

Advocacy Matters:

Advocating for People with Disabilities
in Residential & Day Services During
the Covid-19 Pandemic



Executive Summary
October 2021

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About this Report

This report has been developed by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

It outlines the observations and experiences of our Advocates when providing independent advocacy to people with disabilities living in residential services and attending day services in Ireland during the Covid-19 pandemic, particularly during the period from March 2020 - March 2021.

The report explains the issues faced by people in residential services and day services during this traumatic period, the support provided by our Advocates and the positive outcomes this advocacy support helped to achieve. It shows the key role that advocacy services play in supporting people who may be vulnerable in Irish society, particularly during periods of crisis.

NAS provides a crucial means of support for people with disabilities. Throughout the pandemic, NAS has pursued a human-rights based approach for the people they support, recognising the right of people with disabilities to live with dignity, autonomy, equality and independence. It is crucial that people with disabilities, particularly those who communicate differently, have the right to have their voice heard and to make their own decisions about issues affecting their lives.

It is clear that a human rights-based approach should be the focus of any future plans or strategies that are developed in the State's response to the Covid-19 pandemic and for any future public health emergencies. This will ensure that people with disabilities are at the centre of the decision-making process, leading how they live their lives during periods of crisis and providing input into the development of key policies and legislation.

In response to the challenges posed by the pandemic, NAS and the Patient Advocacy Service have adapted and improvised their services to ensure they have been able to continue to deliver high-quality advocacy to people with disabilities. Almost overnight, both Services moved from office to home working, while also embracing innovative new ways of working such as phone calls, video calls, emailing and text messaging.

Now the initial crisis of the pandemic has passed, it is also crucial that the rights and freedoms of people living in residential services are upheld and restrictions on family visits and access to day services for all are lifted, respite services are made available and transitions from congregated settings continue to progress to ensure that people with disabilities can return to normal, fulfilling lives.

Covid in Residential & Day Services: Responding to the Crisis

Findings

“It’s nice to hear from someone who can put a smile on my face at a time when I really need it; it’s very lonely, so thank you so much.” Joan, who lives in a residential service and has been supported by a NAS Advocate since May 2020.



In ordinary times, people with disabilities face rights restrictions and have poorer access to health, education and employment. They have difficulties in accessing justice and decision making and are more likely to experience discrimination and marginalisation. During the Covid-19 pandemic, these issues were further exacerbated for people with disabilities living in residential services and attending adult day services.

Residential settings have been particularly vulnerable to outbreaks of Covid-19, despite preventive measures. People with disabilities living in residential settings and attending day services have also been more likely to be impacted by the public health and other measures taken to reduce infection which restricted their access to supports, services and their community. The closure of day services has impacted heavily on adults with disabilities and continues to affect some people who still are waiting to go back to their service.

Isolation and mental health

Findings

NAS statistics show that mental health and well-being has been the biggest single emerging issue for people with disabilities receiving the Service's support during the Covid-19 pandemic.

Issues highlighted by people working with NAS include:

- Poor communication of public health guidance to people living in residential services
- Visiting restrictions in residential services
- Withdrawal of day services

There has been an increase in mental health concerns for people with disabilities living in residential services due to restrictions in place. People reported feelings of isolation, anxiety and fear. People faced prolonged periods of time without direct contact with their family and loved ones.

Despite the improving situation in society in relation to Covid-19, NAS is aware that some residential services still have strict visiting restrictions in place. This continues to impact negatively on the physical and mental health of the people living there.



The closure and reduction of day services also had a serious impact on the mental health of people with disabilities, their families and carers. NAS has supported many people who have experienced anxiety and depression, while others have become withdrawn and disengaged from services.

For those living in the community, their carers, faced increased pressure to provide full-time care at home. They have spoken about their feelings of exhaustion and isolation whilst balancing existing family and work commitments, without access to any support or respite.

Daily Activities: Some Positive Outcomes

Findings

After the closure of day and respite services, organisations that provide both day and residential services redeployed staff to work in residential services to provide additional staffing. As a result, those living in these settings were able to engage in meaningful activities and were provided with a service tailored to their individual needs rather than group activities.

For those living in the community following day service closure, some have used this time to explore alternative options to the traditional day service model. Many have expressed a wish to be more independent and to participate in local community-based activities, rather than return to a full-time day service.

Decision Making

Findings:

“Thank you for always showing me how much you respected my views and listening to me. You helped me be ready for all those phone calls and made sure my HSE support team and family listened to me.”

NAS has supported many people with disabilities living in residential services throughout the pandemic to have their voice heard and to progress issues and decision-making in line with their own wishes. This support was particularly important for those people who communicate differently as their voice, will and preferences can get overlooked or not taken into consideration at all.



Transport

Findings



In residential services, transport was only used for medical appointments. It was not permitted for social outings, which had a detrimental impact on the wellbeing and quality of life for people living in residential services.

For those in the community attending day services, transport provided by service providers was limited due to social distancing and infection control guidelines. People were reliant on family members to transport them to and from day services. This was not possible for many families.

The HSE provided additional funding for transport to enable more people to attend services each day, this to be made available for those in need.

Transitions from Congregated Settings

Findings

Concerns were raised in relation to infection control measures. Some services had large numbers of people living in close proximity and the needs of some residents meant it was not always possible to practice social distancing.

Some people in congregated settings benefitted from accelerated decision-making to transfer them to more suitable and appropriate accommodation.

Unfortunately, for some, the move to transfer people from congregated settings as part of 'Time to Move on from Congregated Setting: A Strategy for Community Inclusion'¹, has been delayed due to the Covid-19 pandemic.

¹ Time to Move on from Congregated Settings A Strategy for Community Inclusion <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>

Respite

Findings

While some respite services operated on reduced capacity, many closed completely, leaving people with disabilities without a much-needed service. This has had a devastating impact on people who were unable to access the services and for their families and carers who have spoken about their feelings of exhaustion and isolation in providing full-time care during this time.

Safeguarding

Findings

The most significant safeguarding issues for people living in residential services and in the community with their families related to financial concerns. Other safeguarding concerns related to health and social care services not being able to access homes to check whether a person was being adequately supported.

People who communicated differently who faced safeguarding issues were further affected by the pandemic as their Advocate often could not meet with them face-to-face. Advocates used alternative methods of communication. These were effective for some people, but for others, such as those people who communicate differently, these options proved challenging.

The closure of day services led to safeguarding concerns for some people with disabilities living at home. For some people, the link to day services, outreach and employment support services acted as an additional support for people outside the home.



Key Recommendations in this Report

- ▶ A human rights-based approach should be the focus of any future plans or strategies that are developed for people with disabilities. This will ensure they are at the centre of the decision-making process, leading how they live their lives during periods of crisis and providing input into the development of key policies and legislation.
- ▶ NAS should be adequately funded and resourced to ensure that it can continue to support people with disabilities to have their will and preference in decision making upheld.
- ▶ It is crucial that the rights and freedoms of people living in residential services are upheld and restrictions on family visits are lifted. Residential services need to be innovative and should do their utmost to support people to maintain contact and links with family and loved ones, utilising technology.
- ▶ NAS provided advocacy support for people who communicate differently, helping to ensure their voice, will and preference was represented in the decision-making process. It is also imperative that Service providers adequately support people around decision making, especially those who communicate differently.
- ▶ It is also vital that the restrictions preventing people from accessing day services are removed, in line with the Framework for the Resumption of Adult Disability Day Services².
- ▶ As outlined in the 'Value for Money and Policy Review of Disability Services in Ireland'³ and in 'New Directions: Interim Standards for New Directions, Services and Supports for Adults with Disabilities'⁴, there should be a move away from group-based activities for people with disabilities to a more person-centered service delivery. Working in a person-centred way with individualised supports is more reflective of HIQA's Guidance on a Human Rights-based Approach in Health and Social Care Services⁵

2 Framework for the Resumption of Adult Disability Day Services Supporting People with Disabilities in the context of COVID-19: The Next Year <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/framework-for-resumption-of-adult-disability-day-services.pdf>

3 Value for Money and Policy Review of Disability Services in Ireland <https://www.hse.ie/eng/services/list/4/disability/newdirections/value-for-money-policy-review-of-disability-services-in-ireland.pdf>

4 New Directions Interim Standards for New Directions, Services and Supports for Adults with Disabilities <https://www.hse.ie/eng/services/list/4/disability/newdirections/interim%20standards%20for%20new%20directions%20report.pdf>

5 HIQA's Guidance on a Human Rights-based Approach in Health and Social Care Services <https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

- ▶ NAS has continued to advocate for the full restoration of respite services for people with disabilities. It is also important for service providers to be innovative in their service provision for people in the absence of full respite services.
- ▶ NAS made referrals to the HSE's safeguarding teams and supported people to be involved with their safeguarding plan. NAS has escalated concerns within services and the safeguarding social work teams in CHO areas when necessary. It is critical that the financial rights and the safety of people with disabilities in residential services and in the community are upheld.
- ▶ Essential services like, community-based safeguarding social work teams, should be seen as a vital service for those with disabilities and not redirected into other duties.



Key Conclusions in this Report

- ▶ Advocates have helped people to have their voice heard and to progress issues and decision making in line with their own wishes. Throughout the course of the Covid-19 pandemic, they have made a significant difference to the lives of people with disabilities in residential and day services.
- ▶ Next of kin has no legal basis for anyone to make a decision on behalf of a person with a disability unless they have specific legal authority to do so. However, often decisions are made on this basis about people with disabilities.
- ▶ NAS liaised with services on people's behalf to communicate their questions and concerns and ensured they responded effectively to support the person, representing their will and preference to the residential service providers.
- ▶ NAS supported people in congregated settings to express their will and preference to service providers in respect of their living arrangements and during their transitions to new homes. NAS has continued to highlight the importance of progressing moves in a timely manner to ensure that people with disabilities can return to normal, fulfilling lives.
- ▶ NAS played a key role in ensuring that individuals were kept fully informed by service providers about the latest on public health developments and guidance, including how they might be affected. NAS advocated for these to be proportionate and balanced against the human rights of the person with disabilities.



