address and/or phone number below.

If you would like to be entered into a draw to win a €50 One 4 All Voucher, please leave an email below.

Thank you for your time

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April 2025