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

December 2021

Contents

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 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 support of good quality, 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 disabilities[2].

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.

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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/article-25-health.html**

[2] Disability Act 2005 **http://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html**

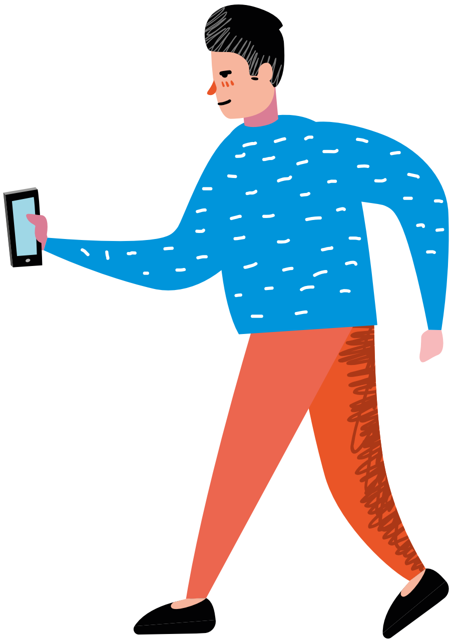
Established in 2011, the National Advocacy Service for People with Disabilities (NAS) is an independent, free and confidential service, funded and supported by the Citizens Information Board. NAS provides representative advocacy to people with disabilities across Ireland, to ensure that their will and preferences are sought and 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 public acute hospital or HSE operated nursing home and in the aftermath of a patient safety incident.

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 UNCRPD.

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 supported by NAS and the Patient Advocacy Service.



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 the 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'[3] complaints process and the 'Incident Management Framework'[4] 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.

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[3] Your Service Your Say **https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/ysys2017.pdf**

[4] Incident Management Framework **https://www.hse.ie/eng/about/qavd/incident-management/hse-2020-incident-management-framework-guidance.pdf**

- 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.

Key Conclusions in this 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 been delayed or cancelled. All of which has had a considerable impact on the health and well-being 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.

Impact of Covid-19 on our Services

Before focusing on the issues Covid-19 has caused for people in relation to Health and Social Care, 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 allowed our services to continue to provide advocacy support.

This has ensured that NAS has 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.

We were often unable to meet the people we support face-to-face. This was 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. The model of empowerment advocacy has allowed for the Patient Advocacy Service to provide the same level of support to the users of its service without interruption. Meeting people face-to-face was not possible in level 5 restrictions, this often also meant that meetings were not taking place in acute hospitals either. The use of technology such a Zoom and conference calls as alternative methods of communication worked well for most people supported by the Patient Advocacy Service and for some people has led to increased accessibility with their Advocate.

The Service liaised with hospitals at a local level to keep up to date with changes that were happening in a rapidly changing environment at the height of the crisis to have the most up to date information to provide to people contacting them. It also 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.

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

“Thank you so much for all that information, you made my issue so much easier to understand”.

Joe, who used the Patient Advocacy Service in 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 and the Patient Advocacy Service 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.

The Services’ empowerment and representative advocacy involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Independent, empowerment and 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, nursing and social care supports are a very diverse group and some within this group face even greater marginalisation. This includes those experiencing mental health issues, those from different migrant or ethnic groups, and those who communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication).

During the Covid-19 pandemic, these issues were further exacerbated for those people supported by our services when it came to issues surrounding Health and Social Care.

In terms of health care, NAS and the Patient Advocacy Service have provided advocacy support for people facing a range of complex, difficult and stressful issues, including concerns about the safety and effectiveness of their support and care. People contacting both Services have cited several issues in relation to care in public acute hospitals such as poor communication with family members, problems with infection control, delayed or inappropriate discharge and difficulty accessing medical records.

Medical procedures have also been delayed or cancelled. This has had a considerable impact on the health and well-being of many people who have contacted both NAS and the Patient Advocacy Service. Many people have spoken about the issues they have faced when it came to communicating and visiting with their loved ones in public hospitals.

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 in residential settings and nursing homes and failures to recognise the will and preference of people in public hospitals.

In general, the issues related to mental health have affected people supported by both Services throughout the pandemic. People have highlighted 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.

Regarding social care, home care packages for people with disabilities, designed to facilitate them to live as independently as possible, were badly affected during the pandemic. In the early months of the pandemic, 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.

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.

When it came to personal care, NAS received several calls from people whose personal assistant service providers paused services or reduced the hours provided during the Covid-19 pandemic. Personal assistant service provision is of vital importance as it provides person centred support with matters such as personal care support for people, for example to get out of bed, dressing and undressing and taking a shower, household tasks, assistance in college or at the workplace. Article 19 of the UNCRPD[5] outlines the rights of people with disabilities to be supported to live in the community with equal opportunities to live a fulfilling life. The reduction of this service provision had a negative impact and led to isolation for a considerable number of people.

Additionally, there were issues around primary care supports such as home support service, which provides personal care support for people, for example to get out of bed, dressing and undressing and taking a shower. 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. Others reported that they had been refused a GP appointment unless they wore a face mask.

Despite the many issues related to health and social care that affected people supported by NAS and the Patient Advocacy Service since the Covid-19 pandemic began, both Services have worked to provide people with advocacy support and guidance.

Advocates from both Services have worked to alleviate the loneliness and anxiety felt by many people, they have ensured people understand their rights, they have helped to improve communications between health professional and the people in their care, and they have helped people to have their voice heard, progressing complaints and decision making in line with each person's own wishes.

Throughout the course of the pandemic, Advocates have made a significant difference to the lives of people with disabilities, those who are elderly or attending acute public hospitals.

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[5] Article 19, UNCRPD **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html**

Covid's Impact on Health and Social Care Services

When the Covid-19 pandemic hit Ireland our acute hospitals, healthcare services and frontline working staff were challenged to respond to a rapidly changing and unknown highly contagious infection. 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. Healthcare services redeployed staff to respond effectively, went lengthy periods without leave and often had to isolate from their own families to keep the people they were caring for safe.

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'[6], 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.

Safe, Effective Care & Support

> **"It is great that your service exists to support help like me, particularly during Covid-19 when I felt really anxious"**
>
> Anne, who was supported by NAS during 2020

The National Healthcare Charter 'You and Your Health Service (2012)'[7] is based on principles which underpin high quality, people-centred care. Its goal is to promote respect for the values and dignity of the people who use health services in Ireland.

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[6] 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**

[7] National Healthcare Charter You and Your Health Service (2012) **https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-healthcare-charter/national-healthcare-charter.pdf**

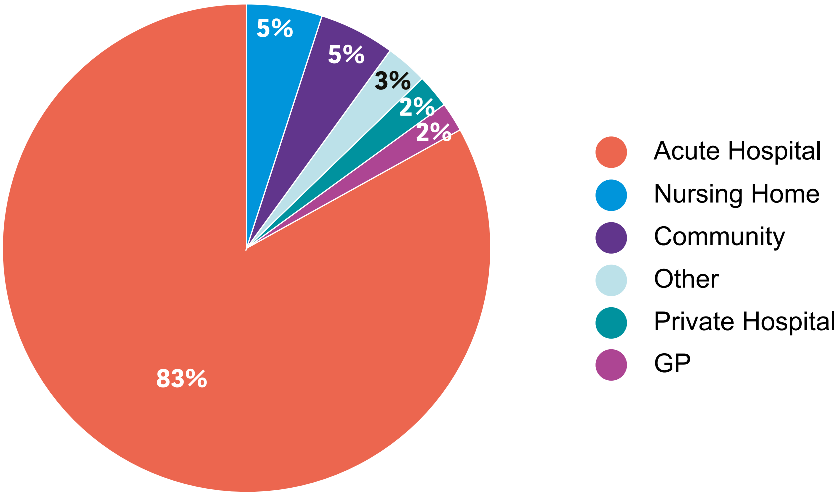
One of the key principles of the Charter is safe and effective care and support which means that a person can expect health services that are provided with professional care, skill and competence, with informed and clinically appropriate care, where all relevant details of a person's health and care plan are appropriately shared between services.

The Health Information and Quality Authority's (HIQA) report 'Standards for Safer Better Healthcare'[8] also places patients at the heart of the care process and supports the need for continuous improvement in the quality and safety of health care.

Despite these commitments, 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.

82% of the calls made to the Patient Advocacy Service from March 2020 - March 2021 regarding the impact of Covid-19 related to an acute hospital setting. Nursing homes and community settings accounted for 5% of each of the calls, while GPs, primary healthcare, private hospitals, home support and others made up for the remainder of the calls.

Patient Advocacy Service - Location of Cases noted due to having been Impacted by Covid-19



People contacting the service 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.

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[8] A Guide to the National Standards for Safer Better Healthcare **https://www.hiqa.ie/sites/default/files/2017-01/Safer-Better-Healthcare-Guide.pdf**

Several of the issues reported to the Patient Advocacy Service surrounded discharge plans from hospitals. The HSE's Integrated Care Guidance[9] addresses discharge and transfer from hospitals, stressing that planning for these actions should begin before or on admission. All relevant details of a person's health and their ongoing needs and supports should be accounted for in a discharge plan so that there is continuity of care and smooth transitions between services which are involved in a person's care.

According to the guidance, service providers should develop a treatment plan within 24 hours of admission and should identify whether a person will have simple or complex needs when they are discharged. This plan should be discussed and agreed with the person and where needed carers and family. Any changes to the treatment plan should be discussed with the person and relevant supports.

Although planned scheduled care, such as elective procedures, was largely put on hold due to the Covid-19 pandemic, unplanned admissions occurred. A number of people contacted the Patient Advocacy Service who felt that their own discharge, or that of family members, was rushed, unsafe and carried out without discussion.

The Service has encouraged and supported people to escalate any concerns they have had about inappropriate discharges, and to request Multi-Disciplinary Team (MTD) meetings bringing together all the hospital staff involved in looking after their care. The Service also gave them information about the HSE discharge planning policy.

The Patient Advocacy Service was also contacted by people with Covid-19 who were being discharged home into the care of at-risk family members without any community or primary care support packages being offered or put in place. Other people who lived alone and who were Covid positive were discharged with no supports such as access to post-surgery therapies like physiotherapy or further diagnostic tests in place.

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[9] Integrated Care Guidance: A practical guide to discharge and transfer from hospital **https://www.hse.ie/eng/about/who/qid/resourcespublications/nationalintegratedcareguidance.pdf**

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. This has been enormously traumatic for families who have expressed feelings of guilt and of inadequacy because their loved one was without their family when they died.

The lack of communication with families whose loved ones contracted Covid-19 while in hospital has been a repeated concern. Some families have explained to the Advocates that they were unaware of a Covid-19 diagnosis. They also had to make it clear to hospital staff that they needed to visit unwell relatives on compassionate grounds and for the sake of their mental health.

At times when family members attempted to contact the hospital ward to ascertain how their loved ones were, they were unable to get through to a ward or to speak to a staff member. Some were promised a return phone call but did not receive one. This caused deep anxiety and frustration for such families.

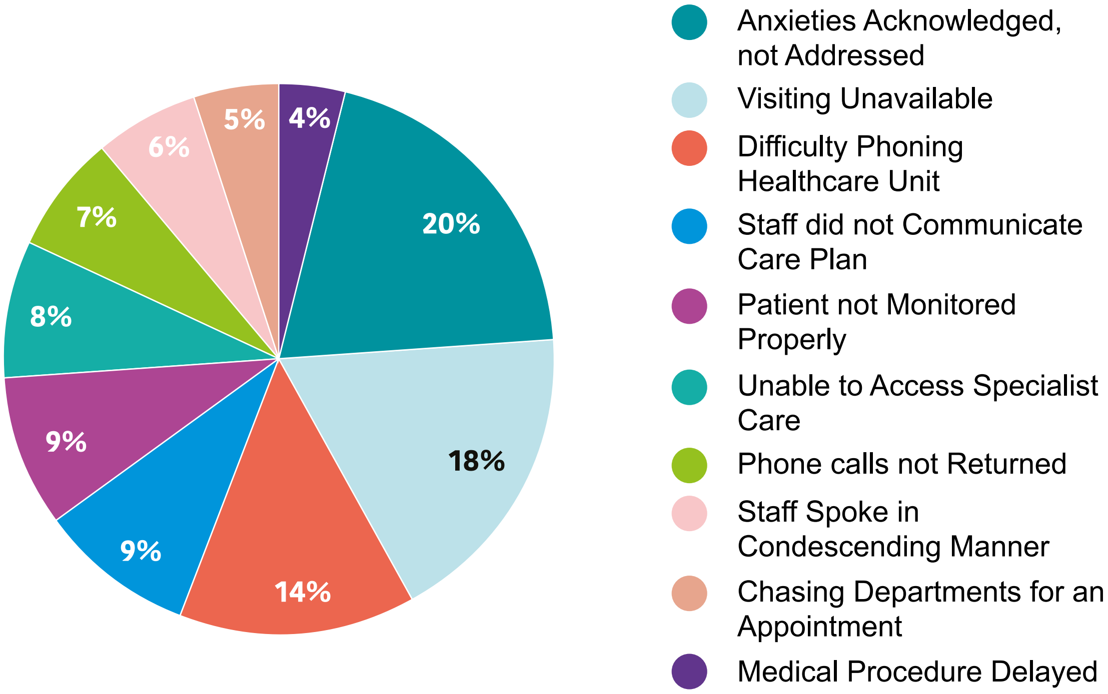
In one example, the Service was contacted by a person whose family member had been admitted for treatment after an illness. The person contracted Covid-19 while in hospital and then sadly died. The family member had concerns about several issues. They were concerned at how their loved one had contracted the virus; they were angry about the lack of communication from staff during their time in hospital and they could not visit or see them. The family wanted to access records and make a complaint, which the Patient Advocacy Service supported them to do.

The Patient Advocacy Service has also supported people who experienced difficulty in accessing their personal or a family members' healthcare records, including their clinical records (medical records, healthcare meetings and discharge plans) and non-clinical records (information on non-clinical meetings or safety issues).

The clinical and non-clinical records of a person give information about the care provided. However, non-clinical records are not filed on a person's hospital chart. Non-clinical records include documents which can be useful in determining safe and effective care. The Patient Advocacy Service has supported many people and their family members to read through clinical and non-clinical records, helping them to understand what they mean and explaining the terminology used. This has helped people who are considering making a complaint to collate questions and concerns.

The most prevalent issues dealt with by the Patient Advocacy Service in relation to cases impacted by Covid-19 are presented below. When recording the complaint issues a person has the Patient Advocacy Service uses the Healthcare Complaints Analysis tool (HCAT)[10]. The HCAT was developed as a framework to gather information on healthcare complaints so this information can be used to improve service delivery. The HCAT captures clinical issues including – quality and safety; management issues including environment and institutional processes; relationship issues, including – listening, communication and respect and patient's rights.

Patient Advocacy Service – Top 10 Issues Experienced Related to Covid-19



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[10] Healthcare Complaints Analysis tool **https://qualitysafety.bmj.com/content/suppl/2016/01/05/bmjqs-2015-004596.DC1/bmjqs-2015-004596supp_new.pdf**

Total	Issue
73	Anxieties Acknowledged, not Addressed
67	Visiting Unavailable
50	Difficulty Phoning Healthcare Unit
32	Staff did not Communicate Care Plan
31	Patient not Monitored Properly
30	Unable to Access Specialist Care
26	Phone calls not Returned
21	Staff Spoke in Condescending Manner
18	Chasing Departments for an Appointment
16	Medical Procedure Delayed

Within the HCAT the complaint issues are broken down into three severity levels, level 1 low severity, level 2 medium severity and level 3 high severity and list the specific types of issues people had in the care received within quality and safety; management issues including environment and institutional processes; relationship issues, including – listening, communication and respect and patient's rights.

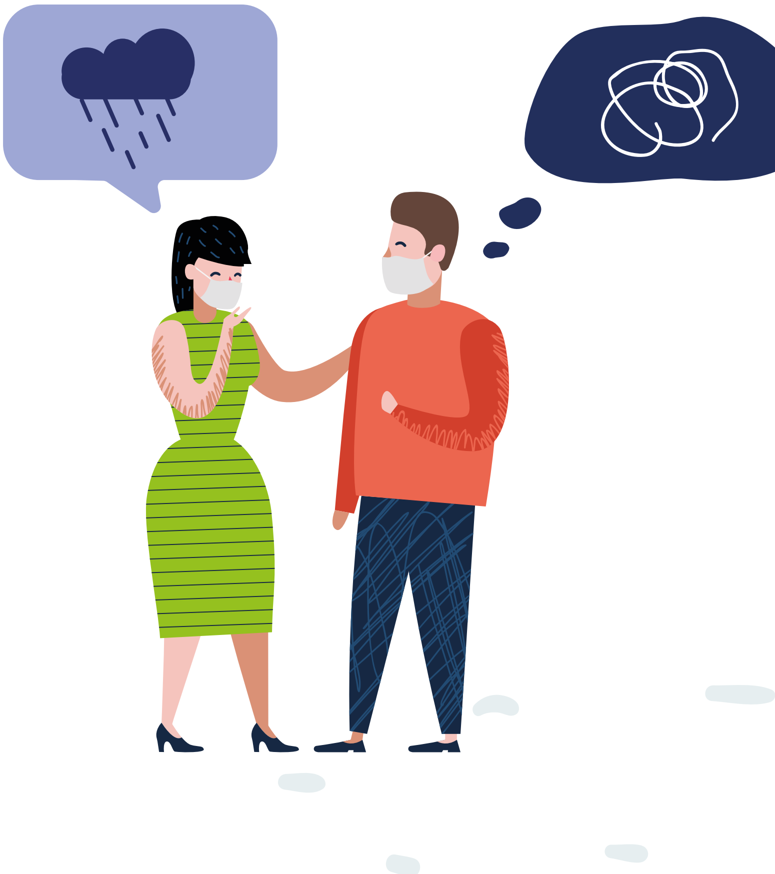
Difficulty accessing a vaccination was another issue highlighted to the Patient Advocacy Service. This resulted in a person's ongoing treatment being cancelled several times. This was having a negative impact on the person's quality of life. The person was told that the cancellations were due to them not having received a vaccination, despite their attempts to do so. The Patient Advocacy Service empowered the person to contact the Risk Management department at the hospital. An Advocate supported them to make a well-structured, formal complaint and an investigation took place. They were satisfied with the response to the complaint and their treatment was scheduled.

NAS has also continued to support people throughout the course of the Covid-19 pandemic, using remote and online supports when in person meetings were not available. NAS escalated concerns and issues arising for people relating to safe effective care and support.

An example of such case work occurred when NAS supported a person who has a disability and long-term health conditions requiring hospital treatment. The person spent several weeks as an inpatient in a hospital which did not have supports in place for their disability and found this period very difficult. The person described having panic attacks at the thought of returning to the hospital, even for follow up appointments.

The worry that they might be too stressed to attend the appointments was causing further anxiety. NAS supported the person to identify what caused the distress and communicate this to the consultant and hospital. The person's will and preference was taken onboard by the hospital and implemented into their ongoing care and treatment to develop a healthcare plan directed by them.

NAS also supported a person with a disability who was in hospital, awaiting discharge. The person did not want to go to a nursing home. With the support of an Advocate, the person's will and preference was communicated and they moved into a residential service.



People with disabilities who were living in hospital settings awaiting a more appropriate placement for a prolonged period had an increased risk of exposure to Covid-19 due to the inappropriate nature of their placement. In one case, NAS supported a person with a disability for whom it was considered unsafe to stay in the hospital due to Covid-19 risks and their underlying medical conditions. The person was transferred to a nursing home where they did not want to live. The Advocate was able to support this person to move out of the nursing home into their place of their choice.

NAS also supported a person whose surgery had been delayed due to Covid-19. The person had been waiting for this surgery for several years. The Advocate helped the person to write a letter to the surgeon highlighting why they wished to have the surgery and asking when it will be scheduled. The person is waiting for a surgery date and will have support to live in their current place of residence, with all supports needed in place.

Delayed or Inappropriate Discharge from Acute Hospitals

Throughout the course of the Covid-19 pandemic, both NAS and the Patient Advocacy Service have continued to support people in acute hospital settings who were awaiting discharge home or to more appropriate supports.

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.

In one case, NAS supported a person with a disability who was in acute care during the pandemic awaiting hospital discharge. The person made it clear that they did not want to go to a nursing home. Due to the pandemic, the Advocate could not meet the person face-to-face. However, the Advocate remotely attended multi-disciplinary team meetings to ensure the person understood what was happening, was aware of their rights and was not pressured into making decisions. The Advocate also supported the person to communicate with the Medical Social Worker and Disability Liaison Services in the hospital about other options for discharge. With advocacy support, the person's will and preference was communicated and they were placed in a residential service.

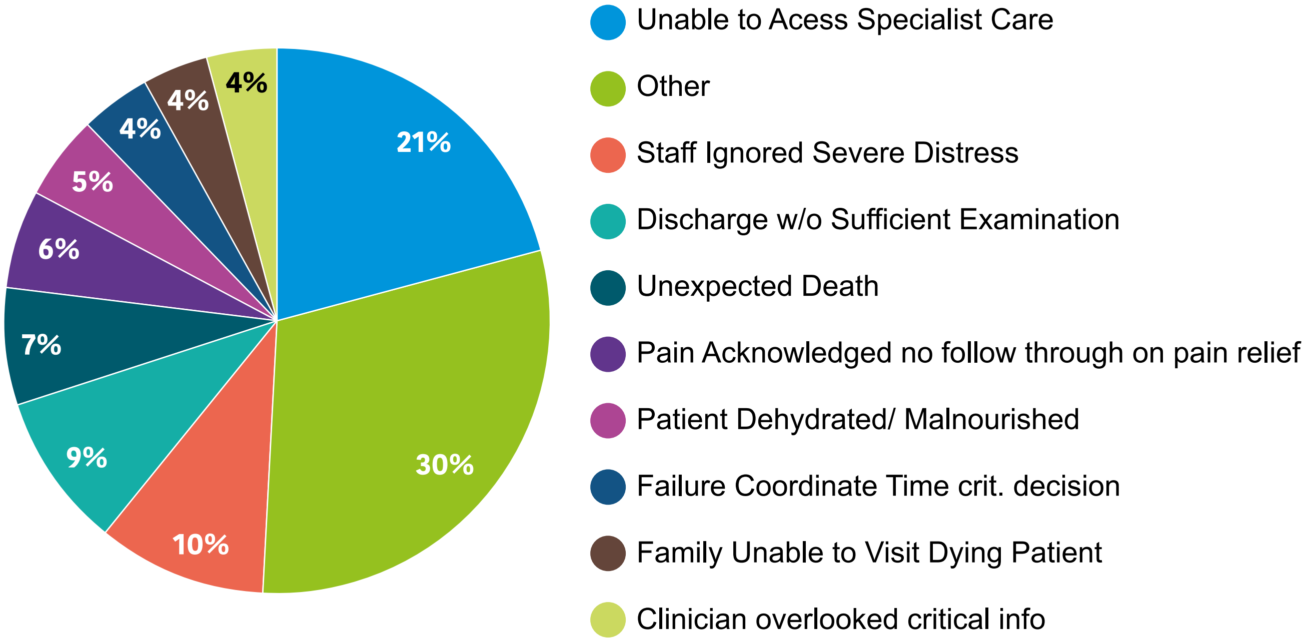
In another case, NAS supported a person with a disability who required medical treatment in hospital. It was deemed unsafe for the person to stay in the hospital due to Covid-19 risks and their underlying medical conditions. The person was transferred to a nursing home where they did not want to live. The Advocate was then able to support this person to move out of the nursing home.

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. In one case, a person in hospital was told they were a close contact with a confirmed positive Covid-19 case. The hospital told them they needed to remain in hospital in isolation for 10 days. The person was displaying Covid-19 symptoms, but the discharge documentation said they had pneumonia and they were discharged before day 10. The person was later contacted by the hospital to say they were discharged in error. The person returned to a different hospital for further treatment.

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. In one case, the family were concerned about what happened to their family member before they died. The family do not know what happened to them after they were discharged from hospital.

The Service has also supported people who had concerns about being moved between wards within the hospitals. People informed us that they had been placed in infectious diseases wards when they themselves did not have an infectious disease. People have also been on wards with other patients who were still awaiting results of a Covid-19 test. In one case, the person's Covid-19 test came back positive when they had already been in a ward with several others for days who were confirmed Covid-19 negative.

Patient Advocacy Service – Level 3 Severity Issues Experienced Related to Covid-19



Sam’s Story: Inappropriate Discharge

My name is Sam and my wife Mary died from Covid-19 in hospital while she was being treated for severe pneumonia.

Mary was given a Covid-19 test and this came back negative. After a few weeks of treatment in the hospital, I was told she could return home and referrals would be organised for her. The hospital said they would get her a new bed to make sure she was comfortable, arrange physiotherapy for her, and get carers to help with her care at home.

However, I was left on my own to look after her. Carers had been organised, but they did not turn up, as they said they had no one available. I also discovered that the referral for physiotherapy had not been done. I tried to get equipment to support Mary’s needs, but I couldn’t get this either.

I contacted Mary’s GP to ask for help. He did not know what else to do and could not manage this himself. The GP saw Mary and said she shouldn’t be home and was too ill, she needed to be in hospital. I called an ambulance, and Mary was transferred directly to hospital. Mary was tested again for Covid-19 and this time it was positive. She died a few days later.

I had several concerns about how Mary was discharged and the lack of help I was given to look after her, so I contacted the Patient Advocacy Service for help. I did not want to see something like this happen to other families.

The Patient Advocacy Service gave me information on how to make a complaint and how to get a review of Mary’s care when she was in hospital. The Advocate also helped me to request Mary’s health records. I was also given information on how to make a complaint about the carers not being provided.

My Advocate supported and empowered me to write my complaint to the hospital. In response the hospital apologised to me and made recommendations about how to improve the discharge process which I was very happy about.

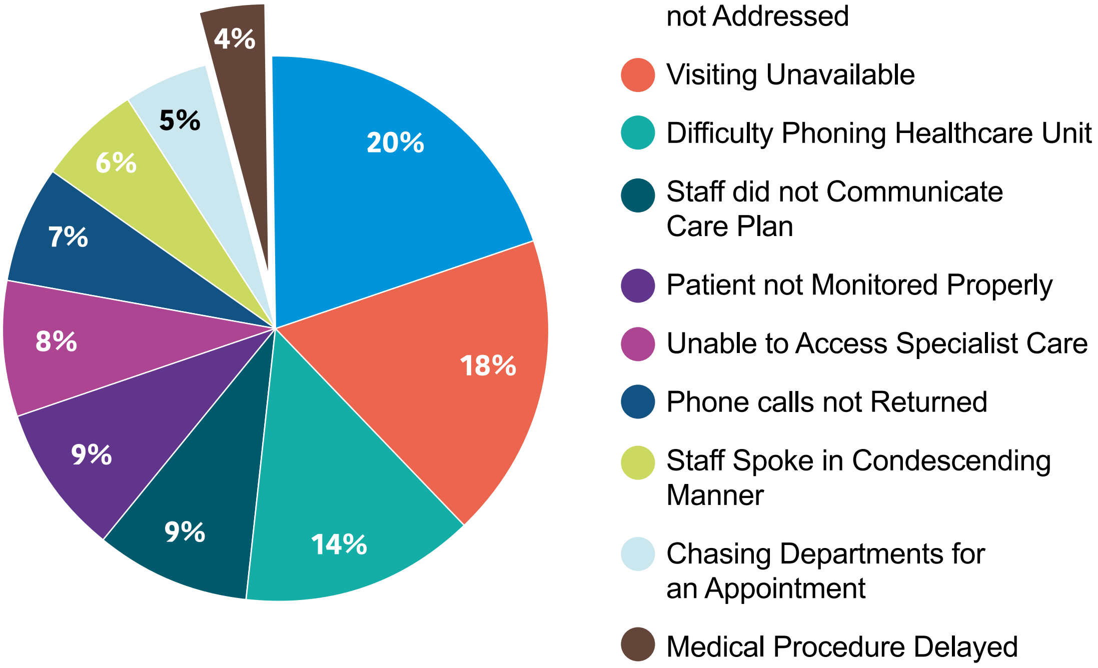
Medical Procedures

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 listed in the top 10 issues experienced (of all reported issues across 3 levels of severity).

Top 10 Issues Identified - Experienced by People in Cases Impacted by COVID-19



The Patient Advocacy Service was contacted by a person with a disability who required a general anaesthetic for a medical procedure that was not deemed to be urgent. The procedure has been postponed for a year. The person continues to be in a lot of pain while waiting for treatment. The Service also supported a person who was due to have surgery and was told to fast each evening. For several days in a row, the surgery was cancelled.

Advocates from the Patient Advocacy Service have also supported many other people who have had their treatment or medical procedure cancelled or delayed, as they were seen as non-urgent. For many people, this has impacted on their quality of life. 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.

In one case, a person was refused a medical assessment procedure because they were Covid-19 positive. The Patient Advocacy Service contacted the hospital to make a general enquiry and informed them that all patients should receive the same treatment and that the decision should be based on medical need. The Patient Advocacy Service was able to support the person to raise their concerns, explain to the hospital that it was not following its own policy, and get the necessary medical procedure.

NAS also continued to support people with disabilities who were required to attend medical appointments and procedures. NAS supported people to ensure their voice was heard in these cases, particularly around their specific needs as a person with a disability.

In one case, NAS supported a person who wanted to have surgery on their hip to relieve the pain they were experiencing. The service provider had concerns regarding the surgery and what level of independence the person would have after the procedure.

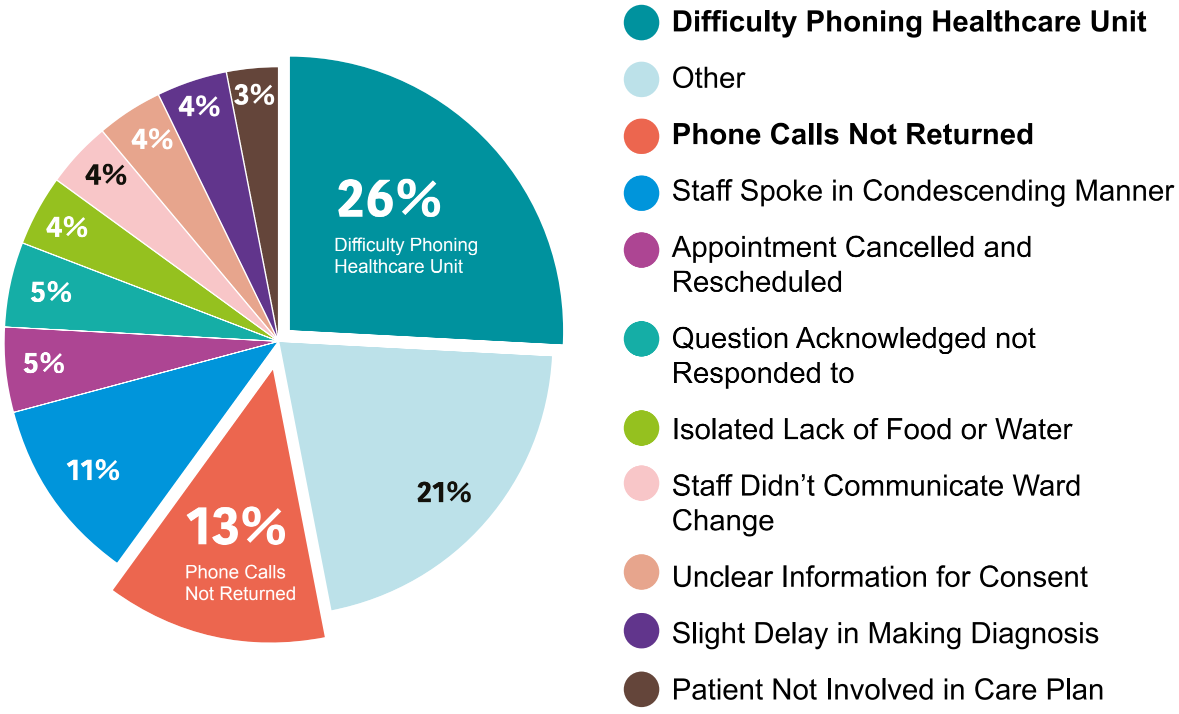
The person had been waiting for several years for surgery. The Advocate supported the person to write to the surgeon outlining their will and preference was to have the surgery and asked when it would be scheduled. The Advocate also liaised with the service provider to discuss how they would support the person in their decision. The service provider agreed to support the person to live in their current place of residence and access any further supports they may require following the surgery. The person is now awaiting a date for the surgery.

Communications and Visiting

> **“It’s great to know I can reach out to someone to give me reassurance and explain things to me. That’s marvellous”**
>
> Adam, who was helped by a NAS Advocate in 2020

Almost 40% of people who contacted the Patient Advocacy Service during the Covid-19 pandemic had difficulty communicating with healthcare units in hospitals. They said they were unable to get a response to their phone calls, or their phone calls were not being returned and they were having to chase hospital department for appointments.

Issues - Level 1 Severity Experienced By People Impacted By Covid-19



This caused significant distress for family members as they were unable to visit their loved ones during this time and phone calls to hospital departments were the only way they could find out what was happening with their care.

In response, the Patient Advocacy Service supported many family members by informing them of their rights under the National Healthcare Charter 'You and Your Health Service' (2012), which aims to ensure that all health services will 'listen carefully and communicate openly and honestly, and provide clear, comprehensive and understandable health information and advice'.[11]

The Charter also says that people can expect their family, carers or other nominated support people to be involved in their healthcare treatment. This did not happen for many people during the Covid-19 pandemic.

Where an immediate need was identified, Advocates from the Patient Advocacy Service provided the contact details for Patient Advice and Liaison Services (PALS) in hospitals which offer confidential advice, support and information on health-related matters. 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 Patient Advocacy Service also advised family members to seek information from the Ward Manager in a hospital and seek a virtual meeting with all 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 in hospital because they were alone and did not have their natural supports with them when they are at their most medically vulnerable. 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.

In one case, the Patient Advocacy Service supported a family who had a young relative in an Intensive Care Unit (ICU). 15-minute scheduled visits were allowed on compassionate grounds while they were in ICU. These visits were hugely important for the young person's wellbeing. The young person's condition improved, and they were moved to a High Dependency Unit (HDU). Once there, visits were ceased without explanation to the family. The Patient Advocacy Service supported the family to seek a multidisciplinary meeting, to re-instate visits on compassionate grounds to support their wellbeing.

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[11] National Healthcare Charter 'You and Your Health Service' (2012) **https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-healthcare-charter/national-healthcare-charter.pdf**

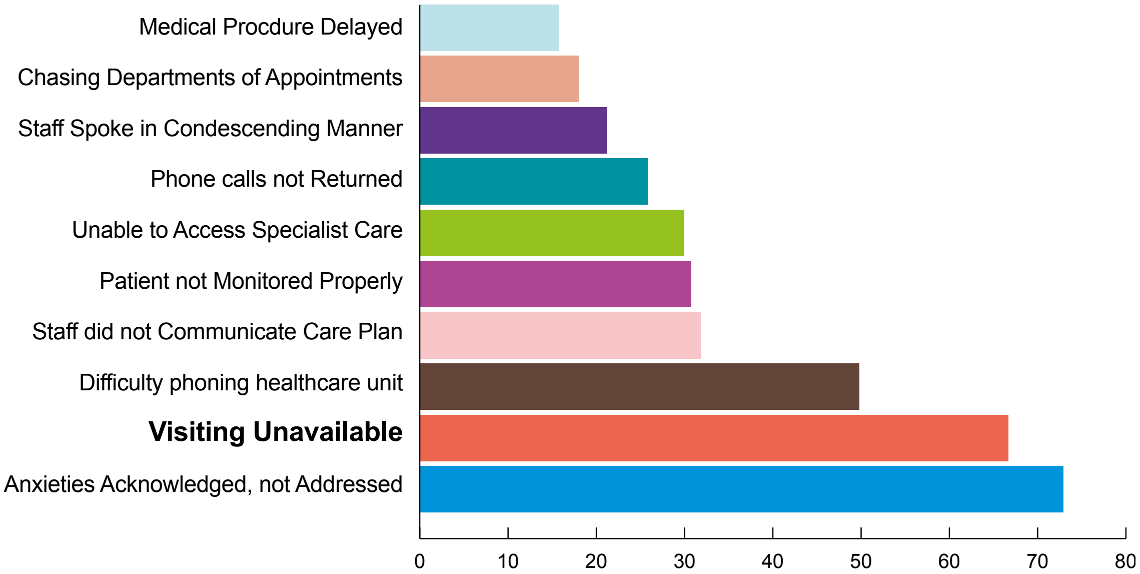
The Patient Advocacy Service was contacted by a person who needed supports when attending hospital appointments due to a disability. The person explained how difficult it was to find the department or even the bathroom on their own.

Similarly, other people who may have needed support when eating while being an in-patient in hospital found that nurses did not have the time to sit with them and help. In one case, a family member had offered to go in at mealtimes to give this support, but this was declined. An Advocate supported the family member to raise this within the hospital, after which they were allowed to enter to provide support.

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. Advocates have provided people with information around visiting rights on compassionate grounds which had not always offered them by the hospital.

In one case, the Patient Advocacy Service was contacted by a person who had an older family member in hospital for treatment. The family were having difficulty contacting the person or the ward. The person was in a room on their own and the family were concerned for them as they were not allowed to visit. This example highlighted the disconnect that families felt during the Covid-19 restrictions, how patients can be left isolated without natural supports and how communication is vital in these circumstances. The Patient Advocacy Service connected the person to hospital advocacy services and supported them to request a meeting with all the teams involved in their care. This resulted in the person and their family receiving clear information on their care and discharge plan. Brief visits were also allowed which brought great relief to the patient and the family.

Patient Advocacy Service - Top 10 Issues Experienced in Cases Due to the Impact of Covid-19

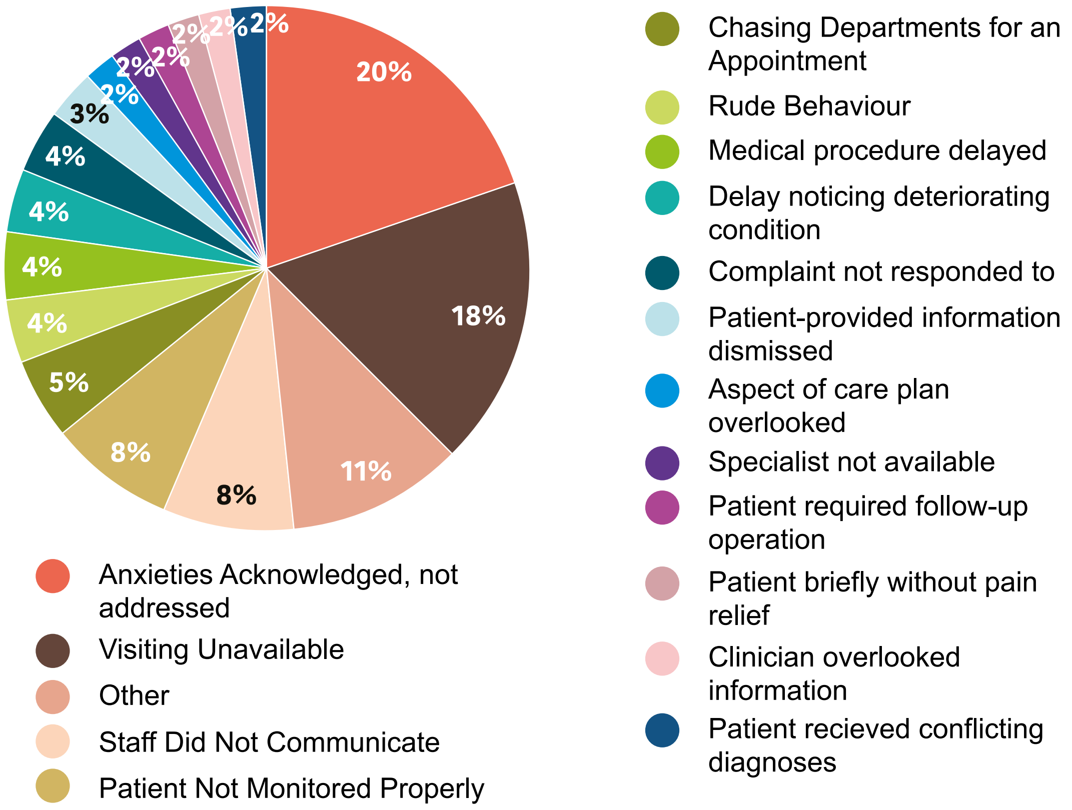


Total Number of Issues Identified by Patient Advocacy Service March 2020 – March 2021 in each of the Top 10 Areas of Experience.

As well as not being able to visit family when they were in hospital, loved ones found it difficult to communicate with the hospital and obtain information on how the person was.

According to data gathered by the Patient Advocacy Service on cases impacted by Covid-19, 26% were around difficulty phoning healthcare units, and 13% were around phone calls not being returned.

Patient Advocacy Service – Level 2 Severity Issues Experienced Related to Covid-19

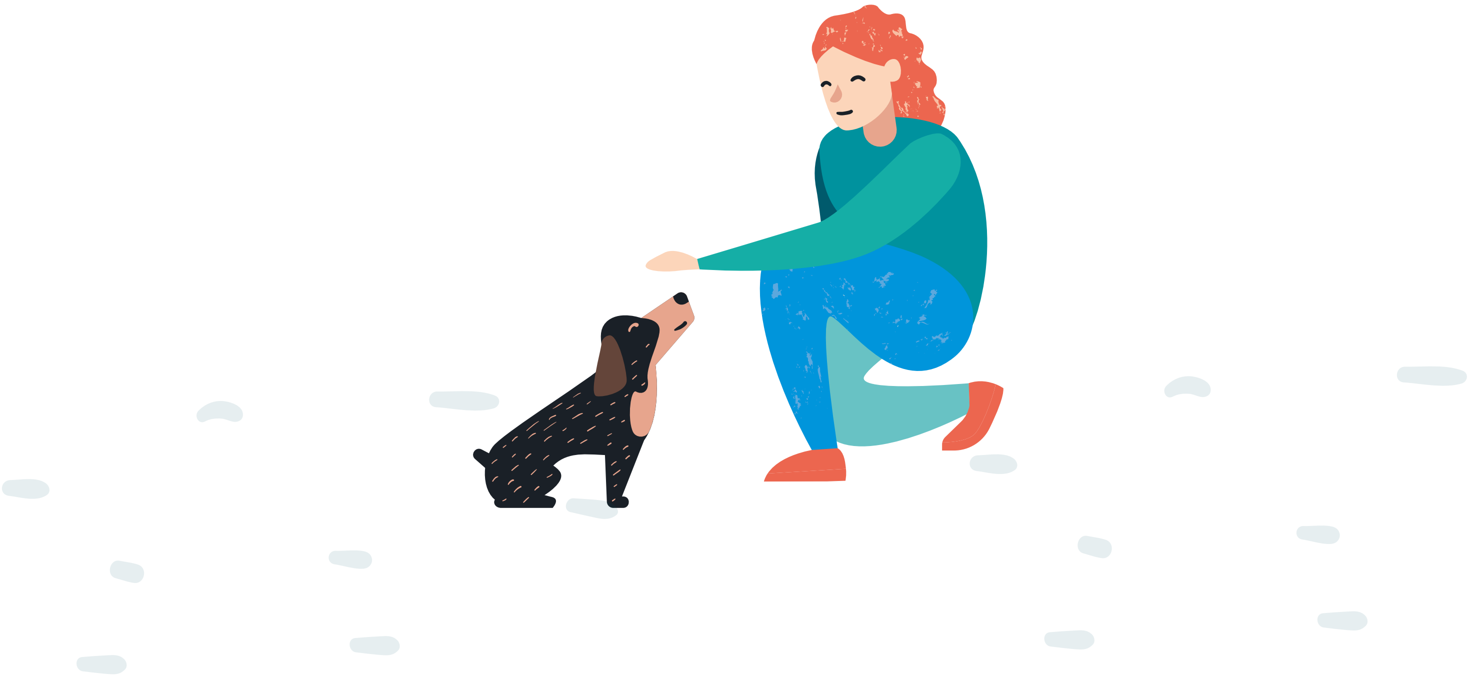


The Patient Advocacy Service had cases where families said they were calling the hospital repeatedly to get an update on the person; however, calls were rarely answered, or they would be placed on hold and the calls would be cut off. This caused acute distress for family members as they were unable to 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.

In one case, NAS was contacted by the family member of a person with a disability who in an acute hospital ward. Their family was not permitted to visit them. The person was unable to answer the phone or make call without assistance. The hospital policy on visitations was far more restrictive than the Health Surveillance Protection Centre (HSPC) Guidance on visiting acute settings. The NAS Advocate collaborated with an Advocate in the Patient Advocacy Service. The Advocates were informed that the person had a fall while in hospital, and the family were not kept informed of any follow up tests or results. The Advocates provided suggestions around organising visits on compassionate grounds and requesting a meeting bringing together all the teams involved in the person's care. Following Advocate support visits were organised.

During the pandemic, NAS advocates also worked to ensure that the rights of those accessing the service were upheld.

The HSE guidance 'COVID-19 Guidance on visits to Long Term Residential Care Facilities (LTRCFs)[12]', states that advocacy services are an essential service for people and were not to be considered as visitors.



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[12] COVID-19: Normalising Visiting in Long Term Residential Care Facilities (LTRCFs) V 1.1 10.11.2021 **https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/infectionpreventionandcontrolguidance/residentialcarefacilities/Normalising%20visiting%20in%20LTRCF.pdf**

Patrick's Story: Lack of Communication when in Hospital

My brother Patrick went into hospital for surgery. He was put onto an ICU ward in an isolation room because he was at high risk of catching infections. His doctor said he was doing well after the surgery, and everything was going to plan.

My brother was not able to speak on the phone and I was not allowed to visit him due to restrictions in the hospital. I depended on contact from the hospital to keep me updated on how he was doing. Unfortunately, there was a complete breakdown in communication from the hospital.

I was informed by the hospital, several days after it had happened, that he had been a close contact of a person with Covid-19 in his isolation room. I was so upset to hear this, but we were really happy to hear his test for Covid was negative.

In the days following this, my brother's condition deteriorated, and I was not informed of how gravely ill he was. Later that week, I was informed that he was in palliative care and his organs were failing because he had pneumonia. I was allowed to visit him the same day. It was a complete shock to me as he had been recovering well after his surgery.

During my visit I was told he did not have Covid, he had severe pneumonia. However, after my visit I was told he had tested positive for Covid. My brother died the following day, and I can't imagine how he must have been feeling in his final few days.

I contacted the Patient Advocacy Service, and my Advocate has been an amazing help. My Advocate listened to my story, understood why I was so upset, and helped me write a complaint to the hospital about my brother's experience.

The hospital has been slow to respond to my complaint and my Advocate has helped me follow up with them. The hospital has agreed to review the care my brother received and to look at how he caught Covid when in isolation.

My Advocate helped me get copies of my brother's files so I can try to make sense of what happened to him in his last days. I'm still working with my Advocate to try get some answers about what happened to my brother.

Dignity & Respect in Person-Centred Care

"My Advocate went out of her way to help me. She showed me respect and gave me the confidence I needed to come to a decision."

Deirdre, who was support by an Advocate from the Patient Advocacy Service in 2020.

The National Healthcare Charter, 'You and Your Health Service' (2012) aims to ensure that health services "treat you, your family and carers with dignity, respect and compassion. We respect diversity of culture, beliefs and values in line with clinical decision making. Please treat staff with dignity respect and consideration"[13].

Person centred care and support is an approach to service development and delivery which ensures that the person's will and preference is central. The service is respectful of the person's needs and values and takes action to ensure these are upheld. Dignity and respect are vital in ensuring that person centred care and supports are provided.

This approach is supported by the HIQA guidance document on a human rights-based approach in health and social care settings[14], in which dignity is described as treating a person in a way that values them as human beings, while respect is described as an unbiased consideration and regard for the rights, values, beliefs and property of other people.

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.

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[13] The National Healthcare Charter, Your Service Your Say pg 7 **https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-healthcare-charter/national-healthcare-charter.pdf**

[14] Guidance on a Human Rights Based Approach in Health and Social Care Settings HIQA 2019 **https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF**

In one case, NAS supported a person who was experiencing restrictions on their movements that were above and beyond those required by public health guidelines. The person was being followed and supervised by staff while they were outside of their residential setting, to ensure that they followed public health guidelines.

This had an impact on the person's dignity and was not in line with a person-centred approach to service provision. The Advocate highlighted the issues with this type of intervention for the person and the practice was stopped with immediate effect. Without advocacy intervention, this practice is likely to have continued.

In another case, a person who was living in a residential setting had several professionals from different disciplines supporting her to move to more suitable accommodation. They set up monthly meetings via conference call to discuss possible accommodation options for the person in the future. However, prior to working with the Advocate, the person was not involved in the meetings in any way, they were not informed when the meetings were taking place and they were only updated occasionally by support staff who attended the meetings. Since the person was referred to NAS, the Advocate has attended all meetings and has ensured the person's will and preference has been communicated. At present, the person is happy for their advocate to attend on their behalf and with the advocate's support, they feel that they are now a part of the process.

In terms of 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

“Thank-you for being empathic, patient and kind to me”

Seamus, who received NAS support in late 2020

Mental Health Reform in July 2020 found that there was a “sharp decline in mental wellbeing in Ireland during the Covid-19 crisis”[15]. The report also states that research conducted during the pandemic found that over a third of people in Ireland were experiencing serious mental ill health. The pandemic has had a negative impact on the mental health of the people supported by NAS and the Patient Advocacy Service.

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, in residential settings and nursing homes. This has been heightened by the high rate of transmission experienced by some services.

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.

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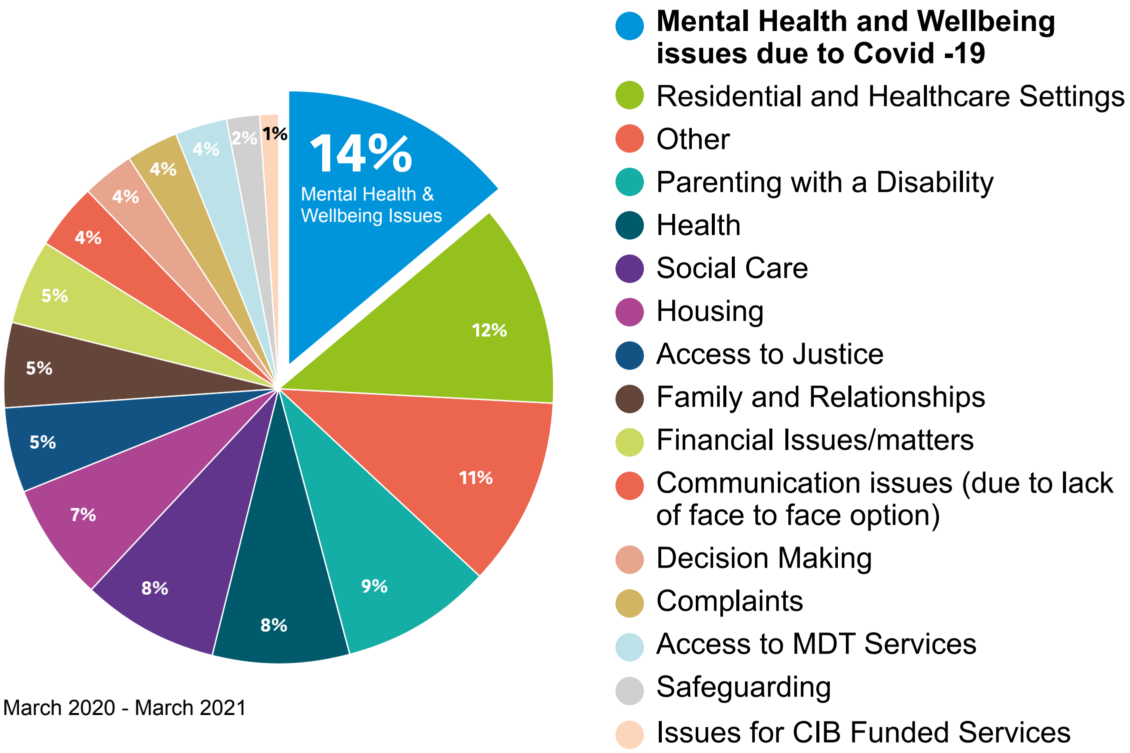
[15] Submission to the Special Committee on Covid-19 Response: The impact of COVID-19 on mental health in Ireland **https://www.mentalhealthreform.ie/wp-content/uploads/2020/07/Submission-to-the-Special-Committee-on-Covid-19-Response-July-2020.pdf**

Issues Impacted by Covid-19 Experienced by People NAS Supported



March 2020 - March 2021

NAS spoke to many people they support who were experiencing feelings of isolation and loneliness during the pandemic. People with disabilities were isolated from their natural supports, including their families and communities. They were told to limit their contact, 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 pre-existing mental health difficulties and those who have required new supports during the pandemic.

During the pandemic, the range of supports provided by NAS 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. NAS has also signposted people to other organisations that might have been able to 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. As a result, NAS expressed the need for out-reach supports and respite for those people who were affected.

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 local community supports to help the person to get groceries and prescriptions. NAS also linked them in with the outreach mental health team and engaged with various professionals on their behalf.

NAS also supported a person with a mild intellectual disability and mental ill health. The person was living at home with family where conflict frequently arose. Prior to the pandemic the person attended a day service and was linked with a volunteering opportunities and community groups. Due to the pandemic, the person lost all of these supports and became very distressed and frustrated. The Advocate worked with the person and the service to re-establish links. Without the NAS’s support, the person would have remained isolated and at risk of mental ill health. The Advocate was able to complete a lot of their advocacy work remotely and had face-to-face meetings with the person.

In another case, NAS linked in a person who was experiencing social isolation with a befriending service. Throughout the pandemic, the service had weekly phone conversations with the person and ensured the person had a weekly connection with another person. The person reported to the Advocate that they looked forward each week to the call and really enjoyed the conversation each week. They stated it made them feel connected to the outside world and they had the chance to talk about things other than the pandemic. The person felt comfortable enough with the Advocate to initially share their feelings of loneliness, isolation and mental ill health. The Advocate was able to support the person then by making the referral to the befriender service on their behalf and support the person to engage.

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, if needed.

In one case example, the Patient Advocacy Service provided empowerment advocacy to a woman who had mental health issues. The Advocate supported the woman to make a complaint regarding her care while an inpatient in an acute hospital. While working with the Advocate the woman spoke of her feelings of isolation and loneliness during her hospital stay.

Peter’s Story: Homelessness and Isolation

My name is Peter, I am in my thirties, and I have mental health difficulties. I was discharged from a psychiatric unit and required emergency accommodation, but my local authority refused to provide it.

This was confusing for me as I was entitled to the Housing Assistance Payment (HAP) which is accessed through your local authority and allows a person to take up full-time employment and keep their housing support. I had to move in with my family as I had nowhere else to go.

I was delighted when I was referred to NAS to help me explore my accommodation options. However, the Covid-19 pandemic took hold soon after and while my Advocate and I stayed in contact over the phone, we were unable to explore my housing options for several months as the country was in lockdown.

I was also linked with mental health services, but the Covid restrictions made it difficult for me to meet my psychiatrist or access the other supports I needed. I struggled to use video and phone calls and I was feeling quite isolated and low. Living with my family was also proved quite difficult.

Things came to a head when I was admitted to hospital due to a deterioration in my mental health. On discharge, I was told I would need to self-isolate for two weeks, but I was not given any options about where I could go. My Advocate gave me a number for the Council's Community Call Line to enquire about emergency housing for self-isolation.

The Advocate contacted the local authority to explore what paperwork was required for my housing application and submitted a support letter advising that I would benefit from a Rental Accommodation Scheme or Local Authority property. The Advocate also helped me get a letter from my psychiatrist explaining my diagnosis.

The Advocate also spoke with the Council's settlement officer and arranged a meeting in person to explore if they could offer me any further support. However, this meeting ended up taking place over the phone due to the Covid restrictions. Nothing came of this in the end. Undeterred, my Advocate supported me to explore my options for private rental accommodation. However, the impact of Covid meant there were very few properties available in my county.

The Advocate then contacted an organisation that supports people with homelessness and helped me to get in contact with one of their support workers who offered me advice on how to look for a suitable home on HAP and supported me to contact property owners in my area. I'm feeling much more positive about the future now and I hope to find my own place to live soon.

Social Care

> **“I really appreciate you checking in on us during the Covid pandemic and making sure we had the supports we needed.”**
>
> Louise, who was supported by NAS while cocooning
> with her parent early in 2020

Home Care

A significant number of people receiving support from NAS live in the community. Many of these people receive home care services which facilitate them to live as independently as possible. For those people seeking such supports, Article 19 of the UNCRPD states that people with disabilities should “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”[16].

Home care packages for people with disabilities 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.

In the early months of the pandemic, people with disabilities living in the community told Advocates how they were being directly impacted by restrictions, with their home care packages either being reduced, curtailed or at times stopped. 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 service 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 safeguarding concerns arose as the person was staying longer than intended at home.

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[16] UNCRPD, article 19 **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html**

In the main, people with disabilities understood why reductions of home care services occurred, although after a period of time this had a greater impact upon people with disabilities living in the community during the pandemic than on people without disabilities. NAS continues to support people with disabilities living in the community who are still facing challenges in securing their full care packages.

The provision and use of appropriate PPE by those visiting homes was also raised with NAS. There was a shortage of home care staff which led to the unexpected withdrawal of home support services in cases. In one instance, the frequency of home care staff arriving at different intervals in full PPE created an issue for the person who had to dispose of the PPE themselves. Staff from the care provider were asked to bring their PPE with them as this was an additional cost for the person.

In one instance, NAS supported a person with a disability who was struggling with the staff that came to support them during the pandemic. The person told the Advocate that different staff wore different amounts of PPE and seemed to follow different guidelines when they called to their house. The person struggled with this as they were concerned about the risk of Covid-19, but also the inconsistency shown by staff. While the person had a good relationship with both the staff and management of the service, they did not feel that they could communicate the issues to them directly and required the support of their advocate to have that conversation. The Advocate supported the person by communicating the difficulties and the inconsistencies to the management of the service. The manager then ensured that all staff followed the same guidelines and wore the same PPE when visiting the person going forward. Without the advocate’s involvement, the staff would have continued to unknowingly cause stress and worry for the person and the person would have felt unable to communicate the issues.

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. In one case, as part of discharge planning, the hospital organised a care package for a person to return home. Once the person was home, they were contacted by the care service providers and informed they did not have staff to provide this. The person was left without any home supports and reliant on family to try to care for them.

In one case, an advocate was informed about an issue regarding the service delivery of personal care for a person during Covid-19. The HSE home care provider stopped providing showers to people because it said there was a risk of water particle borne infection. However, it also stated that showering people was too time consuming. In this particular case, the Care staff made a decision that the person with the disability could not have their hair washed as they were not using the shower. The person's parent contacted NAS for support. The Advocate informed the care provider's staff manager who was not aware of this. There had been no communication from manager to care staff about how to meet the person's needs under the restrictions. The issue was promptly resolved, and staff returned to providing showers and washing the person's hair.

Personal Care

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. A service provider tried to withdraw personal assistants from people's homes by offering a front door delivery of prepared meals only. There was no clinical basis for such a change in service provision once social distancing and hygiene guidance was followed. Supported by NAS, people challenged this decision, and it was reversed.

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.

It is of course important to recognise the work provided by home care staff and personal assistants throughout the pandemic has not gone unnoticed. They provided front-line services to people with disabilities throughout the pandemic and still are, even at risk to their own health.

Early in the Covid-19 restrictions, NAS worked with a young man who had recently been discharged to a nursing home for convalescence. The man's regular Personal Assistant (PA) staff was not able to visit. This meant the man, who communicated differently experienced isolation and loneliness. His PA had been familiar with his communication needs. NAS supported the man's family to liaise with key stakeholders, such as Physiotherapy and Speech and Language Therapy, to identify and document appropriate strategies that could be utilised by nursing home staff to maximise communication and retain the man's physical mobility. Having the Advocate's support meant the man's needs were highlighted as circumstances changed.

As Covid-19 restrictions ease, NAS has become aware of a hesitancy in the resumption of PA hours. In one case, NAS was working with a person living in a residential setting whose PA hours had stopped due to the Covid-19 restrictions. As the restrictions eased, there was still no sign of the PA hours resuming. The person communicated to their Advocate how much they would love to access the community. The Advocate linked with management in the residential setting and the manager of the PA service to see what could be arranged. It was agreed that the person's PA would call to them twice a week and they could spend time accessing the local community. With the Advocate's support, the person's will and preference was communicated and the resumption of their PA hours was prioritised.

Primary Care

Primary Care refers to the health and social care services that are based in the community rather than a hospital setting. The primary care teams, which operate out of local health centres throughout the country, include GP's, Community Nursing Services, Occupational Therapists, Physiotherapists and Home Help/Support staff and in some cases Social Workers.

These teams also link in with other community-based professionals to ensure people's health and social care needs are met. These include Speech and Language Therapy, Dieticians, Mental Health Services, Counsellor/Psychologist, Podiatry, Social Work, Dental and Ophthalmic Services[17].

Primary Care is essential for people with disabilities to maintain good health and manage medical conditions and illnesses. 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.

The National Healthcare Charter You and Your Health Service[18] outlines that there should be equity of access to public health and social care services. Unfortunately, many people with disabilities experienced difficulties accessing primary care services during the pandemic.

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. These refusals occurred despite an exemption for face coverings for those who cannot wear them because of a physical or mental illness or a 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. In one case, a person had recently moved address and registered with a new GP. They had been prescribed medication for anxiety for several years and sought a prescription from their new GP. Over a video call, the GP said they felt the person did not need anti-anxiety medication as they "appeared well". The person explained that they had to take medication prior to the call to be able to speak to the GP. The GP refused to issue the prescription and referred the person to a psychiatrist.

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[17] **https://www.hse.ie/eng/services/list/2/primarycare/pccser.html**

[18] National Healthcare Charter You and Your Service **https://www.hse.ie/eng/services/yourhealthservice/hcharter/**

The person told NAS that they felt if the GP had met them face-to-face, they would have been able to talk about their issues and it would have been clear they needed medication. They felt a judgment based on a phone call or video call was not enough. The person attended the Psychiatrist and was prescribed the medication but said their mental health was impacted hugely by the uncertainty leading up to the appointment.

Both NAS and the Patient Advocacy Service have highlighted the difficulties faced by people with disabilities due to disruption to primary care services during the Covid-19 pandemic and have advocated for the prompt restoration of services.

Of the Covid-19 related issues highlighted by NAS regarding primary care services between March and May 2020 many people 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.

In one instance, NAS supported a person who could not leave their home and required physiotherapy. The Advocate wrote to the person's GP and requested a referral to the Primary Care Team. The person was added to the wait list for a Physiotherapist. The Advocate then wrote a letter to the Physiotherapy Department in Primary Care to call for the person's referral to be prioritised due to the lack of natural supports and the severe nature of their injury. Within four weeks, the person had their first physiotherapy session and their mobility improved within a matter of weeks. With the Advocate's support, the person could avail of the services they needed to improve their overall health and quality of life.

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. NAS has ensured that the voice of these people has been heard and has highlighted the need for an accessible occupational therapy service to address people's individual needs.

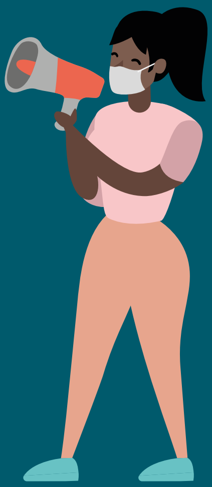
NAS has also supported people to obtain community supports upon discharge from acute settings during the Covid-19 Pandemic. In one instance, NAS supported a person who was a patient of an acute setting who had decided to self-discharge from the setting. They had waited several weeks for a home care package to be agreed without success. As the pandemic took hold, the Advocate was concerned that the person had no contact with any health or social care service. The Advocate contacted the Public Health Nurse, stressing that the person's needs were at risk of being overlooked. As a result, the person was offered an opportunity to re-engage with 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. In cases where the hospital did organise care packages, people were often told that care service providers did not have staff to provide this.

Throughout the Covid-19 pandemic, NAS was contacted by people experiencing difficulties and isolation as a result of cuts to their usual day service and or home supports. NAS linked these people in with their Primary Care Social Worker and advocated for additional supports given the cuts being made to existing services during the pandemic.

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.

Conclusions and Recommendations



NAS provides a crucial means of support for people with disabilities to ensure the persons voice is heard. The Patient Advocacy Services also 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.

The Services uphold the person's rights, ensuring fair and equal treatment and access to services. They make certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.

In normal times, the support offered by both services is of huge importance. People with disabilities already face discrimination and marginalisation in many aspects of their lives, while people who have had a negative experience in a public hospital can often feel they have nowhere to turn for support to have their views and complaints heard.

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.

In relation to health care, NAS and the Patient Advocacy Service have provided advocacy support for people facing a range of complex, difficult and stressful issues, including concerns about the safety and effectiveness of their support and care.

People contacting both Services have expressed concerns about care in public acute hospitals such as poor communication with family members, problems with infection control, delayed or inappropriate discharge and difficulty accessing medical records. Medical procedures have also been delayed or cancelled, which has had a considerable impact on the health and well-being 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.

In general, the issues related to mental health have affected people supported by both Services throughout the pandemic. People have highlighted 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.

Regarding social care, home care packages for people with disabilities, designed to facilitate them to live as independently as possible, were affected during the pandemic. In the early months of the pandemic, 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.

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.

When it came to personal care, NAS received several calls from people whose personal assistant service providers decided to pause services or reduce the hours provided during the Covid-19 pandemic. There were also issues around primary care supports such as home support service, which provides personal care support for people, for example to get out of bed, dressing and undressing and taking a shower.

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.

As a result of the extensive advocacy work carried out by NAS and the Patient Advocacy Service in the period March 2020 - March 2021, the Services has developed several recommendations which should be consider to improve the health and social care services delivered in Ireland.

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 urgently need to 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' complaints process and the 'Incident Management Framework' 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 to 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 to be supported to move to more appropriate settings in line with their will and preference. People to be offered advocacy support from an independent advocacy service should 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.

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.