



**NATIONAL ADVOCACY
SERVICE**

**FOR PEOPLE WITH
DISABILITIES**



**Patient
Advocacy
Service**

INFORMATION | SUPPORT | EMPOWERMENT

Advocacy Matters:

Advocating for People Regarding
Health and Social Care during the
Covid-19 Pandemic



Executive Summary
December 2021

Executive Summary

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

It is the third of four reports which outline the observations and experiences of our Advocates when providing independent advocacy to people with disabilities and people who are attending acute public hospitals, in relation to 'Health' and 'Social Care' during the Covid-19 pandemic in Ireland, particularly during the period from March 2020 - March 2021.

This report, theme three, explains the issues people faced in relation to 'health' and 'social care' during this traumatic period. It focuses on our work, 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.

The term Health refers to the range of health services provided in Ireland, such as public acute hospitals, primary health care, residential settings and nursing homes, and the right of the people using these services to receive safe and effective care and good quality support, and to be treated with dignity and respect. The right to health is outlined in the United Nations Convention on the Rights of People with Disabilities (UNCRPD), article 25, as the '...right of everyone to the enjoyment of the highest attainable standard of physical and mental health.'¹ All health services must be available and accessible to everyone including people with disabilities².

The term Social Care refers to support provided to a person in the community or in day or residential settings. It is designed to enable the person to live, adapt and cope with elements of their day to day lives that they cannot easily address themselves. Social care is a way to directly support people to live fulfilling lives. It helps people who may have a disability, are ill or elderly to promote and maintain their independence and choices to live how they want to. With social care people can be supported to remain living at home or in the community.

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/article-25-health.html>

2 Disability Act 2005 <http://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html>

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.

The Covid-19 pandemic and the subsequent impact on health and social care services have had an even greater impact on the lives of the people supported by the Services.

Based on the extensive work and findings of NAS and the Patient Advocacy Service over the past year of the pandemic, it is clear that independent advocacy is a crucial part of supporting people with disabilities to ensure the person's voice is heard and supporting people who have had a negative experience regarding their care in a HSE-funded public acute hospital and wish to make a formal complaint to the HSE.

Given the ever-changing situation with Covid-19, it is crucial that health and social care services reflect on, review, and continue to improve their service delivery, adapting to the evolving situations arising from the ongoing pandemic. Health and social care services should also consider the experiences of people supported by NAS and the Patient Advocacy Service, along with the learnings of our Advocates, to improve service delivery. It is crucial that people are supported to have their voice, will and preference heard and are included in decisions that impact on their lives.



Our Response to Covid's Impact on Health & Social Care

Findings

Advocates from NAS and the Patient Advocacy Service have ensured people understand their rights and received fair and equal treatment by services. They have helped to improve communications between health professionals and the people in their care. They have also helped people to have their voice heard, progressing complaints and decision making in line with each person's own wishes.

NAS and the Patient Advocacy Service have provided advocacy support for people facing a range of issues in health and social care settings, such as:

- Safe and effective support and care
- Poor communication with family members
- Problems with infection control
- Delayed or inappropriate discharge
- Difficulty accessing medical records
- Medical procedures being delayed or cancelled
- Visiting restrictions and restrictions on people's movements which impacted their will and preference
- A reduction in services available to people with disabilities
- Home care packages and personal care service being reduced, curtailed or at times stopped
- Difficulty accessing virtual GP appointments for people with disabilities



Covid's Impact on Health and Social Care Services

Findings

When the Covid-19 pandemic hit Ireland our health and social care service providers had to adapt how they operated to continue service delivery while keeping the people they care for and staff as safe as possible.

We acknowledge the significant impact Covid-19 has had on healthcare services and frontline staff in Ireland. Many have been left emotionally distressed and frustrated. Concerns of “Psychological distress, exhaustion and burnout” were highlighted in a report ‘The impact of the COVID-19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service capacity and delivery: A plan for healthcare and population health recovery’³, which also highlighted the staff supports available and the need to look after staff so they can continue to care for the people who need it.



³ The impact of the COVID-19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service capacity and delivery: A plan for healthcare and population health recovery <https://www.hse.ie/eng/about/who/qid/covid-19-qi-learning/qi-resources-to-support-learning-from-covid19/covid-19-pandemic-impact-paper-2021.pdf>

Safe, Effective Care & Support

Findings

During the Covid-19 pandemic, both NAS and the Patient Advocacy Service were contacted by people who expressed concerns about the safety and effectiveness of their care.

People contacting the Services highlighted a range of issues around discharges, infection control, access to diagnostic tests, access to post-surgery therapies, access to allied health professional therapies and poor communication with families.

Advocates have supported people who raised concerns around the level of infection control measures in place for people who have been moved between wards during their time in hospital. Some people who did not have Covid-19 have found themselves placed in wards where there have been confirmed Covid cases, or where there have been other people awaiting Covid test results.

The Patient Advocacy Service has supported 24 family members whose loved ones contracted Covid-19 while they were in hospital. Four of these people have passed away after contracting the virus, with families not being able to be with their loved one at the time of their death.

The Patient Advocacy Service has also supported people who experienced difficulty in accessing their personal or a family members' healthcare records. The Service has supported people and their family members to read through records once received. This has helped people who are considering making a complaint to collate questions and concerns.



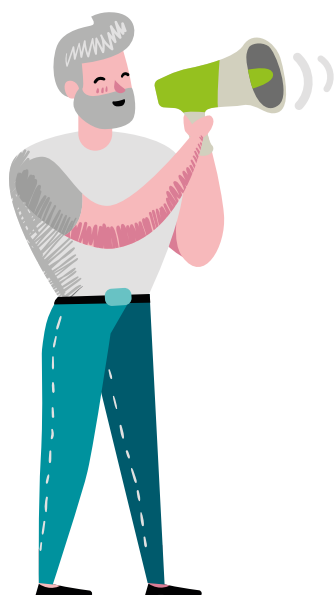
Delayed or Inappropriate Discharge from Acute Hospitals

Findings

At the beginning of the pandemic, people were moved quickly from hospitals to ensure acute hospital capacity for Covid affected patients. This has resulted in people moving to placements that they did not want to live in as they had no alternative options. People under the age of 65 with disabilities were at times placed in nursing homes.

People have also contacted the Patient Advocacy Service about being discharged before they felt they were ready to go home. Of the cases impacted by Covid-19, in 9% of these people felt they were discharged without sufficient examination.

Other concerns have been brought to the Patient Advocacy Service about people presenting for psychiatric services to the hospital and being discharged alone without communicating with their family.



Medical Procedures

Findings

Previously experienced delays for medical procedures before the pandemic were exacerbated throughout the Covid-19 crisis. This affected the health of many people. At the start of the pandemic, procedures that were categorised as routine and non-urgent were reviewed by consultants and postponed or cancelled.

Plans were put in place for urgent procedures to continue to take place, but this did not always occur due to the changing situation in hospitals during the pandemic. According to data compiled by the Patient Advocacy Service on cases impacted by Covid-19, delays in medical procedures was one of the top 10 issues experienced.

There have been delays in scans and x-rays to explore the causes of pain, and cancellations and delays for non-urgent procedures such as hip and knee replacements. For many people, this has impacted on their quality of life.

Communications and Visiting

Findings

Almost 40% of people who contacted the Patient Advocacy Service during the Covid-19 pandemic had difficulty communicating with healthcare units in hospitals. Families said they were calling the hospital repeatedly to get an update on their loved one; however, calls were rarely answered, or they would be placed on hold and the calls would be cut off. This caused acute distress for the person in hospital and their family as they were also unable to visit their loved ones due to the pandemic. In some cases, families were not aware how gravely ill the person was, and they were shocked when they were told the person was dying.

Where an immediate need was identified, the Patient Advocacy Service provided the contact details for Patient Advice and Liaison Services (PALS) in hospitals. Where there were safety issues, Advocates provided contact details for the Quality and Safety Departments in hospitals. Many families did not wish to make a complaint but were seeking information and reassurance regarding the care of their loved one.

The Service also advised family members to seek information from the Ward Manager in a hospital and seek a virtual meeting with the teams involved in their loved one's care to obtain clear information on how they were doing and what the plan was going forward. This often resulted in a positive outcome for all involved.

People contacting the Patient Advocacy Service have said they were in a vulnerable position while attending appointments or staying in hospital because they were alone and did not have their natural supports with them when they are at their most medically vulnerable. Some people had issues finding the department or even finding the bathroom due to a disability, while others needed support eating as an inpatient and found that the nurses did not have time to sit with them. According to the Service's statistics, 82% of the cases noted to be due to the impact of Covid-19 were in an acute setting.

The Patient Advocacy Service has received several calls about family members not being able to visit their loved ones in palliative care. In some cases, people have passed away without seeing or being with their families. Where hospitals did not offer visits, Advocates have provided people with information around visiting rights on compassionate grounds.



Dignity & Respect in Person-Centred Care

Findings

Throughout the Covid-19 pandemic, NAS and the Patient Advocacy Service have experienced many situations and cases where a person's dignity and respect has been negatively impacted, in many cases unintentionally, and there has been a need for advocacy support to assist the person to effect positive change.

Some people have experienced restrictions on their movements that were above and beyond those required by public health guidelines impacting on people's dignity and not in line with a person-centred approach to service provision. NAS highlighted this issue and the practice was stopped with immediate effect. Without advocacy intervention, this practice is likely to have continued.

In the Patient Advocacy Service, around 1 in 5 (20%) of those people who contacted the Service during the pandemic in relation to issues impacted by Covid-19 said their anxieties and worries were not addressed by hospital staff. This caused acute distress for several people as they navigated their way through the healthcare system.

Isolation and Mental Health

Findings

NAS statistics show that mental health has been the biggest single emerging issue 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 13.96% of the emerging issues dealt with by NAS.

The reduction in services available to people with disabilities has had a serious impact on the mental health of people with disabilities, their families and carers. The associated fear and anxiety of contracting the virus has been a continuous burden for people with disabilities living in the community.

NAS spoke to many people with disabilities who were isolated from their natural supports, including their families and communities. They were told to limit their contacts, which in many cases meant they did not leave their home, or go to the shops, were very cautious about going for walks and did not attend health and social care settings.

Pre-existing mental health supports, and services were also seriously disrupted as a result of the Covid-19 pandemic. This has caused considerable distress for people with mental health difficulties and those who have required new supports during the pandemic.

During the pandemic, the range of supports provided by NAS and the Patient Advocacy Service has been vast. Advocates supported people who could not safely access their community to link with community supports such as the Covid-19 Helpline, the Primary Care team, Local Authority, local Garda unit, or other community groups to ensure they had access to fuel, medical supplies and food. Our Services have also signposted people to other organisations that provide appropriate supports.

In addition, Advocates provided the important service of “checking in” and taking time to listen and talk with the people we support who we were aware were experiencing social isolation and mental health issues during this time.

At the outset of the pandemic, NAS noted that HSE Social Workers in some regions were redeployed to other Covid response teams within the HSE, meaning social work supports were only available for emergency cases for periods of time. This gap in social care supports added to the anxiety of those who were isolated during this period.

The Patient Advocacy Service supported several people who felt isolated while in hospital during the pandemic. They could not receive the emotional and social support of their family or visitors. Some spoke of their fear while in hospital as they could only see and communicate with staff who were in full Personal Protective Equipment (PPE).

In addition, the family and friends of the person also felt isolated and frightened as they could not see them to check their condition and general welfare. Many expressed feeling guilty as they could not visit or advocate for their loved one.



Social Care

Home Care - Findings

Home care packages were affected during the Covid-19 pandemic. This was due to several factors including service providers being initially cautious, redeployment of staff to other frontline services, staff shortages and people cancelling services due to their own concerns of Covid-19.

Home care packages were either being reduced, curtailed or at times stopped. This had a greater impact upon people with disabilities living in the community during the pandemic than on people without disabilities. NAS worked to ensure that hours were re-instated or not reduced from the pre-Covid period. There were also cases where people with disabilities decided to cease receiving home care support as they feared contracting the virus.

Many families also decided against health care workers coming into their homes due to infection risk, which made it difficult for health services to determine if a person was being properly cared for and supported. In such cases, NAS found that some safeguarding concerns arose as the person was home for long periods of time without any health or social care support.

The provision and use of appropriate PPE by those visiting homes was also raised with NAS.

The Patient Advocacy Service was also contacted about issues in relation to home care packages and not having enough staff available to cover the hours required. Sometimes people were discharged home from hospital and then informed by the care service provider that they did not have staff to provide the supports agreed. This left people reliant on family to try to care for them.



Personal Care - Findings

In several locations across Ireland, personal assistant service providers took the decision to pause services or reduce the hours provided during the Covid-19 pandemic, which led to isolation for a considerable number of people. In addition, if a staff member was forced to self-isolate due to infection there was often no one to replace them.

NAS made representations to service providers and the HSE to seek full provision of services for the people we support.

The issue of staffing and the resourcing of staff to support people living in the community has not yet been fully resolved. The re-distribution of staff into acute and residential services took resources away from both home care and personal assistance services.

Primary Care - Findings

The Covid-19 pandemic has seen many people with disabilities experience barriers and delays in accessing vital primary care services. NAS and the Patient Advocacy Service have played an important role in ensuring that people's voices have been heard during this time. Our Services have highlighted the difficulties faced by people with disabilities due to disruption to primary care services and have advocated for the prompt restoration of services.

NAS has found that some people with disabilities have had difficulty accessing GP appointments during the pandemic. Some people reported that they had been refused a GP appointment unless they wore a face mask despite having an exemption from wearing face coverings due to an illness or disability, or because it would cause severe distress.

In addition, as many GPs moved to remote consultations some people found that virtual appointments did not meet their needs.

People have reported delays in accessing Public Health Nursing in relation to speech and language, physiotherapy and occupational therapy supports. Some professionals in these disciplines were seconded to Covid response services, such as contact tracing, within the HSE at this time causing disruptions and delays to services.

In particular, the delay in physiotherapy appointments raised concerns relating to people's mobility, especially those who were confined to their homes and were reliant on a physiotherapist visiting them.

NAS has also advocated on behalf of people who have suffered discomfort in ill-fitting wheelchairs due to delays in accessing occupational therapy services. People have also been discharged from hospital without access to occupational therapy services.

The Patient Advocacy Service has also advocated on behalf of people being discharged from acute settings with Covid-19 who were being sent home into the care of old and at-risk family members without any care packages being offered or put in place.

It should be noted that most primary care services have been reinstated at this point, although waiting times have grown due to the disruption to services during the Covid-10 pandemic.



Key Recommendations in this Report

- ▶ 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.
- ▶ The experiences of people supported by NAS and the Patient Advocacy Service along with the learnings of our Advocates should be used to improve service delivery. It is crucial that people are supported to have their voice, will and preference heard and are included in decisions that impact on their lives.
- ▶ Providers and funders of Mental Health Services should ensure that these services are urgently and fully restored and focused on the needs of the person. Further investment is also required for Mental Health Services and supports.
- ▶ Health and social care providers should put measures in place to alleviate the effects of isolation on people who do not have natural supports and may not be supported by disability services. Measures such as remote counselling and outreach services should be explored.
- ▶ Improvements to be made in acute hospitals to ensure their environment, processes and systems work effectively to ensure patient safety and build on the safe and effective care already being provided.



- ▶ In line with the HSE's 'Your Service Your Say'⁴ complaints process and the 'Incident Management Framework'⁵ for patient safety incidents, learning should be drawn from the experiences and feedback from people using the health services. Recommendations should be implemented to improve service delivery.
- ▶ Home care provider services should have business continuity plans in place to ensure continuity of services during times of crisis.
- ▶ Home support services must be regulated under a set of national standards that will standardise service delivery and improve the supports provided to people living in the community.
- ▶ People who are inappropriately placed in acute hospitals on a long-term basis need to be supported to move to more appropriate settings in line with their will and preference.
- ▶ People in need of these services should be offered advocacy support from an independent advocacy service if they wish.
- ▶ Hospitals and home care providers must work together to ensure people have adequate supports in place when being discharged back into the community.
- ▶ Primary Care is essential for people with disabilities to maintain good health and manage medical conditions and illnesses. Any delays barriers to accessing these services need to be addressed as a priority.



4 Your Service Your Say

<https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/ysys2017.pdf>

5 Incident Management Framework <https://www.hse.ie/eng/about/qavd/incident-management/hse-2020-incident-management-framework-guidance.pdf>

Key Conclusions in the Report

- ▶ The Patient Advocacy Services offers an important means of support for people who have had a negative experience regarding their care in a HSE-funded public acute hospital or a HSE-operated nursing home and wish to make a formal complaint to the HSE.
- ▶ NAS and the Patient Advocacy Service upheld people's rights, ensuring their voices are heard and they have fair and equal treatment and access to services. They ensured that decisions were taken with due consideration for a person's will and preference.
- ▶ The Covid-19 pandemic and the subsequent impact on health and social care services have had an even greater impact on the lives of the people supported by NAS and the Patient Advocacy Service.
- ▶ NAS and the Patient Advocacy Service have provided advocacy support for people facing a range of complex, difficult and stressful issues in healthcare settings, including concerns about poor communication with family members, problems with infection control, delayed or inappropriate discharge, difficulty accessing medical records, medical procedures delayed or cancelled. All of which has had a considerable impact on the health and wellbeing of many people.
- ▶ NAS and the Patient Advocacy Service have also supported several people whose dignity and respect has been negatively impacted by their experiences in healthcare settings. This has included restrictions on the movements of people within their own homes and failures to recognise the will and preference of people in public hospitals.
- ▶ People using NAS and the Patient Advocacy Service have spoken about their mental health and how this has been affected, highlighting issues such as the reduction in services available to people with disabilities, the fear and anxiety of contracting the virus, and isolation from family members and communities.



- ▶ Social care services such as, home care packages were reduced, curtailed or at times stopped. Many people were reassessed to determine whether they required the same number of hours provided before Covid-19. Some people declined these services themselves for fear of contracting the virus.
- ▶ The provision and use of appropriate personal, protective equipment (PPE), such as face masks and gloves, by those visiting homes was also an issue, with some people telling NAS they even had to dispose of it themselves.
- ▶ Personal care providers decided to pause services or reduce the hours provided during the Covid-19 pandemic.
- ▶ For some people with disabilities there was a difficulty with accessing GP appointments, as many GPs moved to remote consultations and some people found that virtual appointments did not meet their needs.



