



IRELAND'S AUTISM CHARITY

Submission to the Covid-19 Public Evaluation

About AsI Am

AsI Am welcomes the opportunity to contribute to the Covid-19 public consultation evaluation.

AsI Am is Ireland's Autism Charity. Founded in 2014, AsI Am advocates for an inclusive society that is accessible, accepting and affirming for Autistic people and our wider community. We work to support the Autistic community and our families throughout the lifecycle to fully engage in Irish life and build the capacity of society to facilitate true inclusion. This is achieved through the programmes of support we offer and our advocacy work. AsI Am provides a range of programmes through our national and regional based activities and programmes.

As a Disabled Person's Organisation (DPO), AsI Am is Autistic led, informed by the experiences of Autistic people, and more than half of our staff and board are Autistic or have other differences or disabilities.

AsI Am's work focuses on advancing the rights of Autistic people across Irish society. We use a rights-based, Neuro-affirmative approach in all our work, supporting Autistic people across all supports within the organisation. AsI Am is also a founding member of the DPO Network - an alliance of five national DPOs who collectively advocate for the

rights of Disabled people and to advance the full implementation of the UNCRPD in Ireland, across all our laws and policies.

Introduction

The Covid-19 pandemic which began as we commenced the second decade of the 21st century was a seminal moment in the history of our state. It was a moment in time where all individuals within society were impacted. It was a time when quick decisions were made in the face of uncertainty, unpredictability and precarity and without time to think of the short and long-term impact on individuals and communities. There was no grouping within society who remained unscathed from the impact of Covid-19. The mantra “All in this Together” echoed every corner and side-street within our towns and villages, as we all knuckled down to do what we could do to “flatten the curve”. Whilst all these actions were admirable and praiseworthy, cracks began to appear in the system, in the early months of the pandemic; due to the imbalance that existed in how some of the policies enacted at this time disproportionately impacted the disabled community.

The Covid-19 pandemic was a time that was captured by fear, anger, uncertainty, and worry within our communities and families, and with the benefit of hindsight we can see the impact this pandemic had on the disabled community. It was time which exposed significant systemic weaknesses and prejudices in how our state services and universal policies adapted at the time impacted on certain cohorts within society. Whilst we are a few years out from the pandemic, the remnants of this moment in time have left an indelible mark on the Autistic community and wider disabled community in terms of accessing services and supports, and the long-term implications, the withdrawal of services had on the Autistic community.

Our submission in particular draws upon the lived experiences of our community members and our organisational activity during this time. It highlights how Covid-19 measures disproportionately affected Autistic people and families and sets out key lessons that should shape future emergency responses. This submission also highlights how members of the Autistic community are still feeling the impact of some of these policy implications that were taken at this time. We also situate these issues within

Ireland's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly in relation to equal access to services, inclusive education, independent living, and the right to participate fully in community life.

Disruption to Services and Supports

The sudden withdrawal of essential services such as schools, day services, disability services, and in-school therapies had a devastating and regressive impact on Autistic individuals and families. The closure of these supports removed not only education and health supports but also vital structure and predictability for many individuals and families during the Covid-19 pandemic. Families, already stretched in ordinary circumstances, experienced acute pressure without respite services or access to external disability supports. There was a pressure put on parents to provide care for their children during the school day while many were trying to work from home and balance many different tasks and family life. For adults, many residential services were impacted with visits stopped initially and day services closed as staff were redeployed elsewhere within the health system. Such measures took their toll on the disabled community with residents restricted from seeing their loved ones and day services withdrawn, without a thought given as to the impact this would have on the mental health of individuals all had a consequential impact.

The below outlines in further detail the impact and disruption Covid-19 had on services for Autistic people and families.

Education

Children in Ireland experienced one of the longest school closures amongst European countries during the first wave of the pandemic. School children lost 141 days of face-to-face teaching time during the 2019-2020 academic year. This significant loss of face-to-face learning had a significant impact on the social, emotional and educational learning of Autistic students. As well as having one of the longest school closures in Europe, Ireland was an outlier when it came to the closing of special schools in Europe. Such a decision had a grossly negative impact on many Autistic students across the country.

Whilst the government took steps to introduce distance learning/online learning for the school going population, these measures did not work for many Autistic children, particularly those with a co-occurring diagnosis. A 2024 publication by the National Council for Special Education noted a research study conducted in 2021 on the impact of the COVID-19 pandemic on the education of children with additional educational needs. This research highlighted “89.3 percent of schools reported a detrimental impact on students with additional educational needs”. This impact was captured at the time by our community support team who were providing direct information and advice to community members during this time.

Many of the parent's engaging with our service referenced the impact of school closures on their Autistic child, with daily reports of regression and meltdowns taking place, especially when the limited supports provide to families was not working effectively or were not appropriate. In a recent publication by the CSO (March 2025) *Covid-19- Our Lives Five Years On: Interrupted Education*, it was noted that “parents with a child attending a special school in March 2020 are most likely (82%) to report that school closures have had a negative impact on their child’s social development”.

School closures had a particularly damaging impact on Autistic children and young people. Not only were educational routines disrupted, but critical therapies and supports delivered in schools were withdrawn. The deployment of staff from disability services into broader healthcare roles compounded the problem, leaving families without specialist supports at a time when they were most needed. The in-school therapies programme was withdrawn during the pandemic and has not since been restored fully. Although there is now an active pilot among 45 special schools, there has been a shortfall in meeting the educational needs of Autistic children across the education system since the withdrawal of the supports over five years ago.

The impact of school closures on our Autistic student population is still something families and individuals are working through today. During this period, AslAm was actively pursuing a campaign to have special schools re-open (advocating for key staff within these educational settings being offered the first opportunity to get vaccinated to mitigate against the spread of the virus) so that our community members who were worst impacted by school closures could try and regain the lost knowledge and skillset during

this period of time. Given what we know now, there is significant learning to be applied if we find ourselves in the unfortunate position of another pandemic in relation to school closures for those who require access to a special school or an autism class.

Disability Services

Prior to the pandemic in 2020, access to children's disability services was limited and under resourced with a significant wait time experienced by families waiting on an autism assessment and access to key supports. When the pandemic hit, children's disability services were effectively shut down and restricted within a short period of time with key clinicians and therapist redeployed to support with swabbing within our test centres. This seismic redeployment directly impacted on the wide-ranging needs of the Autistic community and wider disabled community with families no longer in a position to get access to appropriate supports (including therapeutic and social). Several parliamentary questions issued during this time highlighted the impact the withdrawal of services had on Autistic people. It was evidenced by organisation such as AsIAM, et al, the little impact clinical/therapeutic phone consultations had on children who were non-speaking or who had other communication differences.

The withdrawal and abrupt stoppage of these services gave the impression that autism was something Autistic people and families could just park. This was the reality for many Autistic people at this time. The abrupt closure of key therapeutic and social supports has had a lasting negative impact on our current Children's Disability Network Team's (CDNT's) as some staff within these divisions did not return to their previous posts due to a variety of reasons including long-term covid illness. This has led to ongoing chronic issues within our CDNT's. Not only was it children and young people impacted by these disruptions, but so to for those who were engaged with Adult Disability Services.

The closure of day services for disabled adults was another major decision taken by the National Public Health Emergency Team (NPHE) at this time. Disabled people at this time were identified by NPHE as a vulnerable group and as a result were deemed to be at a higher risk of contracting the Covid-19. Measures were introduced, such as online/tele supports with limited direct support; however, the type and number of

services varied across the country and were at a much-reduced level of support than pre-covid. Part of this reduction was due to the redeployment of key staff to covid-19 test centres. In early July 2020, 4 months after the announcement of day services closing the HSE published the '*Guidance to Support the Framework for the Resumption of Adult Disability Day Services*'. This document allowed for services to finalise plans for the reopening of day service locations for disabled people. Unlike the budget allocated to support the opening of schools (€375 million), the guidance to support the resumption of disability services was not accompanied by a commitment of government financial support initially. The impact of these closures and the incremental timelines on reopening had a devastating impact on service users who relied, depended on and required these services. **Mental Health and Wellbeing**

The long-term closure of the school system during Covid-19 had particularly severe consequences on the mental health of Autistic individuals and families. This heightened sense of anxiety and distress was compounded by the fact that many services of support were withdrawn from Autistic people and families. Notwithstanding the fact that the services provided to individuals and families prior to the pandemic were insufficient. A 2020 (O'Sullivan et al) study with 48 families with children who have additional needs noted the impact of the pandemic on children and young people's mental health. Higher levels of stress, anxiety and depression were noted. The author of this study noted "autistic children and adolescents faced mental health challenges attributable to the changes in routine necessitated by the COVID-19 pandemic". Asbury et al., (2021) suggest that the abrupt closure of schools caused mental health challenges for children with additional educational needs. These presentations married with the experience of our community support team, who again fielded many questions from Autistic individual and families about the impact the Covid-19 restrictions placed on Autistic people, from loss of routine, predictability, structure and opportunity. The experience of these measures greatly impacted on the experience of isolation for many of our community members.

Isolation measures, while necessary for public health, were experienced as a form of confinement by many Autistic people and families. The restriction on movement, visiting loved ones in community-based supports and remaining within a certain radius of one's

home, added to the uncertainty and negative experience of the Autistic community. This was particularly felt by Autistic people who lived on their own or were living in supported living environments or children who had particular routines. Parents noted that the closure of residential services had an incredibly negative experience on their mental health and their child's. The prolonged absence of social interaction and peer support led to widespread distress, sadness, and a sense of loss. For some, the lack of tailored mental health supports made the isolation burdensome. Families reported a deterioration in the mental health of both Autistic people and families. This, coupled with the lack of available supports to Autistic people made this experience that more unbearable. The failure to provide these key services adversely impacted our community.

In a commissioned survey taken at the time of the pandemic by AsIAM, many individuals and families noted a negative experience on their mental health. The below insights give some insights to these experiences at this time:

- 70% of family members reported the COVID-19 crisis as being very hard to manage;
- 72% of autistic people do not have an alternative support person or organisation if their key support person became sick or unavailable during this time;
- 74% of families do not have access to support;
- 78% of family members did not think their autistic family member would cope with the requirement to self-isolate;
- 55% of autistic people described coping with social distancing restrictions as hard or very hard;
- 67% of autistic people were finding it hard to cope with the uncertainty of what was happening.

Communication and Public Understanding

As we reflect on the period 2020-2022 a number of key learnings are required. One key learning is how key and essential communication was delivered to the disabled community, taking into consideration peoples communication differences. Throughout the pandemic, many community members experienced uncertainty and anxiety due to the inaccessibility of some of the communication that was coming from some state agencies. Clear, accessible communication was often lacking. Families and individuals struggled to interpret complex and rapidly changing guidance with daily announcements

creating a sense of fear within our community. Official messaging did not adequately consider the needs of people with intellectual and developmental disabilities, nor did it provide Autism-friendly formats to this information. Often the breaking down of information was left to advocacy organisations. This lack of accessible communication unnecessarily created worry for our community members at this time. Moreover, the absence of public education campaigns addressing disability-specific issues—such as sensory differences posed by masks—contributed to stigma and misunderstanding by the public toward Autistic people and families. A more inclusive communication strategy would have reduced fear and panic, while promoting compassion and social solidarity across the different groups.

The AslAm Team

Covid-19 presented many obstacles and challenges for organisations such as AslAm. Many of our services became operational online, our fundraising streams were radically reduced, but demand for our service increased. Like many organisations we had to adapt our services. We had to develop new ways of reaching our community in ensuring the Autistic community were supported and guided throughout this period. These included the following:

- A series of support webinars covering issues such as self-regulation, managing sensory processing at home and emotional regulation;
- Developed a bank of resources to help autistic people when it came to maintaining structure, dealing with the unknown and understanding the crisis as it develops;
- A dedicated staff member was assigned to deal with queries from the community arising from COVID-19;
- Providing ongoing support in issuing Autism ID Cards to community members who found this card useful, especially when the 2km and 5km measures were introduced.
- Liaised with the HSE and An Garda Síochána on the impact of social distancing restrictions and the broader COVID-19 crisis on the autism community and advocating for autism-specific supports where appropriate

- Worked with business partners to meet the needs of autistic people in accessing essential services at supermarkets;
- We offered several online supports which focused on “dealing with change”, “creating social stories around self-isolation, testing and new government measurements”

Our community support team provided ongoing direct support to community members through the many queries that were fielded to our service at this time. Many of these calls fielded by our community support team focused on the following:

- Difficulty interpreting rules around covid tests
- Does a fully vaccinated child who is non-symptomatic have to remain home from special school.
- Disrupted routines when having to self-isolate
- Difficulty getting accommodations for a child in a vaccination centre
- Looking for information on the lifting of restrictions in day services
- Sensory issues with nasal tests
- Difficulty accessing covid boosters, due to HSE communication
- Looking for social stories around the vaccine
- How to get vaccine for someone who won't leave the house
- Clarification on whether Autistic people were classed as "vulnerable" under the HSE guidelines for accessing vaccines
- Accessing exemptions when required to wear masks whilst out in public
- Concerns around data protection with the enforcement of vaccine mandates

Learning from Positive Experiences

Despite the challenges, certain aspects of the Covid-19 response provided unexpected benefits for some Autistic people. Smaller groups in day services, quieter transport arrangements, and increased opportunities for one-to-one support created calmer environments in which individuals could thrive. These outcomes suggest that service design should incorporate greater flexibility and choice, ensuring that supports are responsive to diverse sensory and social needs.

Rather than returning to a “one-size-fits-all” model post-pandemic, Ireland should seek to embed these lessons into long-term policy of support. Doing so would not only make services more resilient in future crises but also enhance the everyday inclusion of Autistic people, and the rights enshrined under the United Nations Convention of Person with Disabilities is upheld.

Policy Recommendations

Future emergency planning must be guided by the principles of equality, accessibility, and participation. Specifically:

- Education and access to disability services must be deemed “essential” and prioritised in any future national emergency
- Emergency measures should include contingency plans to maintain essential services for Autistic people, including education, respite, and therapies.
- A national framework of respite and family supports should be established to prevent carer burnout during crises.
- Public health communication must be accessible, Autism-friendly, and widely disseminated in plain language formats.
- Public awareness campaigns should promote understanding of Autism-specific differences to reduce stigma and discrimination.
- Positive lessons from the pandemic—such as smaller service groups and quieter transport—should be integrated into long-term service design.
- Cross-departmental coordination must be strengthened to ensure that health, education, and social protection responses are consistent and inclusive.
- Increased financial supports for those in receipt of Disability Allowance, Domiciliary Care Allowance and Carers Allowance due to the additional pressures that present during a time of crisis.

- Better public understanding on the wearing of masks and the issue this might present for those with sensory differences or intellectual disability.

Conclusion

The Covid-19 pandemic exposed the extent to which Autistic people, and their families were overlooked in crisis planning. The removal of essential supports, the lack of accessible communication, and the absence of tailored mental health provision all contributed to a decline in Autistic people and family's mental health. These experiences must inform a more inclusive approach to public health policy, grounded in Ireland's commitments under the UNCRPD.

By embedding accessibility, flexibility, and support into future emergency responses, Ireland can ensure that Autistic people and families are better supported in ensuring their needs are met during a time of crisis. Autistic people and the wider disabled community cannot be considered an afterthought in future emergency responses. We must learn from the areas we got wrong and build on the areas we got right.