NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

Patient Advocacy Service
INFORMATION | SUPPORT | EMPOWERMENT

Advocacy Matters:

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

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 is the first of four reports which outline our observations and experiences in providing independent advocacy to people who required our support during the Covid-19 pandemic, particularly during the period from March 2020 - March 2021. Each report will look at a different theme.

This report, theme one, explains the issues faced by people with disabilities in residential services and day services during this traumatic period. It focuses on the work carried out by NAS, outlining the support we provided 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.

Established in 2011, the National Advocacy Service for People with Disabilities (NAS) is an independent, free and confidential service, funded and supported by the Citizens Information Board. NAS provides representative advocacy to people with disabilities across Ireland, to ensure that their will and preferences are heard in decisions that affect their lives.

NAS also hosts the Patient Advocacy Service, established in October 2019, which is commissioned and funded by the Department of Health. This free, independent and confidential Service provides information and empowerment advocacy to people who want to make a formal complaint through the HSE 'Your Service, Your Say' complaints policy in relation to their care in a HSE-funded public acute hospital or a HSE-operated nursing home.

The vision of NAS is one where people with disabilities can exercise their rights, with dignity, autonomy, equality and independence at the core. NAS recognises the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities[1] (UNCRPD). NAS works to advocate for the person's will and preference and to have their voice heard.

Both NAS and the Patient Advocacy Service recognise the rights of all people to support, guidance and information when issues arise in relation to their care and treatment which may lead to their wish to complain about their treatment or care or seek answers in the aftermath of a patient safety incident.

Please note, all statistics presented in this report are specifically looking at the period March 2020 – March 2021. They report on emerging and ongoing issues, resulting from the Covid-19 pandemic, which impacted on the lives of people with disabilities supported by NAS.

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[1] United Nations Convention on the Rights of People with Disabilities **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html**

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 Services[2].
- 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 Services[5].

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[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.

Impact of Covid on Our Services

Before focusing on Covid-19's impact on residential and day services, it is important to note the impact of the virus on the services provided by NAS and the Patient Advocacy Service.

The emergence of the Covid-19 virus in March 2020 meant it was impossible for the two services to continue their normal way of office working, including meeting people face-to-face. Overnight, they moved to working from home, a situation which continues over one year later.

However, while some organisations struggled to respond effectively to operational changes, NAS and the Patient Advocacy Service manage national phone lines and online methods of enquiry (email, website). This has ensured that both Services have continued to advocate for people with disabilities to ensure that their voices are heard when decisions are being made on public health grounds, and to advocate with them and for them to have access to services and supports at this challenging time.

In addition, particularly at the beginning of the pandemic lockdown, NAS Advocates provided support beyond their remit by helping people to access services such as shopping, GPs and pharmacies, as well as Covid-19 pandemic unemployment payments.

Meeting the people we support face-to-face also proved challenging as Advocates could not spend time with them to observe and understand their will and preference fully. Responding to these difficulties, Advocates utilised alternative methods of communication such as, phone calls, video calls, emailing and text messaging. To continue with the provision of advocacy for some people, particularly those who communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) Advocates had to rely on the support of families and service providers to aid with continued communication. Despite these communication challenges, NAS worked with the person to ensure their will and preference were carried out.

The Patient Advocacy Service has also continued to provide advocacy support and information to users of its service during the pandemic through its national phone line and online forums. It provided long arm support to people around difficulties they experienced with their home-based care, whether living in their own home or community setting, including providing access to information.

Covid in Residential & Day Services: Responding to the Crisis

"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.

NAS has a particular remit to work with those who may be isolated from their community of choice or mainstream society, those who may communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) and those who have limited informal or natural supports. NAS upholds the person's rights, ensuring fair and equal treatment and access to services.

Advocates make certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.

NAS representative advocacy involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Independent, representative advocacy is directed by the people who use it. Where the person communicates differently, the Advocate is still directed by the person.

In ordinary times, the people that NAS works with 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.

People with disabilities and those accessing health and social care supports are a very diverse group and some within this group face even greater marginalisation. These include those experiencing mental health issues, those from different migrant or ethnic groups, and those who communicate differently.

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. There has been an increased risk of infection for people living in these settings who, despite preventive measures, may not be able to socially distance, wash their hands or wear their masks. The people living there also have a higher risk of transmitting the virus[6]. People with disabilities are also more likely to have existing health issues which increase their risk if they contracted Covid-19. This has been a cause of great anxiety for many people with disabilities living in residential services.

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. Restricted access to non-Covid-19 health services has impacted people with disabilities to a greater extent. When combined with reductions in other public services, including transport, education, housing supports and limited access to technology, this led to increased mental health concerns for people with disabilities.

Of the 1,300 registered residential disability services, with approximately 8,300 people living in them, "it is estimated that sadly 21 people to date living in such facilities have died from Covid-19 (0.2% of residents)"[7]. In January 2021, HSE Chief Operations Officer, Anne O'Connor, stated that there were 183 outbreaks of Covid-19 in disability and mental health services[8].

Visiting restrictions introduced in residential services to prevent the transmission of the virus have also meant that people living in these services have dealt with prolonged periods without face-to-face contact with friends or family. This has led to isolation, loneliness and anxiety for many people with disabilities.

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[6] Rapid review of public health guidance for residential care facilities in the context of COVID-19 **https://www.hiqa.ie/sites/default/ files/2021-05/Rapid-review-of-public-health-guidance-for-residential-care-facilities-in-the-context-of-COVID-19.pdf**

[7] Disability Services - Preparedness and Ongoing Response to Covid-19 **file:///C:/Users/Lisa%20Walsh/Downloads/120324_03288a70-bf9e-4312-919c-b3a24b6adc82.pdf pg. 3**

[8] **https://www.rte.ie/news/coronavirus/2021/0121/1191078-covid-19/**

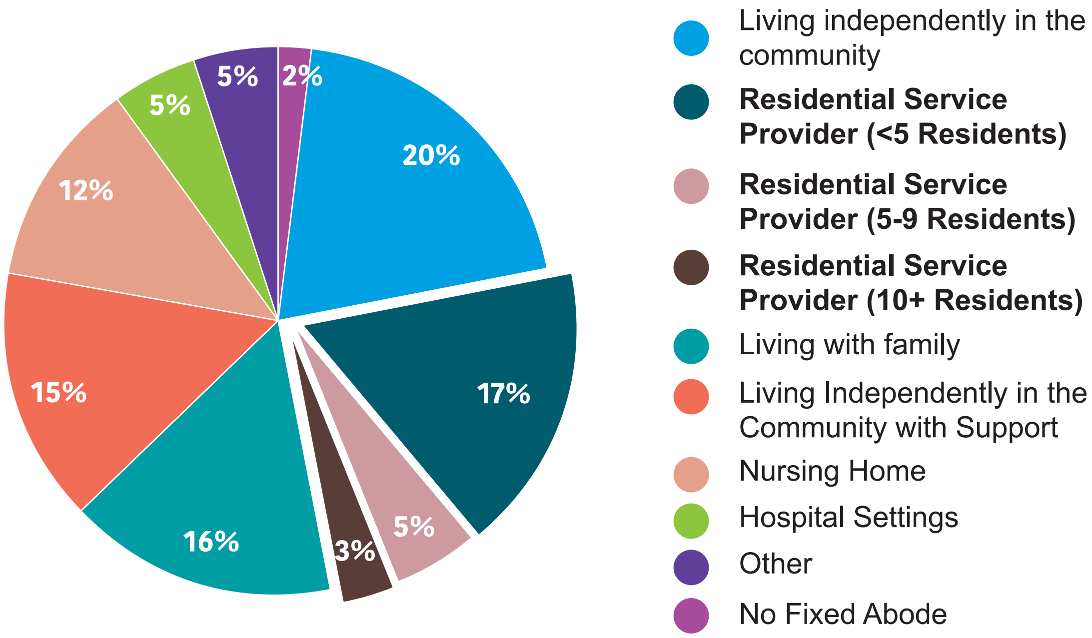
Location of People with Issues Impacted by Covid-19

25%	Residential Service Provider
20%	Living independently in the community
16%	Living with family
15%	Living Independently in the Community with Support
13%	Nursing Home
5%	Hospital Settings
5%	Other
2%	No Fixed Abode

NAS estimates that of those it supported with an issue impacted by Covid-19, from March 2020 - March 2021, 25% were from people with disabilities living in residential services. Of the 25%, 17.05% with an issue impacted by Covid-19 were in relation to those living in a residential service with <5 residents, 5.11% were those living in a residential service with 5-9 residents, and 2.61% were those living in a residential service with 10+ residents (congregated settings).

Location of Person with an Issue Impacted by Covid-19

Residential Services - 25%



Congregated settings are institutions or residential campuses where ten or more people share accommodation. According to the Health Information and Quality Authority (HIQA) in their ‘Annual overview report on the inspection and regulation of disability services in 2019’, 1 in 3 people continue to live in these types of settings and “are at greater risk of having a poor quality of life compared to residents who live in community settings”[9]. In relation to Covid-19, people living in congregated settings are also at a higher risk of contracting the virus[10].

As part of ‘Time to Move on from Congregated Setting: A Strategy for Community Inclusion’[11] it is planned that all people currently living in a congregated settings will move to live in their community and have individualised supports to meet their needs. This move to transfer people from these settings continued throughout 2020, with 95 people moving according to the ‘Disability services – preparedness and ongoing response to COVID-19’[12]. However, for some people supported by NAS the move from these settings has been stalled and had challenges.

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[9] Annual overview report on the inspection and regulation of disability services in 2019 **https://www.hiqa.ie/sites/default/files/2020-09/HIQA-Disability-Services-2019-overview-report.pdf, pg.6**

[10] ECDC Rapid Risk Assessment (19 Nov 2020) ‘Increase in fatal cases of COVID-19 among long-term care facility residents in the EU/EEA and the UK’ **https://www.ecdc.europa.eu/sites/default/files/documents/Increase-fatal-cases-of-COVID-19-among-long-term-care-facility-residents.pdf**

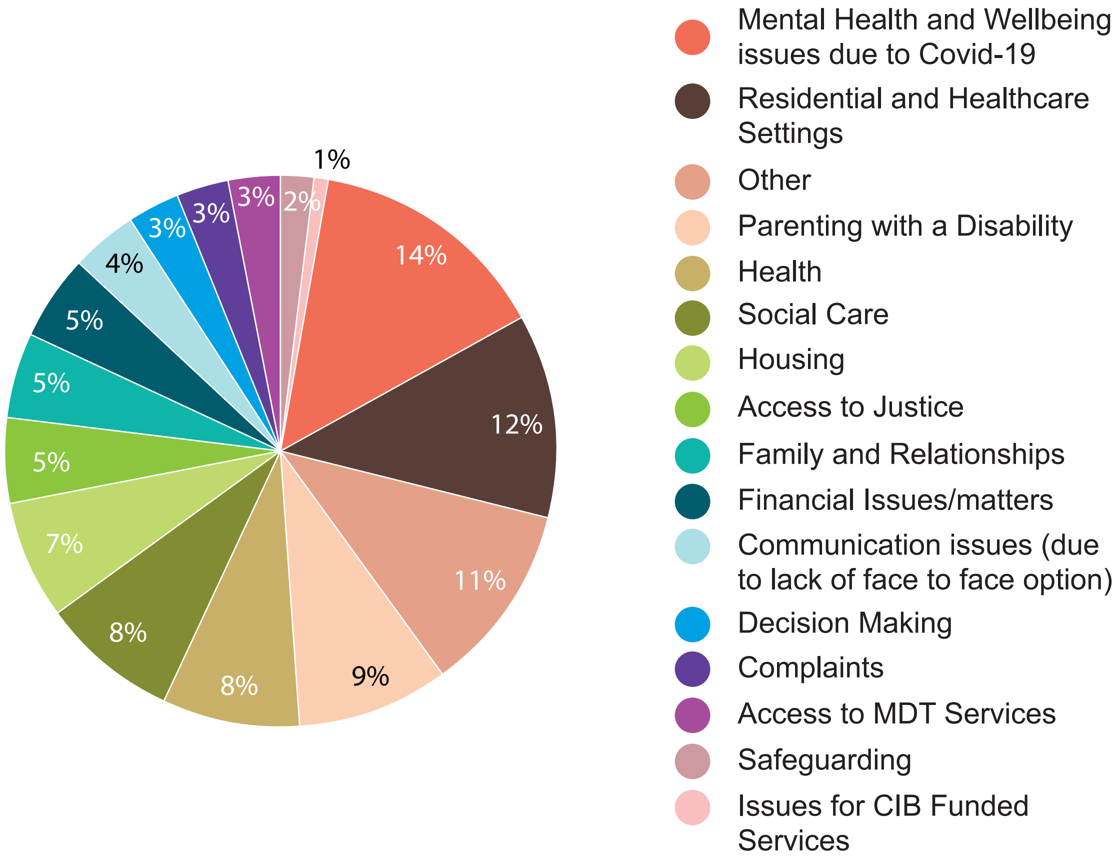
[11] Time to Move on from Congregated Settings A Strategy for Community Inclusion **https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf**

[12] Disability Services – Preparedness and Ongoing Response to Covid-19 f**ile:///C:/Users/Lisa%20Walsh/Downloads/120324_03288a70-bf9e-4312-919c-b3a24b6adc82.pdf**

Adult day services were closed as part of the Covid-19 restrictions introduced in March 2020. They remained closed for a significant period even after lockdowns were lifted across the country for businesses to open their doors. This has impacted heavily on adults with disabilities who attend day services and continues to affect some who still are waiting to go back to their service. These individuals have lost access to the social interaction, structure, and routine they required. It has impacted on people's mental health and led to isolation, anxiety, and a loss of confidence and skills for many people.

Issues Impacted by Covid-19 Experienced by People NAS Supported

March 2020 - March 2021



In response to these issues, the work carried out by NAS since the onset of the Covid-19 pandemic has shown the importance of advocacy services. Advocates have worked to alleviate the loneliness and anxiety felt by many people, they have helped to improve communication between staff, residents and families, and they have negotiated increased support for people with disabilities in particularly difficult situations.

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 pandemic, they have made a significant difference to the lives of people with disabilities in residential and day services.

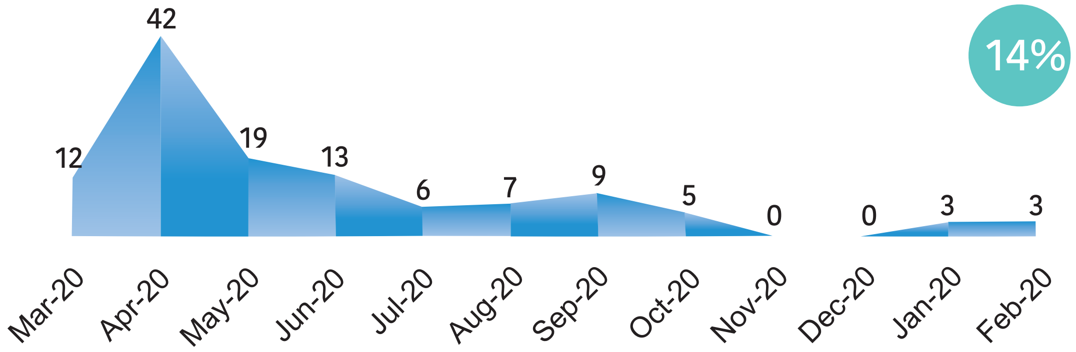
Isolation and Mental Health

> **"Thank you so much to you [the NAS Advocate] for all your hard work. It's not everyone I can connect with, but I knew that you cared."**
>
> Anne, who lives in a residential service and was supported by a NAS Advocate during the Covid pandemic.

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

For the period March 2020 - March 2021, mental health and wellbeing accounted for 14% of the emerging issues impacted by Covid and dealt with by NAS. These issues peaked for people availing of our service in March - May 2020 when all services were closed almost overnight. Issues around mental health were at their highest in April, when they were reported almost twice as much as any other issue in this month. Mental health and well-being were the most reported issues to NAS. Issues highlighted by people working with NAS included the poor communication of public health guidance to people living in residential services, visiting restrictions in residential services and withdrawal of day services.

Mental Health and Wellbeing Issues Impacted by Covid-19



Communication on Public Health Guidance

At the start of the pandemic, NAS learned that poor communication about public health developments was a major cause of worry for people with disabilities living in residential services. Many people said they were not being kept up to date on the latest Covid news or government advice and that communication was lacking from the staff in these settings. They were concerned about the unknown aspects of Covid and how to stay as safe as possible while following healthcare protocols and risk management.

Media reporting was heightened, particularly in the early months of the first lockdown, and residential services were identified as being in this high-risk category. Many people with disabilities were also identified as high-risk due to concerns about their underlying medical conditions and living in a congregated setting if they contracted the virus. All these factors contributed towards an increased sense of fear and worry for people with disabilities within residential settings.

NAS supported people to ensure they received the most up to date and accessible information from services. Advocates were told that some people feared "breaking rules" as guidance was changing. NAS liaised with services on people's behalf to communicate this worry and ensure they responded effectively to support the person.

NAS also played a key role in ensuring that individuals were kept fully informed in a timely manner by service providers about the latest public health developments and guidance, including how they might be affected. This helped alleviate the stress felt by people in relation to Covid-19.

Visiting Restrictions in Residential Services

People living in residential services also reported to NAS that visiting restrictions imposed during the Covid-19 pandemic had a negative effect on their mental health. People faced prolonged periods of time without direct contact with their family and loved ones.

The restrictions also created issues for NAS Advocates. Following the first initial lockdown, when restrictions began to ease, they were able to meet with people face-to-face to progress advocacy case work. This was facilitated by residential services, many of whom created designated meeting rooms. However, during level 5 restrictions, face-to-face visits were no longer permissible for Advocates which meant they were unable to provide the full advocacy support that many people required, particularly to people who communicate differently.

These restrictions understandably led to feelings of isolation, anxiety and fear for many people in residential services. The restrictions also failed to reflect HIQA's National Standards for Residential Services for Children and Adults with Disabilities[13] and the recently published Guidance on a Human Rights-based Approach in Health and Social Care Services[14]. These reports stress that the residential service provider must ensure that people with disabilities are supported to maintain and develop personal relationships with family and others. The rights of people with disabilities do not change during a time of crisis and services need to be creative in how they support people.

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[13] HIQA's National Standards for Residential Services for Children and Adults with Disabilities **https://www.hiqa.ie/sites/default/files/2017-02/Standards-Disabilities-Children-Adults.pdf**

[14] 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**

With this in mind, NAS encouraged residential services to be innovative and to do their utmost to support people to maintain contact and links with family and loved ones during this difficult time. This included the utilisation of technology such as WhatsApp and Zoom.

Staff within residential services supported people to use phone and video technology to communicate with their Advocates. This also ensured that they were able to keep in regular contact with their families and loved ones which helped to reduce their isolation and fear.

In addition, NAS worked with people with disabilities and service providers to ensure that visits with family, where appropriate, could be accommodated safely as guidelines eased. However, despite this easing, NAS learned of some cases where strict guidelines remained in place in residential services.

Advocates supported people in these cases to ensure the public health measures that were in place were proportionate and balanced against the human rights of the person with disabilities.

During this difficult time, Advocates also increased the support they provided for people with disabilities in residential services. They regularly carried out meetings over Zoom to check people were coping as well as possible and when required they ensured people had access to mental health professionals.

Despite the improving situation in society in relation to Covid-19, NAS is aware that some residential services still have visiting restrictions in place. This continues to impact negatively on the physical and mental health of the people living there. NAS continues to help these individuals represent their will and preference to the residential service providers.

Withdrawal of Day Service Provision

The reduction in essential 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.

Day services provide opportunities for people with disabilities to take part in activities they enjoy. They offer them the chance to participate and engage in their communities and employment, access Multi-Disciplinary Team (MDT) supports, and meet friends and peers. For many, they also provide an important link to supports outside the family home.

As a result of the reduction in services, people were unable to socialise and take part in activities which were already limited before the Covid-19 pandemic began.

Although they were aware of the dangers caused by the pandemic, many people with disabilities were conscious that their freedoms were going to be disproportionately impacted when compared with the general population.

In May 2020, the HSE developed the Framework for the Resumption of Adult Disability Day Services[15], a plan for day service supports for the next year. Throughout the closure of day services, they typically maintained some contact on a weekly basis, via telephone or video calls, with those living in the community but the supports that could be provided remotely were limited. Some day services organised Zoom video group activities for people in the community or sent activity packs to people.

As a result, family members and carers, many of whom were older parents, faced increased pressure to provide full-time care at home. They have spoken about their feelings of exhaustion and isolation during this period as they struggled to provide full-time care whilst balancing existing family and work commitments without access to any support or respite.

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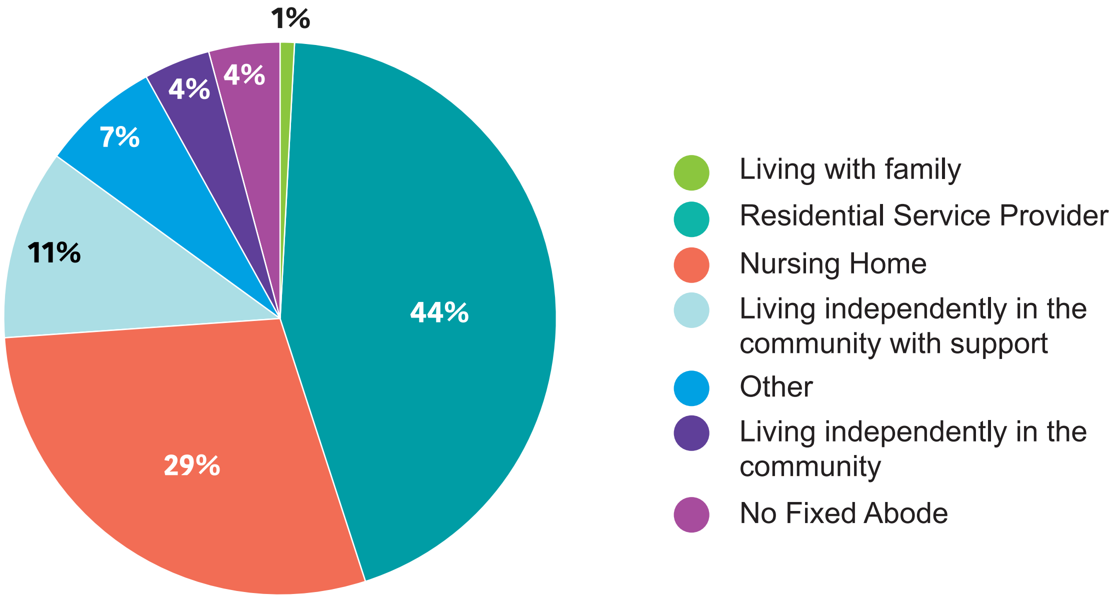
[15] Framework for the Resumption of Adult Disability Day Services Supporting People with Disabilities in the context of COVID-19: The Next Year **https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/framework-for-resumption-of-adult-disability-day-services.pdf**

In response, the range of supports provided by NAS for people living at home has been comprehensive, from checking in with people, to linking them in with appropriate services and supports in their own community, such as Primary Care Teams, Gardaí or local authorities so they can receive assistance with food and medication.

Advocates have also supported people to access appropriate personal protective equipment (PPE) if carers were accessing their homes and they negotiated with care providers to ensure that they removed PPE from people's homes and did not leave it to be disposed of by family members.

Location of those reporting day service issues



Of the people who contacted NAS with day service issues impacted by Covid, 44% of them were living at home with family. In one case, NAS supported a young person with agoraphobia and poor mental health. The person, who experienced chronic anxiety and was socially isolated, was linked in with NAS constantly during the pandemic.

The Advocate worked closely with the Covid Helpline and Civil Defence to support the person to get essential groceries and prescriptions. Without support of the NAS, this person would have been at significant risk of harm. NAS also linked them in with the outreach mental health team and engaged with various professionals on their behalf. With the help of the Advocate, this person has been supported to address housing needs and much needed medical and psychological services.

The withdrawal of day service provision has had a similar impact in residential services, where many people with disabilities rely on day service provision to get outside, socialise and meet friends. However, this can often require detailed planning. Of the people who contacted NAS regarding Covid related issues, 25% were living in a residential service provider. Those supported by NAS said that the reduction in day care services had impacted on their physical and mental health and left many people confused and unhappy.

In response, NAS frequently held planning meetings and negotiations with service providers to secure alternatives for people living in residential services. Advocates participated in Multi-Disciplinary Team (MDT) meetings to explore options and highlight the impact for the person as the public health measures were further extended. Advocates were able to agree phased planning for people with disabilities to access additional supports absent during level 5 lockdown and agree opportunities to access day supports or activities within a residential programme.

In many cases, services responded to the needs highlighted by NAS by providing additional staff for the residential service to facilitate regular access to the community for activities in line with public health measures. In some cases, Advocates managed to negotiate the allocation of a dedicated staff member who would support people in residential services by providing a one-on-one day service for a set number of hours per week.

In one case, NAS supported a person living in a residential service who had used local services independently without any need for staff support. The person sought assistance from NAS when they were told by their service provider that they were no longer allowed to leave their home unless they were supported by two staff members on account of Covid-19. The Advocate listened to the person’s concerns and liaised with the residential service provider to highlight how the practice negatively impacted on the person’s quality of life. As a result of this advocacy intervention, the practice was changed, allowing the person to access their local community on their own once more. NAS support helped the person to regain their independence and had a real and positive impact on the person’s quality of life.

Daily Activities: Some Positive Outcomes

NAS has also noted some positive impacts to the lives of adults with disabilities living in residential services during the Covid-19 pandemic. 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. This is in line with the 'Value for Money and Policy Review of Disability Services in Ireland'[16] which recommends that there is a move from group-based activities for people with disabilities which is often the case in residential settings to a more person-centered service delivery.

Regarding day service closure, some of those supported by NAS have also had positive experiences. They have told Advocates that they have used this time to explore alternative options to the traditional day service model.

Many have expressed a clear wish to be more independent and to participate in local community-based activities rather than return to a full-time day service, which is in line with the 'New Directions: Interim Standards for New Directions, Services and Supports for Adults with Disabilities'[17].These standards outline principles for service providers to deliver on supports that are person-centred and allow people with disabilities to be part of their community as an active participating citizen.

Supporting people in both residential and day services in a person-centred way with individualised supports is more reflective of the 'Guidance on a Human Rights-based Approach in Health and Social Care Services' from HIQA. When services adopt a human rights-based approach this allows them to focus on the needs of the person. A human rights-based approach to working with people with disabilities builds a collaborative way of working and allows the person to be at the centre of and to lead on how they want to be supported.

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[16] 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**

[17] 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**

Simon’s Story: Coping with Day Service Restrictions

My name is Simon. I am middle aged, and I have an intellectual disability. I enjoyed a busy, independent life before the Covid-19 pandemic. I live in a residential service and before the pandemic I would take public transport to meet friends and family for coffee and lunch. I also attended day service five days a week, which I really enjoyed.

My life was badly affected with the pandemic, and I struggled with the restrictions. I wasn’t able to meet with anyone and my day service was reduced to one hour of outreach per week because I was living in a residential service.

Later on, I became aware that other people were returning to day service, and I felt it was unfair that I couldn’t attend too. I contacted NAS as I was feeling lonely and isolated, and I needed support to have my wishes heard.

I was able to explain to my Advocate how I was feeling and my need to return to my day service as soon as possible. My Advocate talked to me about the government health guidelines that were in place for Covid 19, I understood the risks, but I felt I should be able to attend my day service at least 1-2 days per week. I wanted to explore my options and have my voice heard.

My Advocate helped me write a letter to the day service manager explaining how I felt and that I wanted to return to my day service on a part-time basis. My Advocate also helped me to arrange a meeting with the day service manager and the manager of my residential service to discuss a plan of how my wishes could be achieved.

Prior to this meeting, I had worked with my Advocate to discuss what I wanted, and I was able to explain this clearly during the meeting. The managers expressed their concerns, and I was able to with the support of my Advocate address how those concerns could be addressed. It was agreed that I would take part in outreach and day service for a set period of time per week. I was over the moon with this outcome.

Unfortunately, I got a call from my Advocate to explain that several professionals involved in my care had expressed their concerns and wanted, what had been agreed to be put on hold until the Covid restrictions had been eased further. I thought everything had been agreed and I was disappointed with this and did not want my return to be put on hold. I discussed my wishes with my Advocate, who told the professionals that I understood the importance of following government guidelines and felt a return to day care service would be of huge benefit to me. My views and wishes were taken on board and within two weeks I had returned to day care.

I now enjoy meeting up with my friends at the day care service each week and I’m relieved to be back into some form of a routine. None of this would have been possible without the support of my Advocate.

Decision Making

> **“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.”**
>
> David, who lives in a residential service and was supported a NAS Advocate to have his views heard during the pandemic.

From the experience of NAS and the Patient Advocacy Service, very often people with disabilities are not included in making or informed of decisions made about their own lives. In the HSE’s ‘Effective Participation in Decision-Making for People with Disabilities and Families. Planning for Ordinary Lives in Ordinary Places’[18] it stresses that the person with a disability has the right to participate in decisions made about their lives. The person’s voice, and choice, their will and preference, should be heard in the decision-making process and they should be given control over the decisions made about their lives.

The rights of people with disabilities to be involved in decision making is also underpinned in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Assisted Decision Making (Capacity) Act 2015[19].

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 whose voice, will and preferences can get overlooked or not taken into consideration at all.

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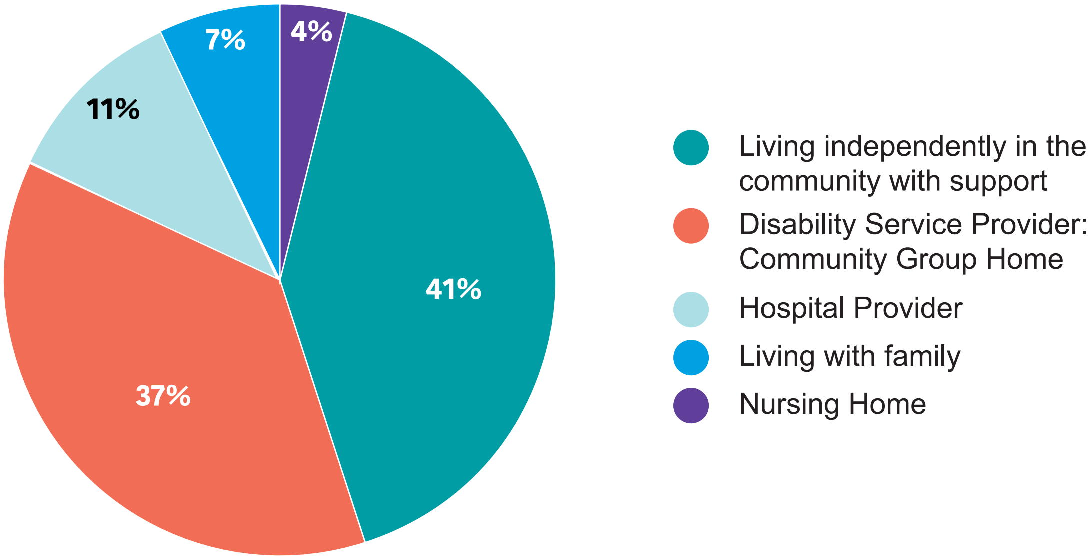
[18] Effective Participation in Decision-Making for People with Disabilities and Families Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff **https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-implementation-for-hse-staff.pdf**

[19] Assisted Decision Making (Capacity) Act 2015 **http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html**

Of the people who contacted NAS, 3% of the Covid-19 related issues were linked to decision making. Breaking this down further to look specifically at the location of where people were residing, it was a similar experience for people living independently in the community at 41% and people living in residential services at 37%.

Decision making issues due to Covid-19 Location of person



In the early months of lockdown, NAS supported a person who communicated differently and had a visual impairment. The person had to self-isolate for two weeks with very little sensory stimulation or interaction. The Advocate explained to the residential service provider that this would be an extremely challenging situation for the person, and they needed additional support. It was not possible for the person to sit in a room for two weeks with no engagement other than at mealtimes and bathroom supports. As a result of the Advocates intervention, the service provided additional resources for the person. This included supporting the person to communicate their consent for testing or treatment, helping them move to other houses for infection control purposes and having access to activities and therapeutic supports.

Another key piece of work undertaken by NAS in relation to decision making during the Covid-19 pandemic has been in relation to the Covid Vaccination Programme. NAS has advised and guided service providers on the importance of supporting people living in residential services around the consent process for the vaccination programme particularly for people who communicate differently. This has allowed people to have informed consent to make their own decisions about getting the vaccine or not if that is their decision and to explore other supports needed without any fear or worry about getting vaccinated.

NAS has been involved in a series of webinars explaining how an Advocate supports a person who communicates differently in relation to consent called, **Supporting the consent process for the vaccination programme against Sars-CoV-2 (Covid 19)**.

This work has played an important role in highlighting the duty of service providers to adequately support people around decision making. It has also ensured that the will and preference of many people with disabilities living in residential services is given due consideration by service providers in major life decisions such as the Covid Vaccination Programme.

Mary’s Story: Support with Decision Making

My name is Mary, I am in my thirties, and I live in a residential service. I have an intellectual disability and a physical disability. I had an issue with a member of my family during the Covid-19 pandemic. This person was pressuring me to discharge myself from a Right of Residency from my family home which was part of my parent’s Will.

I was given forms to sign by my family member, but I was not supported to understand what these forms were about. A staff member who supports me in my home put me in touch with an Advocate from NAS and explained what had happened.

Further travel restrictions were put in place just after this incident, which meant it wasn’t possible for anyone to visit the residential service, even for a window visit. However, I was able to chat to my Advocate on Zoom calls. The Advocate helped me understand my rights and explore my options and to weigh them and helped me to get legal support, so that I could make an informed decision.

My Advocate also put me in contact with the HSE Safeguarding and Protection Team who were a massive support to me and I can’t thank them enough. They put a safeguarding plan in place to protect me and my rights. They helped me to put a plan in place to ensure my rights were upheld and I had the support that I required.

Thanks to my NAS Advocate, I now have the time, space and support I need to make sure my own views are listened to and protected and that I am supported to make an informed decision that I am happy with.

Transport

Another difficulty experienced by people with disabilities living in residential services and attending day services during the Covid pandemic was the lack of access to transport.

Earlier in the pandemic, transport in residential services 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.

In some residential services, the service providers made the decision that people were not permitted to take public transport due to public health measures and to ensure the health and safety of all living there.

It was a similar situation for people using day services. It is estimated that 8,000 adults require transportation to access these services. In the Framework for the Resumption of Adult Disability Day Services[20] it was outlined that many adults in receipt of day service supports would be unable to attend day services if transport was not provided.

People supported by NAS said that transport links to day services were not immediately reinstated or were limited as a result of the Covid restrictions, prolonging delays for people accessing day services.

For other people who did resume day services, transport provided by service providers was limited due to social distancing and infection control guidelines. Many people accessing day services reported being reliant on family members to transport them to and from day services. This was not possible for many families in circumstances where they did not have access to a vehicle or where they had employment commitments. Taking public transport was also not possible for many people. In some cases, independent access to the community and day services was curtailed due to Covid-19 guidelines.

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[20] 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**

NAS highlighted to service providers the issues being faced by people with disabilities, stressing that these measures limited the independence and freedoms of some people, affecting their confidence and mental health as they felt trapped and were unable to meet family and friends.

The HSE provided additional funding for transport to enable more people to attend services each day.

Transitions from Congregated Settings

> **“I can’t thank you enough for all of your work on behalf of my son. You have made such a difference to all of our lives.”**
>
> A person whose son was supported by NAS to move to a new residential service during the Covid pandemic.

In Ireland, approximately 2,000 people live in congregated settings. These are institutions or residential campuses where ten or more people share accommodation[21]. People who live in congregated settings have been disproportionately impacted due to Covid-19. The pre-existing quality of life issues they are faced with have been further compounded[22] and they are at higher risk of contracting the virus compared to those who are living in residential services in the community.

The HSE’s Time to Move on from Congregated Settings – A Strategy for Community Inclusion Policy[23] provides a model of support for people with disabilities to move from congregated settings to new homes in the community. Transition planning was underway for many people living in congregated settings to make this move prior to the Covid-19 pandemic.

When the pandemic began, concerns were raised in relation to infection control measures in some congregated settings. 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.

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[21] Disability services – preparedness and ongoing response to COVID-19. Department of Health and HSE (with input from HIQA). **file:///C:/Users/Lisa%20Walsh/Downloads/120324_03288a70-bf9e-4312-919c-b3a24b6adc82%20(3).pdf** Pg. 3

[22] Annual overview report on the inspection and regulation of disability services in 2019 **https://www.hiqa.ie/sites/default/files/2020-09/HIQA-Disability-Services-2019-overview-report.pdf**

[23] 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**

As a result, some people in congregated settings benefitted from accelerated decision-making to transfer them to more suitable and appropriate accommodation. While their moves were fast tracked, NAS ensured that the quality of transition planning by service providers in preparation for the moves was of a high standard and adhered to best practice.

NAS supported people in congregated settings to express their will and preference to service providers in respect of their living arrangements. NAS ensured that these wishes were taken into consideration in all decisions regarding their transition.

Advocates also liaised with the transition co-ordinators with responsibility for the moves and reviewed each person's transition plan to be certain that it met the needs and wants of the person. By reviewing the transition plans, Advocates ensured that service providers put all necessary supports in place for people before any move took place. People gained confidence in the transition process while working with NAS as they knew that every effort had been made to make their move a success.

Unfortunately, for some people living in Congregated Settings the transition process has been delayed due to the Covid-19 pandemic. NAS has continued to support these residents to have their voice heard during this period.

Advocates have contacted the transition co-ordinators and sought clarity on the issues causing the delays. NAS intervention has resulted in a clear line of communication between service providers and the person, with the person being kept fully informed in developments in their transition plans as and when they occur.

NAS has continued to highlight to service providers the importance of progressing moves in a timely manner so that people's human right to live in the community in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities can be realised.

Respite

Respite offers people with disabilities the opportunity to take a break from their home environment which can reduce stress for them and their carers. It also provides a social outlet for people to meet with others and to avail of community activities.

There has been nationwide disruption to residential respite services during the Covid-19 pandemic. While some services operated on reduced capacity, many respite services closed completely leaving people with disabilities without a much-needed service. The disruption to respite services during the pandemic 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.

By December 2020, residential respite services were generally providing respite at 40-60% occupancy levels. The reduction in capacity was due to necessary precautions for physical distancing and infection control[24].

NAS has encouraged service providers to be innovative in their service provision for people in the absence of full respite services. This has resulted in positive outcomes for people NAS have supported. In several cases, NAS became involved when people were told there was no respite service available during Covid-19. Following negotiations between NAS and service providers, individuals were offered the opportunity to avail of respite in residential placements which have been vacated as a result of the pandemic.

NAS played a crucial role in helping people to access much needed respite services in these cases. Access to respite has greatly improved people's quality of life and given them and indeed their families and carers a much-needed break during the Covid-19 pandemic. Respite services also provide an important link to supports and multi-disciplinary teams for people who are living at home.

NAS has also continued to advocate for the full restoration of respite services for people with disabilities.

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[24] Disability services – preparedness and ongoing response to COVID-19. Department of Health and HSE (with input from HIQA). **file:///C:/Users/Lisa%20Walsh/Downloads/120324_03288a70-bf9e-4312-919c-b3a24b6adc82%20(2).pdf** Pg. 14

Safeguarding

> ***"Thank you again, you have been a phenomenal support to the person and indeed to our team. You provided us with so much knowledge."***
>
> A staff member in a residential service who was supported by a NAS Advocate to provide information to a person with a disability about their financial and legal entitlements.

Supporting people with disabilities who are involved with safeguarding concerns is work NAS Advocates are involved with on an ongoing basis. Safeguarding involves the protection of a person's health well-being and human rights. It ensures that the person is enabled to live a life that is free from harm, abuse and neglect[25].

People contacting NAS in relation to safeguarding concerns made up 2% of the overall issues impacted by the Covid-19 pandemic. Most of these issues were reported when level 5 restrictions were in place, with visiting restrictions and service closures. Advocates apply the NAS Disclosures, Observations and Suspicions of Abuse policy, which reflects the HSE's Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures[26], when supporting a person involved with a safeguarding concern.

The most significant safeguarding issues for people living in residential services related to financial concerns. NAS was contacted by a few individuals and service providers during the pandemic about irregularities and issues around transparency in relation to accessing the person's money.

Some families had removed their family member from their residential service, moving them to their own homes to keep them safe from contracting Covid-19. In some instances, it was apparent to NAS that financial irregularities were occurring. The rights of people with disabilities to access their own money was not being fulfilled. There were also concerns that health and social care services were unable to access homes to check whether a person was being adequately supported.

People who communicated differently who faced safeguarding issues were also adversely affected further by the pandemic as their Advocate often could not meet with them face-to-face and could not spend time with them to observe and understand their will and preference fully.

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[25] Safeguarding Guidance: Prevention and creating a safeguarding culture. National Safeguarding Office. **https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/creating%20a%20safeguarding%20culture.pdf Pg.39**

[26] Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures **https://www.hse.ie/eng/services/publications/corporate/personsatriskofabuse.pdf**

When Advocates were not able to meet people face-to-face, alternative methods of communication had to be utilised, such as phone calls, video calls, emailing and text messaging. These options were effective for some people, but for others, such as those people who communicate differently, these options proved challenging. To continue with the provision of advocacy for some people, Advocates had to rely on the support of the service staff to aid with continued communication.

Despite these communications challenges, NAS worked to ensure the financial rights and safety of people with disabilities in residential services was upheld. They worked with the person to ensure their will and preference were carried out. They also communicated with residential services, providing them with information on protocols and guidance documents available. Advocates further supported people's decision making by providing information about next of kin and the fact that there is 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.

Advocates supported people to contact banks to access their funds and to highlight the person's right to access their own money. They liaised on behalf of the person with all relevant parties involved such as safeguarding social workers, the Gardaí, banks, solicitors, day services, residential services, and family members. Advocates ensured that the person was kept fully informed at all times and at the centre of all decisions being made and actions being taken.

In some instances, the closure of day services led to safeguarding concerns at home for some people with disabilities. The link to day services, outreach and employment support services acted as an additional safe link of support for people outside the home. In some cases this link was lost during the pandemic. In one instance, a person living in the community was supported by NAS to relocate to alternative accommodation due to safeguarding concerns at home.

Unfortunately, due to the pandemic, community-based safeguarding social work teams were diverted into other duties, such as contact tracing teams, so their resources were stretched, raising concerns about the possibility of limited checks and follow up on people living in the community with no day services available to them.

In supporting these people, NAS continued to make referrals to the safeguarding teams and helped people to be involved with their safeguarding plan so they could be part of decisions made. NAS escalated concerns within services to the designated liaison person to ensure concerns were reported and advocated for the persons need for extra support like online or outreach support. Advocates also did extra check ins with people to help their mental health and explore alternative supports for the person. Where appropriate, NAS escalated safeguarding concerns to the principal safeguarding social worker in CHO areas.

John’s Story: Support to Access My Money

My name is John, I am in my 20’s and I have an autism spectrum disorder. I live in residential accommodation.

I had inherited a large sum of money several years ago, but it was in a family member’s possession. Staff tried to support to get my money and put it in a safe place, but I could not get my money back.

With my agreement, my Advocate sent several letters to my family member requesting that they transfer my money into my bank account.

When the Covid-19 restrictions took place, my Advocate was unable to meet with me in person, so we spoke over the phone instead, with support from the staff at my home. When the restrictions eased out of level 5, as an essential service provider my Advocate was able to continue to meet with me to work on my case.

Even after my Advocate sent the letters, I still didn’t receive my money. My Advocate explained that I could complete a Safeguarding Report Form in relation to my money during one of our phone calls.

The Advocate discussed financial abuse with me and explained that I had the right to access my own money at all times. They ensured that I fully understood the situation and made sure I had the opportunity to voice any concerns or questions I had.

With the support of my Advocate, I agreed to complete the Safeguarding Report Form which was then sent to the HSE’s Safeguarding Team. Following discussion with an HSE Safeguarding Officer, I agreed that the issue should be reported to the Gardai. My Advocate liaised with the Safeguarding Officer and the Gardaí on my behalf and provided me with an update after every conversation.

After discussing my options with my Advocate, staff in the residential service and other family members, a plan was put in place to allow for my money to be forwarded to me. This plan was completed, and I received my inheritance in full.

Without the support of NAS, I don’t think I would have been able to get my inheritance money. My Advocate has been such a great help and is continuing to support me with other advocacy issues.

Conclusions and Recommendations

NAS provides a crucial means of support for people with disabilities. The Service upholds the person's rights, ensures fair and equal treatment and access to services. It makes certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.

In normal times, this support is of huge importance, given that people with disabilities already face discrimination and marginalisation in many aspects of their lives, including poorer access to health and education, and difficulties in accessing justice and decision making.

The Covid-19 pandemic and the subsequent restrictions in residential and day services have had an even greater impact on the lives of people with disabilities.

People have been significantly impacted by the public health measures taken to reduce infection which restricted their access to supports, non-Covid-19 health services (such as physio and public health nurses) and their community.

For many people living in residential services, communication with their families, loved ones and health services has been severely restricted. In some cases, people's right to make decisions about situations affecting their own health and well-being has been significantly curtailed, while they have also faced an increased risk of infection and a higher risk of transmitting the virus.

When combined with reductions in other public services, including transport, education, housing supports and limited access to technology, this has led to a major increase in mental health concerns for people with disabilities.

Despite the improving situation in relation to the Covid virus, with most residents fully vaccinated and the number of cases being well managed by the health services, visiting restrictions remain in place in many residential services, while several day services are still not fully operational.

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.

NAS has worked to ensure that people with disabilities, particularly those who communicate differently, have had their voice heard and have been able to make their own decisions about issues affecting their lives.

This advocacy support has been even more important during a period when it has been almost impossible to meet face-to-face with people living in residential services. The risk of their views being neglected or abused has increased considerably when it comes to making decisions about key issues affecting their lives, such as their finances or whether they wish to receive a vaccination.

In response to these challenges, NAS has adapted and improvised its services to ensure it has been able to continue to deliver high-quality advocacy to people with disabilities. Almost overnight, its Service moved from office to home working, while it has also embraced innovative new ways of working such as phone calls, video calls, emailing and text messaging.

By utilising these technologies, Advocates have been able to increase contact with the people they support, helping them to access key public service information, organising catch ups with family members, connecting them with health professionals, and negotiating with residential services to provide extra support and resources for people with disabilities.

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.

NAS has also 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. The Service 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 has continued to advocate for the full restoration of respite services for people with disabilities, stressing the importance for Service providers to be innovative in their service provision for people in the absence of full respite services.

NAS has made referrals to the HSE 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.

As a result of the advocacy work carried out by NAS in the period March 2020 – March 2021, the organisation has developed several recommendations which should be considered in any future strategies and policies designed to support people with disabilities in Ireland.

First and foremost, 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.

To achieve this, 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 also imperative that service providers adequately support people around decision making, especially those who communicate differently. When supporting decision making it should be noted that 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.

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 to do their utmost to support people to maintain contact and links with family and loved ones, utilising technology. 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 Services[27].

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[27] 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**

As outlined in the 'Value for Money and Policy Review of Disability Services in Ireland'[28] and in 'New Directions: Interim Standards for New Directions, Services and Supports for Adults with Disabilities'[29], 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 Services'.

In conclusion, by presenting these recommendations, NAS is seeking to ensure that the voice, will and preference and human rights of the person with a disability are always recognised, particularly during periods of crisis.

Based on our findings, advocacy support, specifically the National Advocacy Service for People with Disabilities, has a crucial role in achieving this goal. We will continue to work to ensure that the concerns and wishes of people with disabilities living in residential services and attending day services are upheld.

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[28] 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**

[29] 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**