



**NATIONAL ADVOCACY
SERVICE**

**FOR PEOPLE WITH
DISABILITIES**



**Patient
Advocacy
Service**

INFORMATION | SUPPORT | EMPOWERMENT



Annual Report **2020**

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1.1 Easy to Read Summary of Annual Report



What is NAS?

NAS is the National Advocacy Service for People with Disabilities. It is called NAS for short.

NAS works to protect the rights and choices of people with disabilities. NAS supports people with disabilities to have their voice heard.

NAS supports people with disabilities who may not have a lot of other supports or who may find it difficult to be a part of their community.

NAS supports people with disabilities including people who communicate in different ways.

The people who work for NAS to provide this support are called Advocates.



The Patient Advocacy Service

NAS also provides another important service called the Patient Advocacy Service.

The Patient Advocacy Service gives information and support to people who want to make a complaint about something that happened to them in hospital.



Who Supports NAS?

The government gives money to the Citizens Information Board and then the Citizens Information Board gives this money to NAS.

NAS uses this money to fund its work.



An Roinn Sláinte
Department of Health

Who Supports the Patient Advocacy Service?

The Patient Advocacy Service is paid for by the Department of Health.

They give money to NAS to run the service.

The Patient Advocacy Service is an independent service.

It does not get money from the HSE.



How NAS Advocates Work

NAS Advocates work alongside people with disabilities. They work out together what the person wants and make a plan called an advocacy plan.

We all have different ways of showing what we want. NAS Advocates watch and learn the different ways people communicate.

Advocates also talk to friends, family and staff to find out more about what the person wants.



How Patient Advocacy Service Advocates Work

The Patient Advocacy Service offers information, support, and guidance to a person about their issue or complaint.

This is called empowerment advocacy.

Patient Advocacy Service Advocates also support people with their complaints and can attend meetings.



Strategic Plan

NAS has a plan for its work called the Strategic Plan.

The plan is about 3 important parts of NAS work. These are service, standards and policy.

The plan is about NAS giving a good quality service and telling people about the issues that matter.



Covid-19 and our Work

Covid-19 meant changes for everyone. It changed the ways that NAS and the Patient Advocacy Service could do its work.

Covid-19 also meant changes to the way services and hospitals worked.

There were lots of closures to services. There were also delays dealing with hospital complaints.

New rules meant it was not always possible to have meetings with people face to face.



New Ways of Working

NAS and the Patient Advocacy had to work in new ways during the Covid-19 time.

Staff from both services had to work from home. Staff supported people by phone, emails and in video meetings.

People were still able to contact NAS and the Patient Advocacy Service by calling the national line, emailing or visiting the websites.

In this way both services kept providing a high quality advocacy service to people who needed it.



NAS Work in 2020

NAS Advocates worked on 1,051 cases supporting people with disabilities with their advocacy issues in 2020.

NAS Advocates helped people speak up, write letters, make phone calls, attend meetings and think about important decisions.

NAS also provided information and short-term advocacy support to 2,705 people in 2020.

NAS has a telephone number people can call for help with their issue.

1,903 people called this number in 2020.



Patient Advocacy Service work in 2020

The Patient Advocacy Service provided support to 535 people in 2020.

Advocates worked on 1,281 complaint issues for the people they supported.

Advocates supported people to write letters, attend meetings and to speak up for themselves.

The Patient Advocacy Service has a website and it was visited by over 7,000 new users in 2020.



Key Issues for NAS in 2020

NAS dealt with a lot of important issues for people with disabilities in 2020.

The biggest issues were around capacity building, housing, residential and healthcare settings, decision making and social care.

NAS helped people with disabilities to work on these issues to try and make things better.



Key Issues for the Patient Advocacy Service in 2020

The Patient Advocacy Service worked on important issues for people in 2020.

These top complaint issues were people feeling their anxieties were not listened to, difficulty phoning healthcare units, not being able to visit hospitals and hospital staff not communicating care plans to the patient.



Who Contacted Us?

NAS was contacted by people with many different types of disabilities. Some people had more than one disability.

Many people who were connected with NAS lived in residential services or attended day services.

People contacted NAS themselves or were supported by family, friends or support staff to be connected with an Advocate.

People contacted the Patient Advocacy Service in different ways such as visiting the website or through hospitals.



Other Important Work in 2020

NAS and the Patient Advocacy Service helped with the response to Covid-19 by supporting people in different ways.

They helped government agencies and services to think about what people needed and make plans.

They helped ensure that the rights, will and preferences of people were respected during the Covid-19 time.

NAS and the Patient Advocacy Service were members of groups that looked at important issues.

NAS and the Patient Advocacy Services also wrote papers called Policy Submissions. These were sent to the government and other expert groups.

NAS and the Patient Advocacy Service explained why issues like adult safeguarding, disability matters and safety in nursing homes are important for the people they support.

They also explained the serious issues the people they supported had experienced during covid-19 such as closures to day services.

NAS and the Patient Advocacy Service took part in meetings to discuss important disability and patient issues.



Telling People About Us

Covid-19 rules meant that NAS and the Patient Advocacy Service could not attend many events in person to tell people about the work we do.

We did take part in lots of online events to talk about the work of the Advocates.

We told people how both services could support people with their advocacy issues.

We also used social media like Facebook and Twitter to tell people about both services and the work we do.



Training

Training is important for NAS and Patient Advocacy Service Advocates.

Advocates attended courses to learn more about disability issues and patient issues.

Training helps NAS and the Patient Advocacy Service provide a high quality service to the people they support.



Thank You

NAS and the Patient Advocacy Service thanks all of its staff for all their hard work in 2020.

Thank you also to the Citizens Information Board and the Department of Health for their support in 2020.

NAS Case Study on Impact of Day Service Closure: Tom

My name is Tom and I live in a residential service with other people. I also have a physical disability. I like to keep busy and enjoy meeting my friends and family as much as I can.

I go to a day service, which I really like as I meet lots of people and do activities that I enjoy. My day service had to close because of Covid-19 and this was very hard on me. I missed my friends and my routine. I started to feel anxious and unhappy.

My Advocate chatted to me on video calls and listened to how I felt. My Advocate supported me to tell my residential service how I was feeling. We decided to ask my residential service to make a plan of activities that I could do every day. This new routine really helped me feel less anxious and happier. I also learned new skills and could choose the activities I liked best.

I am very grateful to NAS and my Advocate for supporting me during the Covid-19 time and making sure that my wishes were heard by my service.

Patient Advocacy Service Case Study on Visiting Hospitals: Anne

My name is Anne and my dad Sean was in hospital for a few weeks during the Covid-19 time. I am very close to my dad as he lives with me and my family and we support him with his care needs.

While my dad was in hospital I was not allowed to visit him because of the no visiting rules. This was very hard on me and also on my dad as he didn't really understand why I could not visit him.

I did not know how my dad was doing in hospital. I tried phoning the hospital but there was no answer.

I contacted the Patient Advocacy Service and my Advocate gave me lots of information and ideas for how I could support my dad. My Advocate helped me ask for a meeting with my dad's doctors and nurses. My Advocate also helped me think of the questions that I could ask at this meeting.

My Advocate supported me to ask the hospital to let me have a short visit with my dad every day. This really helped my dad as he knew we were all thinking about him and he was not alone.

NAS Case Study on Housing: Clara

My name is Clara and I am in my 30s. I have a physical and an intellectual disability. My family were doing their best but they knew I needed more support. They contacted NAS for me.

I was living in a very small and crowded apartment with my family. I had no home care support in the apartment. My Advocate met me and we agreed that my Advocate would tell the local authority and the HSE Disability Services about my situation.

Covid-19 meant that my day service had to close. I was now in my apartment all day every day with no supports. I also had to leave the country for a few months with my family. While I was gone, I was offered a house but the offer was taken away because I was out of the country. My social welfare payments were also stopped.

My Advocate helped explain why I was away and helped me get my payments started again. My Advocate also helped me with the local council and I was offered the house again. I was able to move in with a member of my family.

I am now living in an accessible home with supports. I am also attending my day service again. My Advocate helped make my life better and get me the support I needed.

1.2 Foreword by Chairperson



2020 was a very difficult year for us all. None of us could have been prepared for the hugely negative impact the Covid-19 pandemic would have on the lives of people across Ireland.

It was also a particularly tough period for the

National Advocacy Service for People with Disabilities (NAS). Although I did not commence my role with NAS until January 2021, I witnessed the difficulties our organisation faced as a result of the Covid crisis and the many challenges the people we support had to endure. I was also extremely proud of the way NAS responded to the crisis, adapting our Services and our way of working, and continuing to support people with disabilities when they needed our help the most.

For people with disabilities, the Covid crisis, its restrictions and the subsequent disruptions to healthcare services, proved particularly challenging. They faced many traumatising and life changing experiences, and their views about their own lives were often overlooked by the Services tasked with their care.

The pandemic impacted on NAS services too, particularly during the first lockdown. Face-to-face meetings were limited and many service providers focused on the safety of their residents and were unable to engage properly with our advocates.

It was also a demanding period for the Patient Advocacy Service, provided by NAS, which had just commenced its second year of operation. The Service, commissioned by the Department of Health, provides support to people who wish to make a complaint to the HSE about their care in a HSE-funded public acute hospital. The impact of the Covid virus meant that some hospital patients were unable to communicate with their loved ones, families were unable to visit, and medical procedures were delayed. It was hard for the Patient Advocacy Service to progress complaints, and meetings with hospitals were postponed, leaving people waiting for months to discuss their issues.

Both our Services also dealt with the challenges of working from home throughout most of 2020. The pandemic meant it was impossible for our staff to continue to work in our offices. In March, almost overnight, all staff moved to home working.

“For people with disabilities, the Covid crisis, its restrictions and the subsequent disruptions to healthcare services, proved particularly challenging.”

Despite these issues, NAS and the Patient Advocacy Service have adeptly modified our services to make sure we have been able to deliver high quality, professional advocacy to the people we support. Our Services have continued to operate as normal throughout the pandemic and our staff showed huge agility and adaptability to embrace new technologies such as video calls and text messaging. This has ensured we have continued to help people across Ireland, upholding their human rights and supporting them to have their voice, will and preference heard.

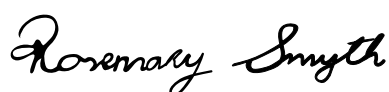
This Annual Report provides a detailed breakdown of all the key data covering the work of NAS and the Patient Advocacy service in 2020. The report describes the issues our advocates encountered during 2020, many of which were altered due to the pandemic. I want to thank those who used our services for their courage throughout this distressing period. I wish to express my sincere thanks to the Citizens Information Board for their continued championing of NAS and their ongoing support and assistance of our work.

I would also like to thank the Department of Health for their guidance and support of the Patient Advocacy Service.

In addition, I would like to express the Board's gratitude to all the staff of NAS and the Patient Advocacy Service for their dedication and commitment in providing professional advocacy services throughout 2020. Covid-19 had a devastating impact on the lives of people across Ireland in 2020, including the people we support, some of whom sadly lost their lives to. We send our condolences to their families. We also recognise the many difficulties the HSE and health services continue to deal with.

Finally, I would like to thank my predecessor, outgoing Chairperson of NAS, Nuala Doherty, who retired from her position at the end of 2020. I want to thank her for the smooth handover and I wish her all the best for the future.

The Covid-19 virus remains in our lives and it will continue to affect the people we support for the foreseeable future. We remain committed to providing the highest level of advocacy to the people who need our support.



Rosemary Smyth

Chairperson of NAS Board

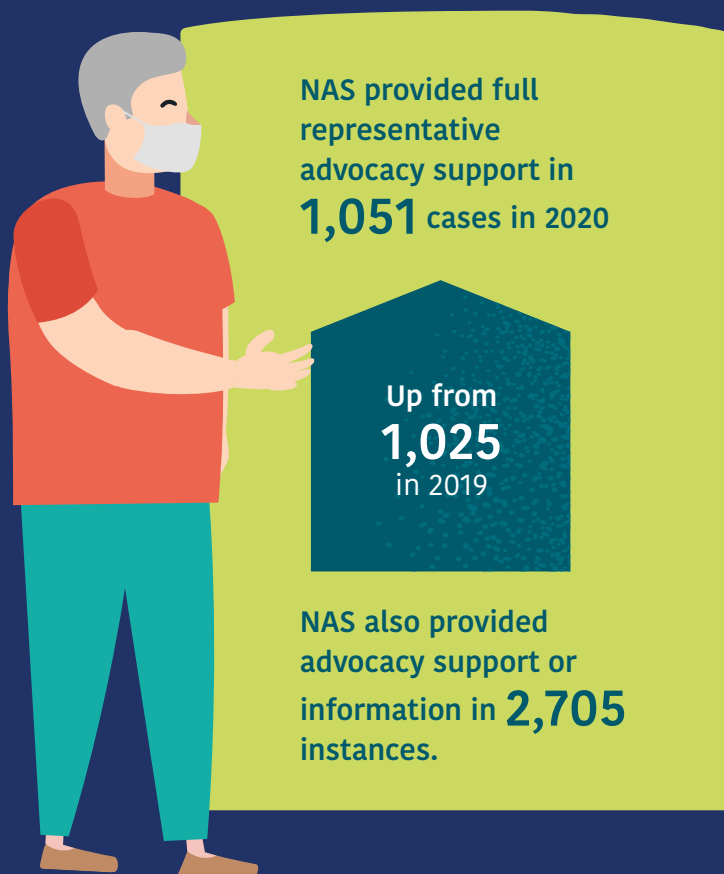
1.3 NAS Highlights

NAS Highlights



**NATIONAL ADVOCACY
SERVICE**

FOR PEOPLE WITH
DISABILITIES



NAS staff engaged in **203** promotional events and presentations in disability services and other services throughout Ireland.



Some of the biggest issues for people with disabilities worked on by NAS advocates in 2020 related to capacity building; housing and accommodation; residential and healthcare settings; decision making and social care.



NAS opened **458** new cases and closed **507** cases, having achieved outcomes for clients.



The NAS national phone line received **1,903** calls in 2020.

1.4 Patient Advocacy Service Highlights



The Patient Advocacy Service provided support to **535** people in 2020, covering **1,281** separate complaint issues.



The Patient Advocacy Service carried out over **600** promotions in 2020, including presentations and offers of leaflets and posters.



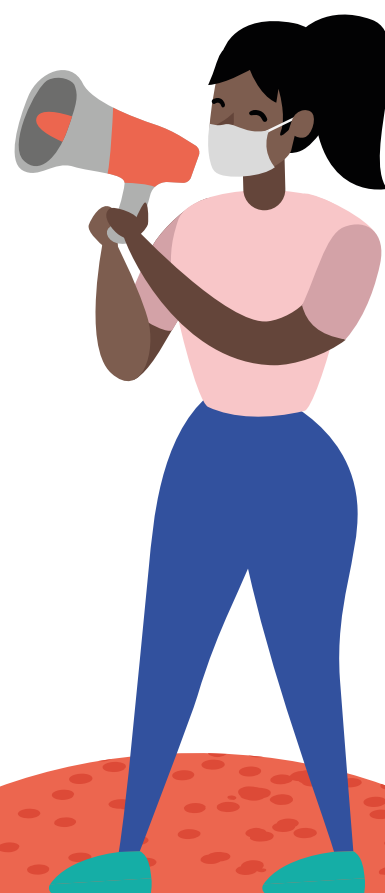
The Patient Advocacy Service closed **475** cases in 2020. **11** of those were carried forward from 2019, the rest were opened in 2020 and closed in 2020.



Some of the biggest complaint issues for people in public acute hospitals worked on by the Patient Advocacy Service's advocates were people's anxieties not being addressed; difficulty for families when it came to phoning hospital healthcare units, and hospital visits being unavailable.



The Patient Advocacy Service website was visited by over **7,000** new users in 2020.



2. Vision, Mission and Values

Vision statement

Our vision for society is one where people with disabilities can exercise their rights – with dignity, autonomy, equality and independence at the core. We recognise the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

We also recognise the right 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.



Mission statement

The National Advocacy Service for People with Disabilities (NAS) is a registered charity that provides an independent, confidential and free advocacy service that works exclusively for adults with disabilities. Our role is to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and have limited informal or natural supports. We act as a catalyst for change through collaboration, capacity building and representation to make the rights of people with disabilities a reality.

NAS also provides an independent, confidential and free Patient Advocacy Service, established in October 2019, that works to support and empower all patients in public acute hospitals through the (i) HSE Complaints Process 'Your Service Your Say' and (ii) in the aftermath of Patient Safety Incidents.

Core Values

Our Strategic Plan establishes the following five Core Values that underpin the work of NAS and the Patient Advocacy Service.

1. Independence

We work with the person independently of others and free from all conflicts of interest. The advocacy process is led and guided by the person.

2. Autonomy

We support the right of the person to self-direction/determination (i.e. to be in control of their own life) and to make informed decisions based on their will and preferences. We also empower people to have their complaints processed in a balanced, fair and transparent manner.

3. Equality/Citizenship

We support the right of every person to assert and enjoy their human rights, to participate in society as an equal citizen and to fulfil their full potential within a life of their own choosing.

4. Respect

We work with the person in a way which demonstrates respect for the person as an individual and for their privacy, dignity and autonomy. All staff, partners and directors of NAS and the Patient Advocacy Service will act in a way that demonstrates respect for the people who use our services and each other.

5. Empowerment

We aim to facilitate the person to be an active participant in decisions which affect their life, through the way in which the advocacy process is carried out as well as the outcomes it seeks to achieve. We also aim to empower the person to make a complaint or engage with a review process and seek answers when things go wrong.

3. Introduction



The National Advocacy Service for People with Disabilities (NAS) provides an independent, confidential and free, issues-based representative advocacy service.



The Patient Advocacy Service is provided under the auspices of the National Advocacy Service for People with Disabilities (NAS). Following a competitive tendering process, NAS was awarded the Department of Health (DoH) contract in 2018. Launched in October 2019, the Patient Advocacy Service provides information and support to people who want to make a complaint about an experience they have had in a HSE-funded public acute hospital, and in the aftermath of patient safety incidents.



3.1 National Advocacy Service Remit

“My advocate really listened to me. It was really good to have someone on my side.”

Emma, who used the NAS Service in 2020

NAS provides an independent, confidential and free issues-based representative advocacy service.

NAS is funded and supported by the Citizens Information Board (CIB) which has a mandate under the Citizens Information Act 2007 and Comhairle Act 2000 to support the provision of advocacy for people with disabilities.

NAS operates on the principles that people with disabilities:

- Make decisions about their lives.
- Access the supports they need to enable them to live their lives and enjoy meaningful participation in family, work and leisure.

- ▶ Are listened to and consulted by their families and those who provide their services.
- ▶ Can enjoy the benefits of participation in and contribution to their communities if they so choose.

NAS has a particular remit to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and those who have limited informal or natural supports.



3.2 Patient Advocacy Service Remit

“Speaking to a patient advocate was a big help, even our chat helped me to offload my anxiety.”

Jack, who was supported by the Patient Advocacy Service in 2020

The Patient Advocacy Service is commissioned and funded by the National Patient Safety Office in the Department of Health. The Patient Advocacy Service is fully independent of the HSE and its hospitals.

The Patient Advocacy Service empowers people by supporting them to assert their views and seek answers and outcomes through the HSE complaints process.

The Service’s advocates do not take sides on an issue, but rather seek to ensure that a process is fair, and that the individual’s views, concerns, and decisions are addressed. The Patient Advocacy Service also aims to work with hospital teams to improve complaints systems.

3.3 Our Funders

The National Advocacy Service is funded by the Citizens Information Board (CIB). Since 2019, NAS has also received funding from the Department of Health (DoH) to provide the Patient Advocacy Service.

Citizens Information Board (CIB)

The Citizens Information Board (CIB) has, under the Comhairle Act 2000 section 7, as amended by Section 4 of the Citizens Information Act 2007, among its functions the following:

- ▶ to support the provision of or, where the Board of CIB considers it appropriate, to provide directly, independent information, advice and advocacy services so as to ensure that individuals have access to accurate, comprehensive and clear information relating to social services and are referred to the relevant services;
- ▶ to assist and support individuals, in particular those with disabilities, in identifying and understanding their needs and options and in accessing their entitlements to social services;
- ▶ to promote greater accessibility, co-ordination and public awareness of social services and of information, advice and advocacy services provided in relation to such services whether by a statutory body or a voluntary body;
- ▶ to support, promote and develop the provision of information on the effectiveness of current social policy and services and to highlight issues which are of concern to users of those services.

Department of Health (DoH)

The Department of Health's (DoH) mission is to improve the health and wellbeing of people in Ireland by delivering high quality health services and getting the best value from health system resources. Its role is to provide strategic leadership for the health service and to ensure that government policies are translated into actions and implemented effectively.

3.4 What the National Advocacy Service Does



NAS advocates take affirmative action to uphold the person's rights, ensure fair and equal treatment and access to services. They make certain that decisions are taken with due consideration for their unique preferences and perspective. The work of advocates ranges from providing information and advice, to longer term full representative advocacy.

Independent, representative advocacy is directed by the people who use it. It is person centred, accountable, accessible, impartial and independent of service providers, families and other supports. NAS representative advocacy involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Issues can be about any aspect of a person's life and the advocacy plan is directed by the person. Where the person communicates differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication), the advocacy plan is still directed by the person.

3.5 What the Patient Advocacy Service Does



The Patient Advocacy Service provides free, independent and confidential information and support to people who want to make a formal complaint through the HSE 'Your Service, Your Say' complaints policy in relation to the care they have experienced in a HSE-funded public acute hospital, and in the aftermath of a patient safety incident. The service's trained advocates can:

- ▶ Support people to get information on the formal HSE complaints process 'Your Service, Your Say.'
- ▶ Explain what to include in their formal complaint, and how to write a formal complaint.
- ▶ Help people to prepare for meetings.
- ▶ Support people to explore their options following a response from the HSE to their formal complaint.

4. Strategic Plan

The National Advocacy Service strategic plan for 2020 brought together our leadership role and experience in providing professional, independent, advocacy services. The plan highlighted our role as a collaborative champion in developing and driving standards of practice in advocacy for people across Ireland.

The Strategic Plan was based around three strategic priorities: service, standards and policy. This plan can be found on the NAS website at:

https://advocacy.ie/app/uploads/2019/05/NAS_StrategicPlan_2018-2021.pdf



NAS Case Study*

Tom's Story: Impact of Day Service Closure

My name is Tom. I like to keep busy, meeting with my friends and family as much as I can. I have a physical disability and I live in a residential service with several other people.

I go to a day service which I really enjoy as I meet lots of people and get to socialise which is important to me. Unfortunately, the service was closed due to a Covid-19 outbreak and this was very tough on me.

I couldn't take part in my usual activities, such as meeting my friends, taking part in sports and enjoying crafting. I became bored and distressed as my daily routine had been interrupted. I felt anxious and unsettled and I didn't know how to cope. I contacted my NAS advocate remotely using messaging as this was my preferred option.

My advocate chatted with me on video calls and I was able to tell them how unhappy I was with my situation and explained that I wasn't doing anything in my residential service.

Together we discussed my advocacy plan and we decided to ask the residential service to give me a structured timetable for each day and to ensure I had support do different activities while my Day Service was closed.

I don't know what I would have done if it hadn't been for my NAS advocate. They supported me to have my wishes heard. The advocate came with me to meetings and helped to make sure that the residential service developed a new activity timetable for me.



This was reviewed every three weeks. I am now so much happier with the support plan in place. I have developed new skills, and new activities which I enjoy have been added to my schedule.

I'm grateful to NAS and my advocate for their support which made a hugely positive change to my life during the Covid-19 crisis.

This case study shows how NAS supported Tom to have his voice heard and his wishes upheld. The support of the advocate highlighted Tom's unhappiness and how he was being impacted by the Covid-19 restrictions. Tom was supported to speak out to have the opportunity to try new activities and learn new skills to overcome the impact of Covid-19 closures he was experiencing. The NAS advocate empowered Tom to make a change in his life.

* Please note, all of the case studies presented in this annual report have been anonymised in line with the services Case Anonymisation Policy. All personal details have been changed to ensure protection of the person's identity.



Patient Advocacy Service Case Study

Anne's Story: Visiting Access to Hospital

My name is Anne and my dad Sean was in hospital for a number of weeks during the Covid-19 pandemic. He lives with my family and we provide his daily care. Dad is elderly and has dementia so he can't use his mobile phone without help.

While he was in hospital I was not allowed to visit him due to restrictions. I found it very difficult to communicate with the hospital to find out what was happening. Most of the time I had no idea what was happening and I had to ring the ward several times a day to try get an answer. While in hospital my dad fell twice.

I offered to visit my dad for a short period each day as I was worried he would be feeling lonely and confused. My offer was turned down. I didn't want to cause trouble or make a complaint, I just wanted to be able to speak with my dad. I contacted the Patient Advocacy Service and spoke to an advocate.

My advocate gave me information and advice. She suggested I try to contact the Patient Advocacy Liaison Service at the hospital which I did but I wasn't able to get through. She then helped me ask for a meeting with my dad's team of doctors and nurses.

My advocate helped me with the types of questions I could ask, how I could raise my issues, and how I could raise my concerns for my dad and the impact this was having on his mental health.

With my advocate's supports, I was able to get visiting access to see my dad on compassionate grounds for 15 minutes a day. This was just enough time for my dad to know we were thinking of him and he was not alone.

This case study demonstrates the impact our advocacy can provide for people who contact the Patient Advocacy Service. It shows that our advocates always aim to direct the person to local supports provided by the hospital and to improve Anne and Sean's experience with an early resolution if possible. The pathway offered by the advocate allowed Sean to see his family and know he was not alone.



5. Strategic Priority Services

“My advocate showed so much professional integrity in pursuing my rights, despite all the issues caused by Covid-19. She would be an asset to any organisation.”

Laura, who was supported by a NAS advocate in 2020



5.1 Impact of Covid on Our Services

The Covid-19 pandemic had a significant impact on the services provided by NAS, particularly during the first lockdown. Prior to the first diagnosed case of Covid-19 in Ireland in March 2020, many health and social care providers entered into a state of preparation for the arrival of the virus. They focused on infection control measures and discharging of patients from acute hospital setting into nursing homes.

From mid-February 2020 until May 2020, many service providers were entirely focused on the safety of their residents and staff and there was little opportunity to engage meaningfully with NAS.

This inevitably led to a reduction in enquiries into NAS from third party referrers over that period. Moreover, ahead of the introduction of public health measures in March 2020, many providers had already moved to a no visitor policy. This meant that face-to-face meetings with both staff and residents were limited, which had an impact on enquiries into NAS.

Additionally, many of the issues normally present in NAS casework also changed in profile. For example, many people for whom NAS had been advocating to secure independent living finally came to fruition as services sought to reduce the number of residents.

The Patient Advocacy Service was also affected by the Covid-19 crisis. During different stages of the pandemic, depending on Covid-19's impact, it proved difficult to progress complaints and gain access to freedom of information requests.

Initially, people were understanding that acute hospital settings were dealing with a crisis and often did not submit their complaint, choosing to delay this process until the crisis was over. As a result, the period from March – May 2020 saw a reduction in the number of new contacts to the service.

However, as the months passed and delays continued for both new complaints and ongoing complaints, it led to frustrations. There was a lack of communication from hospitals with people regarding issues or delays. This led to complaints being escalated.

Similarly to NAS, the biggest challenge for staff in the Patient Advocacy Service was not being able to attend meetings with the people they support due to Covid restrictions. Most meetings were postponed, leaving families waiting for months to discuss review findings or complaint issues.

Move to working from home

One of the biggest impacts on the Services provided by both NAS and the Patient Advocacy Service was the forced switch to home working. Like most organisations in Ireland, the emergence of the Covid-19 virus in March 2020 meant it was impossible for staff in both Services to continue their normal way of office working, including meeting people face-to-face. Overnight, we moved to working from home.

This involved several issues and challenges, including the management of staff, the transfer of the Service's IT systems and the ability to engage with the people supported by the Services, given that face-to-face contact was no longer possible.

5.2 Response of our Services to Covid's Impact

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.

From a management perspective, both Services adapted their approach to peer support and learning by ensuring advocates communicated with each other. Team meetings, professional development and one-to-one peer support continued through online video calls.

In addition, both services manage national phone lines and online methods of enquiry (email, website). This meant they were able to continue to provide people with advocacy support at this challenging time. They have also embraced innovative new ways of working such as video calls, emailing and text messaging.

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

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.

It was not possible to meet with the people we support face-to-face, which meant NAS 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 communications challenges, NAS worked with people to ensure their will and preference were carried out.

When restrictions were partially lifted in 2020, NAS advocates were supported to restart face-to-face work in as safe a way as possible. Risk assessments were carried out for each visit, strictly adhering to infection prevention control measures, and assessments where face-to-face engagement was essential often took place in outdoor settings, including going for walks in public areas, often with the assistance of family members or keyworkers. Many Disability Service providers also organised meetings in gardens or large indoor spaces which were well ventilated and unoccupied.

Despite only being established in October 2019, the Patient Advocacy Service continued to support users of its service during the pandemic through its national phone line and online forums.

Working outside their remit, the Service's advocates also provided information and guidance to people around difficulties they experienced with their home-based care, whether living in their own home, community setting or nursing home. The Service also provided valuable links for people who have had difficulty in accessing information from their care settings.

At the beginning of the pandemic, the Patient Advocacy Service made proactive efforts to contact all acute public hospitals and offer its service to support communication with the public.

The Service sought updates on changing policies within hospitals as the pandemic progressed. This ensured that advocates could provide up to date and localised information to people who contacted its service.

It's advocates regularly reached out to acute public hospitals to seek updates on how they were progressing complaints received and Freedom of Information requests.

In addition, as part of the response to the first wave of Covid-19, the Service's provided empowerment advocacy on a pilot basis to the families of residents who died in a nursing home during the first wave of the pandemic. The advocates provided the families with support to make a complaint about their experience in the pandemic.



5.3 National Advocacy Service Work in 2020

NAS provides services to adults over 18 with disabilities. The range of issues which advocates have to navigate continues to grow, both in numbers and complexity.

NAS aims to provide a high-quality advocacy service with a focus on continuous improvement. We measure the quality of the work we provide through regular case review and supervision, provision of regular team meetings, practice development and formal training. NAS has also developed a Code of Practice underpinned by a suite of policies to support our advocates in their work. These policies are regularly reviewed to ensure we stay up to date with best practice and knowledge.

NAS has identified that as our work has become more complex and is provided to more people, we have a need for an increase in resources. This is most acute in locations where there are waiting lists for access to our service, but it is also needed across the country to ensure that as many people as possible have access to advocacy.

The number of people on the waiting list to access NAS services rose from 130 (in January 2020) to 153 (at the end of December 2020). NAS has not received funding for any new permanent posts since 2011, despite an increase of over 50% in the number of enquiries and cases since 2015.

NAS advocates help people in two ways, with full representative advocacy, and with short-term advocacy and information support.

- Overall, NAS received a total of 2,706 initial enquiries in 2020. This figure was lower than 2019 when there were 3,454 initial enquiries.

As was the case for all essential support services, the overall reduction for NAS was largely due to a drop off in enquiries from April – May 2020, when the first Covid-19 lockdown took place.

During this period, NAS moved to remote working which meant it was not possible for NAS Advocates to meet people face-to-face to fully observe and understand their will and preference. In addition, third party referrers lacked the capacity to make enquiries to NAS due to their focus on the Covid response. It should also be noted that a reduction in NAS resources made it more challenging to encourage and process such enquiries.

- NAS provided full representative advocacy to 1,049 people in 2020. This work involved extended engagement with individuals, ensuring that their will and preferences were heard, understood and taken into account in decisions for each person. It also involved writing correspondence, attending meetings with the person in a variety of settings, speaking up for the person and supporting them to speak up for themselves.

- ▶ In addition, NAS also provided short-term advocacy support and information support to people with disabilities. NAS engaged in 2,706 instances of such support in 2020. This involved supporting individuals to self-advocate, through information provision and empowerment. It included one-off representations, such as writing a letter, information provision by phone, and short-term support. It also included signposting and referrals to other services.
- ▶ Of the 1,049 full representative advocacy cases in 2020, 591 cases had been open from 2019, while 458 new cases were opened in 2020.

Combining both ways that NAS advocates help people, NAS provided advocacy support in 3,755 pieces of work in 2020, continuing the overall pattern of increased yearly engagement since 2015.

The continued demand for the service resulted from several factors:

- ▶ Despite the Covid-19 restriction preventing face-to-face meetings, NAS continued to engage in substantial promotional work in disability services. Alternative technologies, such as video calls, were utilised, with 203 online presentations and meetings held to promote the service in 2020;
- ▶ Ongoing engagement with key stakeholders such as the HSE and service providers to improve and enhance referral processes;
- ▶ External societal factors related to the impact of Covid-19 also impacted on demand for the service. For example, greater numbers of people required support when dealing with mental health and isolation issues cause by the pandemic, while other emerging issues included delayed transitions from residential settings, delayed court hearings and significant waiting lists to access psychiatry;
- ▶ The delayed enactment of the Assisted Decision Making (Capacity) Act 2015 meant that Ward of Court cases continue to consistently feature as a complex element of NAS work;
- ▶ An improved understanding of the rights of people with disabilities to be involved in decision making following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).



5.4 Patient Advocacy Service Work in 2020

“My advocate supported me to feel enabled, empowered and in control. I felt able to make sense of it and make considered decisions through a difficult process.”

Kate, who was supported by the Patient Advocacy Service in 2020

Commissioned by the National Patient Safety Office in the Department of Health and provided by the National Advocacy Service for People with Disabilities (NAS), the Patient Advocacy Service provides information and support to people who want to make a complaint about an experience they had in a HSE-funded public acute hospital.

In line with the services provided by NAS, the Patient Advocacy Service works to ensure a high-quality advocacy service is provided to people who need our support, with professionally trained advocates focused on continuous development. The Patient Advocacy Service is fully aligned with the professional standards and policies operated by NAS.

As is the case with NAS, the Patient Advocacy Service’s goal is to continue to improve. To achieve this, its advocates take part in weekly team meetings, weekly practice development, and ongoing case review and monitoring.

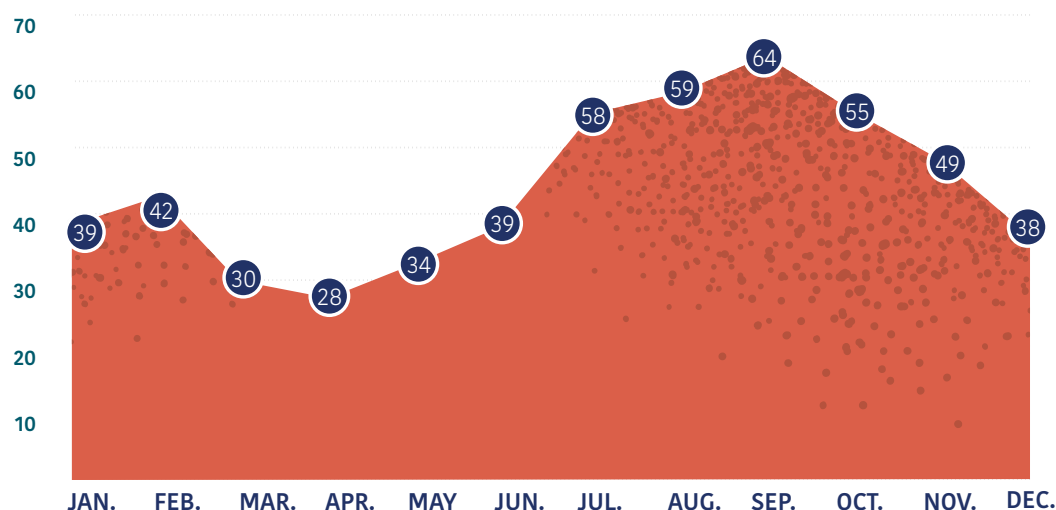
2020 was the first full year of service delivery for the Patient Advocacy Service therefore there is no comparison to previous years’ service delivery.

In 2020, the Service received 535 new complaint enquiries, of which over 1,281 separate complaint issues were identified (since April 2020). 154 of the individuals supported had issues impact by Covid-19.

There was a dip in new contacts received by the Service between March and May 2020, which is likely to be indicative of the impact of Covid and the unwillingness of service users to make a complaint against an already stretched health service. A further dip occurred in November and December 2020 when public health restrictions were again at their peak.



2020 New Contacts by Month for the Patient Advocacy Service



Of the 535 new contacts received by the Service, 451 were short term advocacy enquiries, including one-off representations, such as sending a person a template letter, providing information by phone, and signposting and referrals to other support services.

83 new contacts were given full 1-1 advocate support. This work involved extended engagement with individuals, ensuring that their will and preferences were heard, understood and taken into account in decisions for each person. It also involved writing correspondence, attending meetings with the person in a variety of settings and supporting them to speak up for themselves.

Total Combined NAS and Patient Advocacy Service Work¹

Year	Combined NAS Total Cases & Initial Enquiries	Patient Advocacy Service Cases
2015	2,145	N/A
2016	3,741	N/A
2017	3,628	N/A
2018	3,941	N/A
2019	4,485	65
2020	3,755	535

¹ This table outlines the combined advocacy information support and representation casework carried out by the National Advocacy Service over the past six years. It also includes the Patient Advocacy Service's case work in 2019 and 2020.

5.5 Complexity of Work by Our Services

Complexity of NAS Work

The number of issues per full, representative advocacy case for NAS has continued to increase each year. This was also the case in 2020, underscoring the complex nature of the casework.

Cases with more than one issue can be particularly complex as NAS advocates may have to coordinate communication with a large number of stakeholders and agencies that have become involved in a person's life.

Complex issues can be interdependent. For example, in an access to justice case there can often be an impact on a person's housing or day service situation which also requires advocacy support. Through advocacy plans, the complex work of our advocates can be managed and focused. Casework with individuals are closed when the issues in the advocacy plan are resolved.

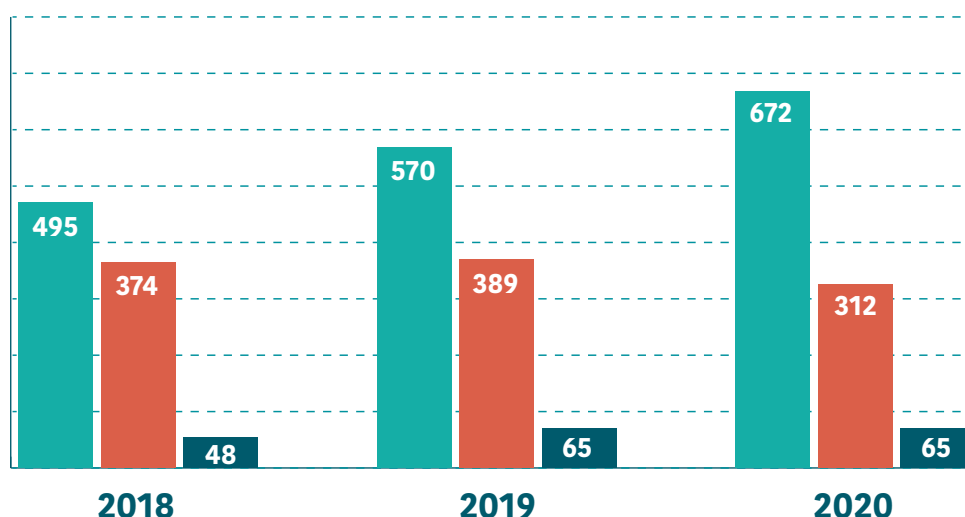
The majority of NAS cases now have between 2 and 7 issues. This has risen from 495 cases in 2018 to 672 cases in 2020.

Of the 1,049 full representative advocacy cases in 2020, 312 (30%) had one issue, 672 (64%) had two to seven issues and 65 cases (6%) had eight issues or more.

This increase is due to several factors:

- ▶ Increased awareness of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) among service providers
- ▶ Embedding of the HSE Safeguarding Policy
- ▶ Increased knowledge among disabled people
- ▶ Increased knowledge and skills among NAS staff
- ▶ Increased complexity of process around accessing e.g. home care, PA hours etc.

NAS Advocacy issues Per Case Nationally



Complexity of Patient Advocacy Service Work

From April 2020, the Patient Advocacy Service used the Healthcare Complaints Analysis Tool (HCAT)², developed by the London School of Economics and Political Science. The HCAT was developed as a framework to gather information on healthcare complaints so this information can be used to improve service delivery.

The Patient Advocacy Service used HCAT to record the complaints issues for 535 advocacy cases in 2020. Of these cases, 121 were outside the remit of the Service.

There were 316 cases that had between 1 and 5 complaint issues, 86 cases that had between 6 and 10 complaint issues, and 5 cases that had between 11 and 15 complaint issues.

These complaint issues included people's anxieties not being addressed; families having difficulty phoning hospital healthcare units, family visiting being unavailable in hospitals, and staff not communicating care plans to patients.

These figures show the range of issues that people in hospitals had in 2020 and how serious and complex some of their complaint cases were. Some cases involved several different complaints at several different levels of severity. For the Patient Advocacy Service, the complexity of some cases was unexpected, but it showed the clear need for the Service, its professional trained advocates and the support they provide.



² London School of Economics and Political Science's Healthcare Complaints (HCAT) Analysis Tool <https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/learning-improving-and-accountability/bmjqs-2015-004596supp-new.pdf>

NAS Case Study

James' Story: Support with Housing, Payments and Custody Arrangements

My name is James. I am in my forties and I acquired a brain injury a few years ago after a stroke. I haven't been able to work since as I have difficulty with memory and planning tasks. My wife and I separated a couple of years ago and she and our children moved out of our family home. I couldn't afford the mortgage repayments so the mortgage had fallen into arrears.

I felt confused and alone, and this was made worse when the Covid-19 lockdown started in March 2020. I contacted NAS because this was a really stressful time for me. I wasn't seeing my children and I was panicking about the mortgage and wondering if I would be able to keep my home. I was getting a lot of letters from the bank.

The NAS advocate help me understand my rights in terms of custody of my children, retaining my home, and advice about how to apply for legal support. I was also finding it hard to manage financially.

Due to the restrictions, I couldn't meet my advocate face-to face-when I made the initial enquiry. The advocate and the HSE acquired brain injury support team organised for me to chat to the advocate using video calls from my home. This use of technology was a big help to me.

Being able to see the advocate's face and hear their voice helped me to relax and I knew someone independent

was there to support me. We talked everything through and I was able to explain my side of the story to someone who really listened.

My advocate reassured me that my rights would be upheld in the advocacy process. We also worked with the acquired brain injury support team to ensure the advocate knew how to support me to manage tasks and understand what communication plan worked best for me.

As I had a lot of issues, the advocate helped me prioritise them. Seeing the children was most important to me. The advocate helped me to apply for legal aid so that I could start legal action to sort out access arrangements, custody of my children and my separation.

The advocate also put me in touch with the money advice and budgeting service (MABS) to talk about mortgage payments, and helped me contact the Department of Social Protection to discuss my social welfare entitlements. I have been supported by my advocate at meetings with all these agencies during the lockdown.

I'm much more positive about life now, having negotiated a payment with the bank that I can manage. I am working with my advocate to have more access to my children. I have more choice and control in my life again.

This case study shows how NAS supported James to regain control over decisions he wanted to make in terms of family life, housing and managing his finances. Independent representative advocacy involves providing information, advice and support on issues affecting the person's Quality of Life. Independent advocacy involves speaking up on behalf of someone at meetings if they find it difficult to do so themselves. James is focusing on building the necessary skills to live as independently as possible.



5.6 Key Issues for Our Services

Key Issues for NAS in 2020

Many of the issues normally present in NAS casework changed in profile in 2020. For example, many people for whom NAS had been advocating to secure independent living finally came to fruition as services sought to reduce the number of residents.

Owing to the impact of the Covid-19 pandemic, the biggest issue worked on NAS advocates in 2020 was Capacity Building. This involved advocacy support for people with disabilities and their supporters, such as family members, to increase their skills and knowledge so they are able to address issues for themselves or the person they are supporting, like access to housing, justice, etc.

Housing and accommodation remained among the most significant issues worked on by advocates, but they made up a smaller percentage of the overall issues that in previous years. In 2019, housing accounted for 50% of issues, while in 2020 this figure was 20%.

Issues relating to residential and healthcare settings also came to the fore in 2020, along with issues around decision making and social care.

Where it was not possible to progress a case due to Covid-19, that case was closed. Cases in that category can be revisited at a later stage should the person so wish. NAS has been tracking the Covid-19 themes emerging in advocacy work throughout 2020.

In a general sense, isolation came up as an issue very frequently. Some other issues which have emerged include:

- ▶ Ward of Court hearings in High Court delayed and subsequently taken place via zoom. Where a person is subject to Wardship their own rights and freedoms are severely curtailed. Any delay is likely to have a significant impact on the individual
- ▶ Delayed court hearings in parenting with a disability
- ▶ Suspended access to children (parenting with a disability)
- ▶ Delayed transfers from residential settings
- ▶ Significant waiting list to access psychiatry
- ▶ Delayed neurological review in Ward of Court
- ▶ People isolated from all services not just advocacy
- ▶ Delays in assessment and provision of new home support and personal assistance services
- ▶ Application for protection orders by families struggling to cope with behaviours that challenge and a lack of mitigating respite and other clinical supports.

- ▶ Unplanned closures or reorganisation of congregated settings also occurred for non-Covid 19 reasons (implementation of requirements of HIQA reports or liquidation). This resulted in a large number of referrals being received from a

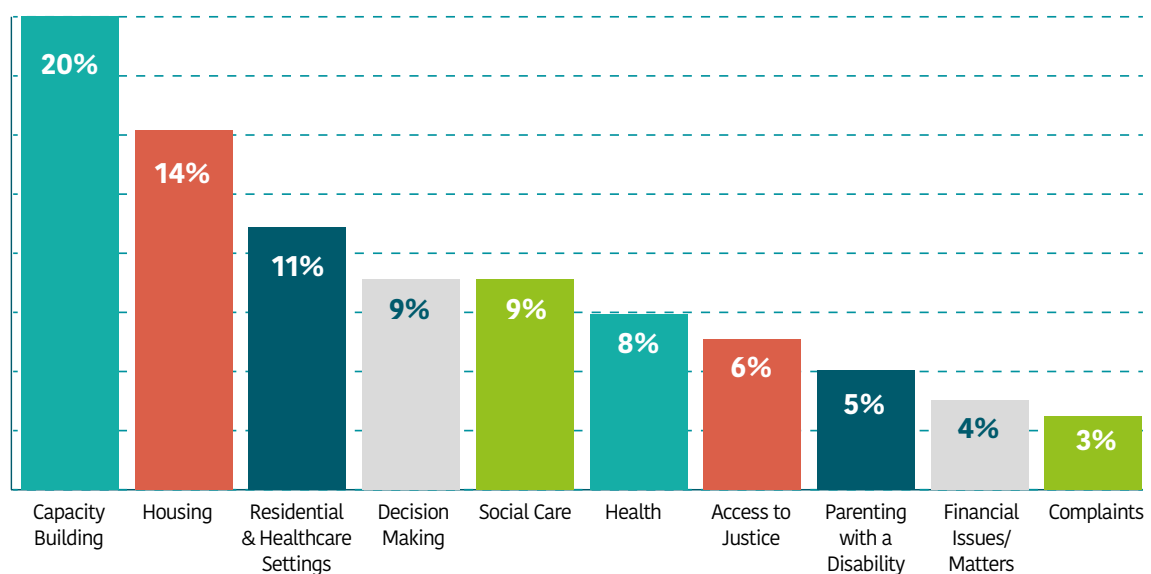
number of locations. NAS teams assessed the enquiries, provided group, and individual advocacy and moved to support in transition planning and support in decision-making. Many of these issues received extensive media coverage

There have also been some positives for people with disabilities:

- ▶ Access to independent living package after lengthy (sometimes years) periods in inappropriate nursing home or hospital
- ▶ Access to social housing due to suspension of evictions
- ▶ People experiencing more connection to their local communities and choice in how they receive supports with outreach services rather than centre-based services being provided.
- ▶ NAS staff worked with local authority Community Call organisations and other emergency outreach organisations (e.g. ALONE, St Vincent de Paul, Lions Club and An Garda Siochana) to have assistance provided to those without natural supports living in the community for assistance with prescriptions, grocery shopping, equipment repair, access to Covid-19 testing etc.

National Advocacy Service Issue Categories in 2020

Areas Requiring Support



Key Issues for the Patient Advocacy Service in 2020

As outlined earlier, the Patient Advocacy Service identifies issues within individual contacts in line with the London School of Economics and Political Science's Health Complaints Analysis Tool (HCAT). The Chart below shows the top issues identified by severity rating:

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).

The HCAT also lists the specific types of issues people had with their care in relation to quality and safety, management issues (including environment and institutional processes) and relationship issues (including listening, communication and respect, and patient's rights.)

The complaint issues received by the Patient Advocacy Service in 2020 are broken down as follows:

Severity Level	No. of Complaints Issues	Types of Complaints
Severity 1	340	<ul style="list-style-type: none"> ▶ Staff spoke in a condescending manner ▶ Phone calls not returned ▶ Difficult phoning healthcare unit
Severity 2	687	<ul style="list-style-type: none"> ▶ Anxieties acknowledged, not addressed ▶ Visiting unavailable ▶ Complaint not responded to ▶ Rude behaviour
Severity 3	257	<ul style="list-style-type: none"> ▶ Unable to access specialist care ▶ Staff ignored severe distress ▶ Discharge without sufficient examination ▶ Patient left with unexpected disabilities

The top 10 complaint issues were:

1. Anxieties acknowledged, not addressed
2. Difficulty phoning healthcare unit
3. Visiting unavailable
4. Staff did not communicate care plan
5. Unable to access specialist care
6. Patient not monitored properly
7. Complaint not responded to
8. Rude behaviour of staff towards patients
9. Chasing departments for an appointment
10. Staff spoke in a condescending manner

Since the pandemic began, the Patient Advocacy Service has tracked all Covid-19 related enquiries to its service. A total of 151 contacts (28% of enquires into the service) had a Covid related element to their enquiry.



The top issues identified were:

- ▶ Unable to access specialist care
- ▶ Staff ignored severe distress
- ▶ Visiting Unavailable
- ▶ Staff did not communicate care plan
- ▶ Rude behaviour of staff towards patients
- ▶ Patient not monitored properly
- ▶ Medical procedure delayed
- ▶ Delay noticing deteriorating condition
- ▶ Complaint not responded to
- ▶ Anxieties acknowledged not addressed
- ▶ Difficulty phoning healthcare unit

Patient Advocacy Service Case Study

Mary's Story: Requesting Access to Information Following Maternity Care

My name is Mary, I'm in my thirties, and had a traumatic experience in relation to my maternity care in hospital. It was a really difficult time for me and I did not feel that I got the support I needed from the hospital staff.

I wanted to make a complaint about my care to the HSE and I requested a copy of all the files the hospital held about me. However, the freedom of information request I sent the hospital was turned down.

I contacted the Patient Advocacy Service, and my advocate was really helpful from the start. They listened to my experiences, gave me the opportunity to explain my concerns and supported me to write a letter appealing the decision. The appeal was successful, and I received all of my files.

My advocate supported me to review the files, write a chronology of what happened, and list the questions I wanted the hospital to answer. While reviewing the files, my advocate and I discovered that the hospital was carrying out its own internal review which they

had not told me about. I was angry as it felt like I wasn't getting the chance to have a say on my own experience.

My advocate helped me to request a copy of all internal reviews relating to my case. When the records arrived, my advocate again spent time supporting me to read through the documents.

It was very upsetting for me to relive such a traumatising and stressful experience. My advocate offered me support and explained the options available, such as having a meeting with the hospital or making a complaint.

Having the advocate there to support me and explain everything gave me the confidence to make my own decision about what to do next. I don't know how I would have coped if I had to do this on my own.

I decided to take part in the hospital internal review process and voice my concerns. I'm happy I did because the hospital have apologised and agreed to improve support in the future.

This case study shows the importance of having a knowledgeable advocate from the Patient Advocacy Service to ensure that the voice of the person is heard and that the person is included in the process. The support and information provided to Mary by the advocate gave her the confidence to voice her concerns and have her own say about her experience. Mary got an apology from the hospital and assurances that they would improve their service.

5.7 Who Engaged with the National Advocacy Service

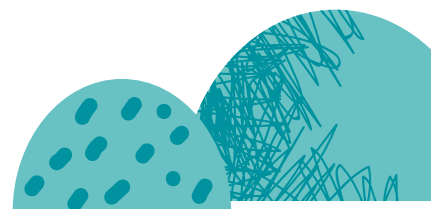
NAS has a particular remit to provide advocacy services to people in particularly vulnerable situations, but we worked with a diverse range of people in 2020 experiencing many different types of disabilities.

As was the case in 2019, intellectual disability continued to make up the largest number of cases, at 48% of cases. People with intellectual disabilities who engage with the NAS service are mainly living in residential services or attending day services.

Also, people with mental health issues increased as an element of NAS work in 2020. This is likely to have resulted from the impact of the Covid-19 pandemic.

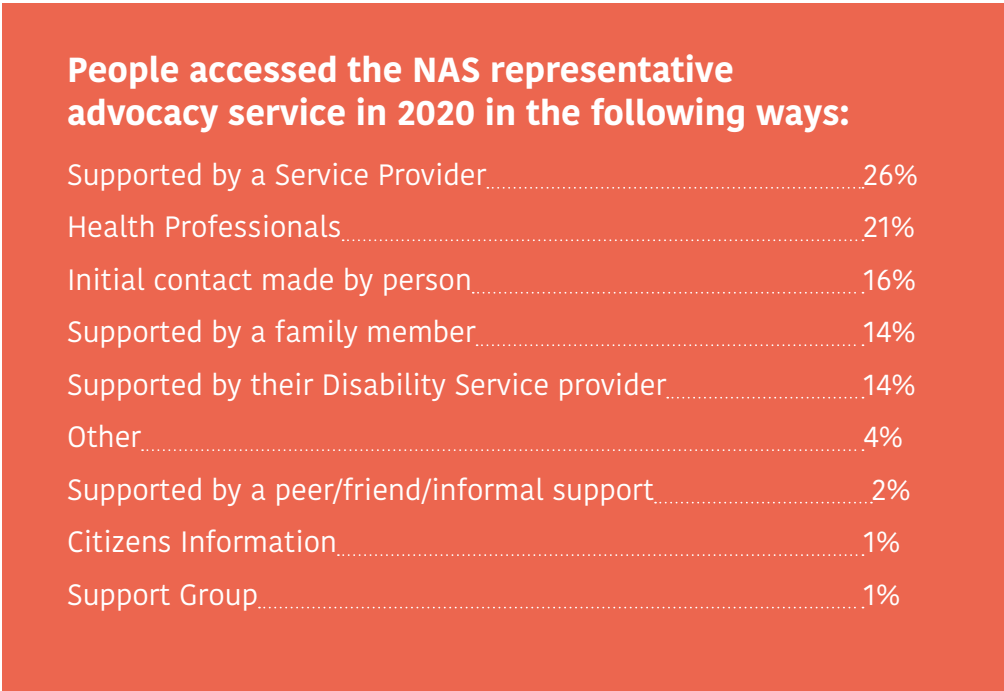
Most notably, 2020 continued to show that a significant element of NAS work is with people who have multiple disabilities. For example, a person may have an intellectual disability and also a physical disability, or mental health issue. The table below outlines the percentage of advocacy cases where a type of disability was present.

Disability Type	2018	2019	2020
Intellectual Disability	45%	49%	48%
Physical Disability	31%	32%	30%
Mental Health	24%	24%	27%
Autistic Spectrum	17%	14%	14%
Learning Disability	12%	11%	13%
Acquired Brain Injury	8%	8%	13%
Sensory Disability	8%	12%	8%



5.8 How did the Person Come to Use Our Services

People can apply to use the services provided by NAS and the Patient Advocacy Service by contacting our national phone lines, filling out a form, or emailing. Other people, such as family, friends or service providers, can also refer individuals to the service.



People accessed the Patient Advocacy Service's empowerment advocacy service in 2020 in the following ways:

Online search engine	40%
Hospitals.....	19%
Other Advocacy Services & Support Groups.....	9%
CIB Services.....	9%
Word of mouth.....	8%
PAS promotions / presentations/ leaflets.....	4%
Politicians.....	4%
People who previously used the Service.....	4%
Regulatory Bodies.....	2%
Media.....	2%



40% accessed the service with an online search engine.



19% accessed the service through hospitals.



6. More Highlights

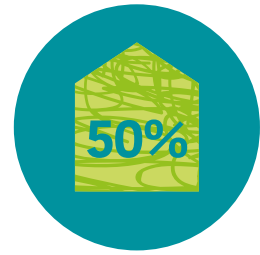




1,049 people supported by full representative NAS advocacy in 2020.



2,706 instances of short-term NAS advocacy support (information provision, one-off intervention & arms-length advocacy).



50% increase in the number of cases worked on by NAS advocates since 2015.



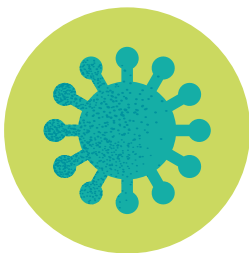
153 people on the waiting list to access NAS services at the end of December 2020. There was an increase of 23 people during 2020.



458 new NAS cases in 2020



453 short term enquiries were dealt with by the Patient Advocacy Service in 2020.



154 of the people supported by the Patient Advocacy Service had issues impacted by Covid-19.



NAS Case Study

Clara's Story: Support with Transition to Housing

My name is Clara, I am in my thirties and I have a physical and an intellectual disability. I need help when it comes to carrying out most everyday activities. I was referred to NAS by my family who were struggling to provide me with the support I needed, despite their best efforts.

I was registered as homeless and I was living in an overcrowded two-bed apartment with several other family members. The lift in the apartment block was often out of order and the apartment was so small that home care agencies could not safely provide me with personal care. As a result, I had no home care hours in place.

I attended a day service three times a week and was supported to get outside into the community for a few hours, but it simply wasn't enough.

I met up with my NAS advocate and we agreed that they would contact my local authority and HSE Disability Services on my behalf to explain my housing issues and ask for respite and home care supports.

Things seemed to be progressing well, but then the Covid-19 pandemic occurred I was no longer able to attend my day service. I was now stuck in the apartment all day.

For family reasons, I had to leave the country for a short time. While I was away, the local authority contacted my family in Ireland to offer me a house. When they were told I was out of the country, the offer was withdrawn, they said I would be removed from the housing list pending an investigation, and my social welfare payment was stopped.

On top of this, my return trip to Ireland was postponed due to Covid-19 restrictions. I was out of the country for several months. This was a very difficult time for me.



My advocate helped me to gather my documents, outline the reasons for my travel and prove that I had tried to return to Ireland. The advocate also supported me to contact the Department of Social Protection to ensure my payment was reinstated. When I was finally able to come home, my advocate spoke with the local authority and I was put back on the housing list. Luckily, the house I had been offered was still available and I was able to move in with a family member.

Following this, the advocate contacted HSE Disability Services and helped me get home care supports. I now have an accessible home, with support from a carer and a small number of home care hours during the week. My social hours have also restarted as Covid-19 restrictions have eased and I am attending my day service one day a week.

Clara was supported by her Advocate to access housing and resume home care hours which had previously been restricted due to the inaccessibility of her previous home. The advocate also acted to ensure that Clara's rights to housing and social welfare benefits were returned to her following a short visit to her family which was affected by Covid-19 travel restrictions. The advocate ensured that Clara was kept informed throughout the process and updated her regularly.



7. Strategic Priority Standards

“The support, empathy and patience I received from my advocate will have a big impact on my quality of life and the quality of life of my family.”

Anna, who used the Patient Advocacy Service in 2020



Over several years NAS has carried out significant work to develop its robust policies and quality working standards. In 2020, this included using its experience and knowledge of the sector to develop the Patient Advocacy Service and align its professional and advocacy standards with those of NAS.

7.1 Ongoing Development of the Patient Advocacy Service

Following its establishment in October 2019, the Patient Advocacy Service began 2020 with the aim of building understanding and awareness of its Services among its stakeholders and the wider public.

The service provides information and support to people who want to make a complaint about an experience they have had in a HSE-funded public acute hospital.

In addition to the significant impact of the Covid-19 virus, this was only the second year the Service had been in operation. The impact of the pandemic led to several operational challenges. The Service also looked to pivot its activities to ensure it could effectively respond to new complaint issues emerging from Covid crisis.

The Patient Advocacy Service responded quickly and efficiently to the Covid-19 restrictions, which meant staff had to move from office to home working overnight.

The Service adapted effectively to the change in circumstances and its national phone line remained open throughout the lockdown, providing invaluable support to those who required it.

This swift move was supported by the effective infrastructure of the Service's ICT system, which made it straightforward to support the change to home working and maintain service standards. The Patient Advocacy Service also continued to build its capacity and effectiveness during 2020.

The Service signed an agreement to provide support to residents and families of residents in a Nursing Home affected by the Covid-19 crisis.

Professional Standards

The Patient Advocacy Service is fully aligned with the professional standards operated by NAS. There were 31 policies adapted in 2020 for the Patient Advocacy Service, including the Child Protection Policy and Procedures, Complaints and Feedback Policy, Conflict-of-Interest Policy, Case Anonymisation Policy, Code of Practice, Planning, Preventing and Responding to Covid-19 in the Workplace, and the Covid-19 Response Plan SOP.

Patient Advocacy Service Strategic Advisory Forum

The Strategic Advisory Forum, established by the National Patient Safety Office (in the Department of Health), continued to monitor the progress in the development of the Patient Advocacy Service in 2020. Despite the Covid restrictions, the forum met virtually in November 2020 to offer strategic advice in relation to the ongoing development of the Service.

The membership of the Strategic Advisory Forum was as follows in 2020:

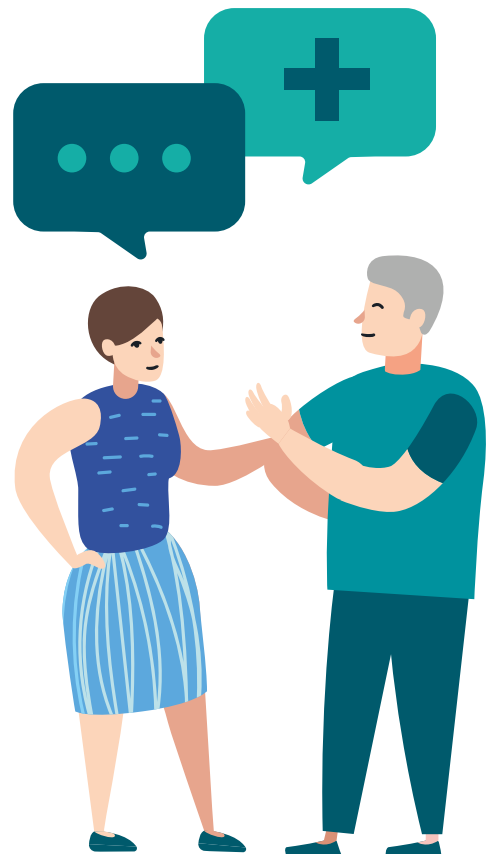
- ▶ Department of Health National Patient Safety Office
- ▶ CEO Mental Health Commission
- ▶ CEO HIQA
- ▶ State Claims Agency
- ▶ HSE Acute Operations National Director
- ▶ HSE Chief Clinical Officer
- ▶ Two Patient Representatives

Joint Working Group to develop a Memorandum of Understanding (MoU) between the HSE and the Patient Advocacy Service

In early 2020, a joint working group between the Health Service Executive and the Patient Advocacy Service was established to develop a Memorandum of Understanding between the services.

Although paused in stages throughout 2020 due to Covid 19 and the draw on HSE resources the MoU was finalised late in 2020 and signed in early 2021.

The MoU outlines how the organisations pledge to work together to further improve services for people who wish to make a complaint about the care they have received in a public acute hospital. It sets out their commitment to co-operate to ensure that people receive a timely, compassionate and comprehensive response to their complaints.



Patient Advocacy Service Case Study

Kate's Story: Complaint to Hospital about Error in Dispensing Medication

My name is Kate and my husband passed away in hospital after a period of illness. However, while my husband was in hospital, I noticed that he was being given the wrong medication.

I raised questions informally with the doctor and nurses who were caring for him about whether the medication was affecting his health but I got no response.

I contacted the Patient Advocacy Service to ask for advice and support. I just wanted answers regarding the mistake and to ensure that it did not happen to anyone else. The communication from the hospital had been poor, so I decided to make a formal complaint to the HSE.

The hospital responded by telling me that they were carrying out an internal investigation and they would let me know about the outcome. I thought progress was being made, but I heard nothing for many months, despite contacting them several times.

Not only was I dealing with the grief of losing my husband, I felt I was being ignored by the hospital and other families could be at risk.

On advice from my advocate, I decided to complain to the Ombudsman about the long delays. The Ombudsman is responsible for investigating people's complaints about how they have been treated by public bodies in Ireland.

This action seemed to have an immediate impact and the hospital invited me to a meeting with the care team who looked after my husband in hospital. My advocate helped me prepare for the meeting, supporting me to decide on the points I wanted to raise and the questions I wanted answered. The advocate also attended the meeting to provide support.

At the meeting, the hospital offered an apology and provided an explanation as to why the mistake with my husband's medication occurred. They said the hospital was introducing a change in practice in relation to the way they dispense medication.

The positive result means I have been able to play a positive part in ensuring that the hospital avoids similar errors and the safety of other patients is protected. I could not have achieved this result without my advocate's support.

This case study shows the longer-term nature of some advocacy work to ensure the voice of the person is heard and that their rights are supported. It demonstrates the escalation pathways the advocate can support the person with when the process is not being followed. The advocate's knowledge ensured that Kate was given an apology and an explanation about what had happened. The help provided by the advocate with the complaint led to changes in policy and practice to ensure similar mistakes will not happen again.

8. Strategic Priority Policy

“Thank you so much for taking me all the way through this. It was so tough and such hard work I would have given up. I’m happy now I can make my own choices”.

David, who used the NAS service in 2020

NAS and the Patient Advocacy Service continued to contribute to social policy in 2020 through stakeholder engagements and policy submissions.

In its policy work in 2020, NAS sought to make sure that advocacy is recognised as playing an important role in ensuring that the equal legal capacity of people with disabilities is recognised and respected under the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The Patient Advocacy Service sought to make sure that advocacy is recognised as playing an important role in ensuring that people’s rights are upheld and they receive the highest level of quality care.

The Services continued to leverage their networks at local, regional and national level to ensure that the voice of people with disabilities continued to be heard, and that people were supported when making a complaint. This included engagement with HIQA, Ombudsman and other key agencies.



8.1 Stakeholder Engagement

Engagement with external statutory bodies on Covid-19 response & Policy response

The expertise of NAS and the Patient Advocacy Service enabled both Services to contribute to the response of statutory bodies to issues which emerged in Covid 19 testing, treatment discussions and monitoring and planning of health and social care delivery as the pandemic progressed.

NAS continued building positive working relationships with the HSE National Office of Human Rights and Equality Policy and National Quality Improvement Division. This was evidenced by:

- ▶ Contribution of chapter on Assisted Decision-Making publication for staff.
- ▶ Inputs into Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision Making during the Covid-19 Pandemic.
- ▶ HSE Quality Improvement Division Webinar on the role of advocacy in supporting decision making, particularly during COVID 19.

NAS was engaged at a national level in other fora:

HSE Disability National Consultative Forum to plan recommencement of non-Covid disability services

NAS took part in this forum for disability service providers, the HSE and advocacy organisations to work collaboratively on issues which emerged during the Covid-19 pandemic.

Department of Health Nursing Home Report Reference Group membership

NAS was part of a group of stakeholders established by the DoH as part of the State's response to the Covid-19 Nursing Homes Expert Panel.

Engagement with Ombudsman on Younger People in Nursing Homes

NAS advocates continued to engage with the Office of the Ombudsman to facilitate interviews with people under the age of 65 who are living in nursing homes.



Patient Advocacy Service Strategic Advisory Forum

As mentioned in section 6.1, the Strategic Advisory Forum for the Patient Advocacy Service continued to operate in 2020. The CEOs of HIQA and the Mental Health Commission, as well as the Chief Clinical Officer of the HSE sat on this Forum, amongst other members.

Signing of MoU between the Patient Advocacy Service and the HSE

A joint working group between the Health Service Executive (HSE) and the Patient Advocacy Service was established to develop a Memorandum of Understanding (MoU) between the services. The MoU outlines how the organisations pledge to work together to further improve services for people who wish to make a complaint about the care they have received in a public acute hospital.

Government Departmental and Inter-Agency Groups

Throughout 2020, NAS and the Patient Advocacy Service were active participating members of the following groups:

- ▶ Reference Group for Implementation Group on Nursing Homes Expert Panel Report
- ▶ National Oversight Group for Implementation of Women's Health
- ▶ HSE Patient Engagement Framework Working Group
- ▶ National Inpatient Experience Survey Board
- ▶ Letterkenny University Hospital Gynaecology Clinical Service Review: Implementation of Recommendations Oversight Group



8.2 Public Consultations and Submissions

NAS and the Patient Advocacy Services responded to public consultations and policy submissions in areas related to our remit, specifically around the impact of Covid-19. These social policy submissions were developed with the support of the social policy team of the Citizens Information Board.

Submission to Special Oireachtas Committee on Covid-19, July 2020

NAS and the Patient Advocacy Service provided a joint submission to the committee explaining how Covid-19 impacted on our Services and the people we support, the issues they faced, our concerns regarding their care, actions taken by the Service's advocates to provide support, and our recommendations for action by Government.

Submission to Nursing Home Expert Group, June 2020

NAS and the Patient Advocacy Service provided a joint submission to the Oireachtas Nursing Homes Expert Panel Consultation Survey in which we outlined our learning and recommendations in relation to the impact of Covid-19 on nursing homes. In the submission, we outlined issues with communication and support for residents and their families, infection control and HSE governance. Our recommendations included the need for test and tracing, improved communication, safe meeting areas, single occupancy rooms, an external HSE safeguarding process and improved infection control measures.

Response to Law Reform Commission consultation on Adult Safeguarding

The Patient Advocacy Service and NAS provided a joint submission outlining our learning and recommendations. Each of the questions listed under the 11 issues were addressed generally or specifically, as far as possible. The issues included defining key terms for adult safeguarding, different types of abuse and neglect, financial abuse, independent advocacy and multi-agency collaboration. There was a specific focus on Issue 9, independent Advocacy. The submission outlined the potential role of NAS and the Patient Advocacy Service developing national standards for advocacy provision and continuing work toward getting statutory powers for advocates.

Consultation on the development of a National Policy Framework for Open Disclosure in Ireland

The Patient Advocacy Service provided feedback on a consultation on the development of a national policy framework for open disclosure in Ireland.

The Services also continued with business-as-usual activities in their policy work, which included:

Submission to Joint Oireachtas Committee on Disability Matters

NAS provided a submission on recommendations for the Committee's programme of work. NAS recommended the following areas for consideration and exploration by the Committee: -

- ▶ Housing and accommodation issues for people with disabilities – choice and control
- ▶ Justice issues – particularly ward of Court and parenting with a disability
- ▶ Impact of Covid 19 on access to services – day services, transport
- ▶ Role of advocacy in supporting people to have their voice heard and to be decision makers

The Patient Advocacy Service carried out the following pieces of policy engagement:

HSE National Care Experience Maternity Survey – Message of Support

The Patient Advocacy Service provided input to the HSE's response to the National Maternity Experience Survey 2020. We welcomed the HSE's response to the findings of the survey and stressed the importance of improving the health system so that the voices and experiences of patients are heard.

Blog for Future Health Summit

The Future Health Summit is a major conference bringing together the health sector across Ireland to discuss current issues and future plans. The Summit was cancelled due to the Covid-19 crisis. As a delegate, the Patient Advocacy Service was asked to write a blog for the Summit's website explaining how it responded to the Covid crisis.



NAS Case Study

Maggie's Story: Application and Administration of Nursing Home Charges

My name is Maggie, I am in my fifties and I have an acquired brain injury. I am currently living in my third nursing home in 13 years. I was referred to NAS about four months after moving to the third home because of some serious financial mistakes that had been made on my behalf.

My situation was quite a complicated one. My original nursing home place was funded by the Nursing Homes Subvention Scheme which in 2009 was replaced by the Nursing Homes Fair Deal Scheme.

The directors of my second and third nursing homes arranged my transfer between them, but they incorrectly told the HSE and the Fair Deal Scheme Office that my place had been fully funded by the old Nursing Home Subvention Scheme.

As a result, an arrangement for me to pay for my share of care through the new Fair Deal Scheme was not set up.

I was shocked when my advocate discovered this mistake meant I had built up a debt of over €45,000 to the HSE. Things got even more confusing when my advocate spoke to the Fair Deal Scheme office who said I wasn't paying enough money to the third nursing home and I also owed them a significant amount of money.

This was a difficult period for me, but my advocate supported me through it. The advocate sent the case to the HSE National Appeals Office for review.

The €45,000 arrears I owed to the HSE was wiped out and my Fair Deal payment was backdated, clearing the money I owed to the third nursing home.

The case study shows how an advocate supported Maggie to appeal the arrears that the HSE said she owed on her nursing home fees and demonstrated that the correct applications or assessments had not been made during the transfer between nursing homes. The advocate made numerous representations to the HSE to have the situation addressed, the significant arrears waived and the correct assessments made so that Maggie was charged correctly and could have some funds for her own personal use. The advocate ensured that Maggie was kept informed throughout the process and updated her regularly.



9. Key Enabler Awareness

“You’ve given me a huge boost. I enjoy our discussions and you have been so kind and professional.”

Eve, who was supported by an advocate from the Patient Advocacy Service in 2020

The NAS Strategic Plan identified two key enablers: awareness and capacity building, to help achieve the goals set in relation to strategic priorities around services, standards and policy. This section outlines work in 2020 in relation to the first key enabler: awareness.



9.1 Outreach and Promotional Work

The Covid-19 pandemic and the subsequent restrictions had a significant impact on outreach and promotional work carried out by NAS and the Patient Advocacy Service in 2020. Covid restrictions meant that public gathering and face-to-face meetings were not possible.

Despite these issues, both NAS and the Patient Advocacy Service continued to proactively promote their Services in 2020.

The aim for NAS was to continue to raise awareness and understanding of its established Service and further build on its reputation as a leading stakeholder in the advocacy sector. As a result of Covid-19, the Service also wanted to make people aware that it was continuing to provide advocacy support, despite the Covid restrictions. It also aimed to reach targeted groups, referring organisations and the people who needed the Service's support to make them aware that it was continuing to provide advocacy support, despite the Covid restrictions.

For the Patient Advocacy Service, moving into its second year of work, its promotional work was focused on continuing to build an awareness about the service with key stakeholders (Hospitals, Professional bodies, the Advocacy sector and Support Organisations) and the wider public. Like NAS, the Covid pandemic meant the Service had to switch its communication, particularly in the first lockdown, to make people aware that it was continuing to provide advocacy support, despite the Covid restrictions.

Promoting the National Advocacy Service

The NAS website, which was developed in 2019, received 14,675 visitors in 2020, of which 14,432 were new users. The website received an average of 50-60 visits per day on weekdays.

As face-to-face meetings were not possible, NAS increased its use of social media in 2020.

- The Service's Facebook page increased from around 1,300 followers at the start of 2020 to nearly 1,800 at the end of 2020.

Also in 2019, NAS advocates, senior advocates and regional managers took part in 203 online outreach events. This included online presentations and meetings with groups in disability services, hospitals, residential centres and day centres.

NAS staff presented to people with disabilities who could potentially use the NAS service, and to staff and other stakeholders amongst whom an increased awareness and understanding of the service leads to increased referrals.

In addition to promoting access to the service, these meetings and presentations help to increase understanding of NAS amongst staff, and therefore can facilitate better cooperation by staff with advocates in terms of allowing access to people, documents and decision-makers.

Presentations to people with disabilities are delivered in a way that is appropriate to the communication styles of individuals, and can involve imagery, videos, simple case examples and games.

These presentations not only promote access to and effectiveness of the NAS service, but also promote a greater appreciation of what a rights-based and person-centred approach to care is. They highlight the need to put the will and preferences of people with disabilities at the heart of decisions that affect their lives.

In December 2020, NAS launched our 2019 Annual Report. The report included several updates on the development, launch and initial activity of the Patient Advocacy Service, which was established in October 2019.

Supporting the launch of the report, we developed a video featuring highlights of the year which has been viewed several hundred times. Several posts about the annual report were made on our social media accounts and the Irish Examiner wrote an article which appeared in both the print and online editions of the paper.

9.2 Promoting the Patient Advocacy Service

Communications Strategy, Presentations and Promotion

Following the work to establish the Service's communications activities in 2019, plans were developed for ongoing promotion of the service in 2020. The Patient Advocacy Service developed a comprehensive communications strategy in 2020 to promote its Service among key stakeholders and the wider public across Ireland.

The objective of the communications strategy was to implement stakeholder engagement, advertising and PR activities that would boost awareness and understanding of the Service and increase the number of people contacting us. However, in the early stages of the Covid-19 pandemic, when the first lockdown took place, these communications plan were significantly curtailed.

Face-to-face meetings were no longer possible, so the Service accelerated its use of social media as a means of promoting its work, engaging directly with stakeholders and people who might benefit from our support. We contacted hospitals, TDs and Senators to let them know we were still operating. We also distributed promotional materials and offered online presentations and webinars.

As the lockdown eased, the Patient Advocacy Service was able to carry out the first stage of its strategy which involved promoting the Service to key stakeholders including hospitals, support and advocacy groups, the NAS network, elected representatives and regulatory bodies.

Significant work was carried out to contact these stakeholders via emails, phone calls and video calls, as face to face meetings were not possible. Over 600 engagements with stakeholders were made, including offers of presentations and promotional leaflets and posters, as well as requests for our information to be shared by stakeholder on their websites.

The second stage of the strategy involved advertising and PR work. Our goal was to promote the Service to the public by placing advertisements in print and online regional media across Ireland. We also planned to create a radio advertisement to be played in regional radio stations across Ireland. Due to the return to lockdown later in the year, the decision was taken to delay the advertising campaign until 2021.

Also in 2020, the Patient Advocacy Service developed our social media strategy to increase social media metrics across all our social media channels, including follows, likes and click throughs to the website. This helps us to reach and actively engage a wider range of stakeholders and potential Service users, including people we may not otherwise reach.

The Service increased its use of social media and developed its first social media strategy. The aim was to reach and actively engage a wider range of stakeholders and potential Service users:

- ▶ The Service's Facebook page, regarded as the key platform for engaging the public, increased from around 500 at the start of 2020 to nearly 2,500 at the end of 2020.
- ▶ The Service's Twitter account, used for engaging with stakeholders, had 273 followers at the end of 2020.
- ▶ A LinkedIn page was also created. It was mostly used for recruitment and had 73 followers by the end of 2020.

As a result of increased interaction and engagement across our social media platforms, visitors to the Patient Advocacy Service gradually increased over the course of the year. The site had 7,167 users in 2020, of which 7,024 were new users.



NAS Case Study

Peter's Story: Support to Deal with Adoption Process

My name is Peter, I am in my forties and have a learning disability that affects my mental health. I have a child who is in care and lives with a foster family. Due to my health issues, I have struggled to keep in contact with my child. I love my child very much and I would like to be able to see her much more often.

I was referred to NAS because my child's foster family had applied to adopt them. I was worried that I was going to lose my child. My social worker thought a NAS advocate would help me to understand what was happening and support me to take part in the process.

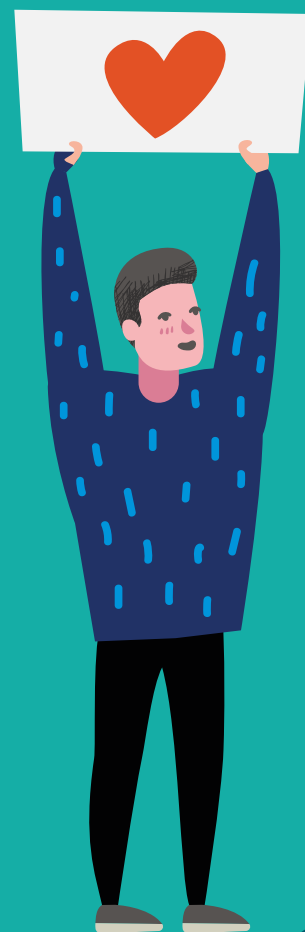
When the Covid-19 pandemic happened, it wasn't possible for me to attend face-to-face meetings with the adoption social worker or the adoption board. I was able to meet my advocate on video call and chat everything through.

My advocate supported me to get information from the adoption board in a format that was easy for me to read, so I could more fully understand the steps through the process, the decisions I was being asked to make and my own rights.

The Advocate also helped me to attend meetings with the adoption social worker, which at times I found very challenging and distressing. My advocate ensured the process went at a pace that suited me and gave me every chance to explore my views on the adoption.

At first, I chose not to consent to the adoption process, as I felt my child was too young to understand the implications of being adopted, and I was worried that I would lose all contact.

I was supported by my advocate to attend a hearing by video call with the adoption board to put across my views. I found this difficult as I wasn't familiar with the technology involved and needed assistance to access the hearing and to participate fully. My Advocate helped me prepare for the meeting and to remember all of the points I wanted to put across.



Soon after, I had a change of heart and I consented to the adoption. This was what my child wanted after all. An informal agreement was drawn up where the family agreed to ensure I could keep contact with my child. My advocate explained what this meant and accompanied me to sign the legal adoption forms.

It was a very difficult, emotional time for me and I really struggled with the process, but my advocate and social worker were sensitive and helped me explore all my questions and concerns. I was given the time and support I need to come to a decision that was right for me and my child.

This case study shows how NAS supported Peter to participate in discussions about the application for the adoption of his child who had been in long term foster care. The advocate supported Peter to access information in an accessible format and prepare for meetings held to discuss the application. This accessible information meant that Peter was able to make an informed decision. The advocate ensured that Peter was kept informed throughout the process and updated him regularly.



10. Key Enabler Building Capacity & Effectiveness

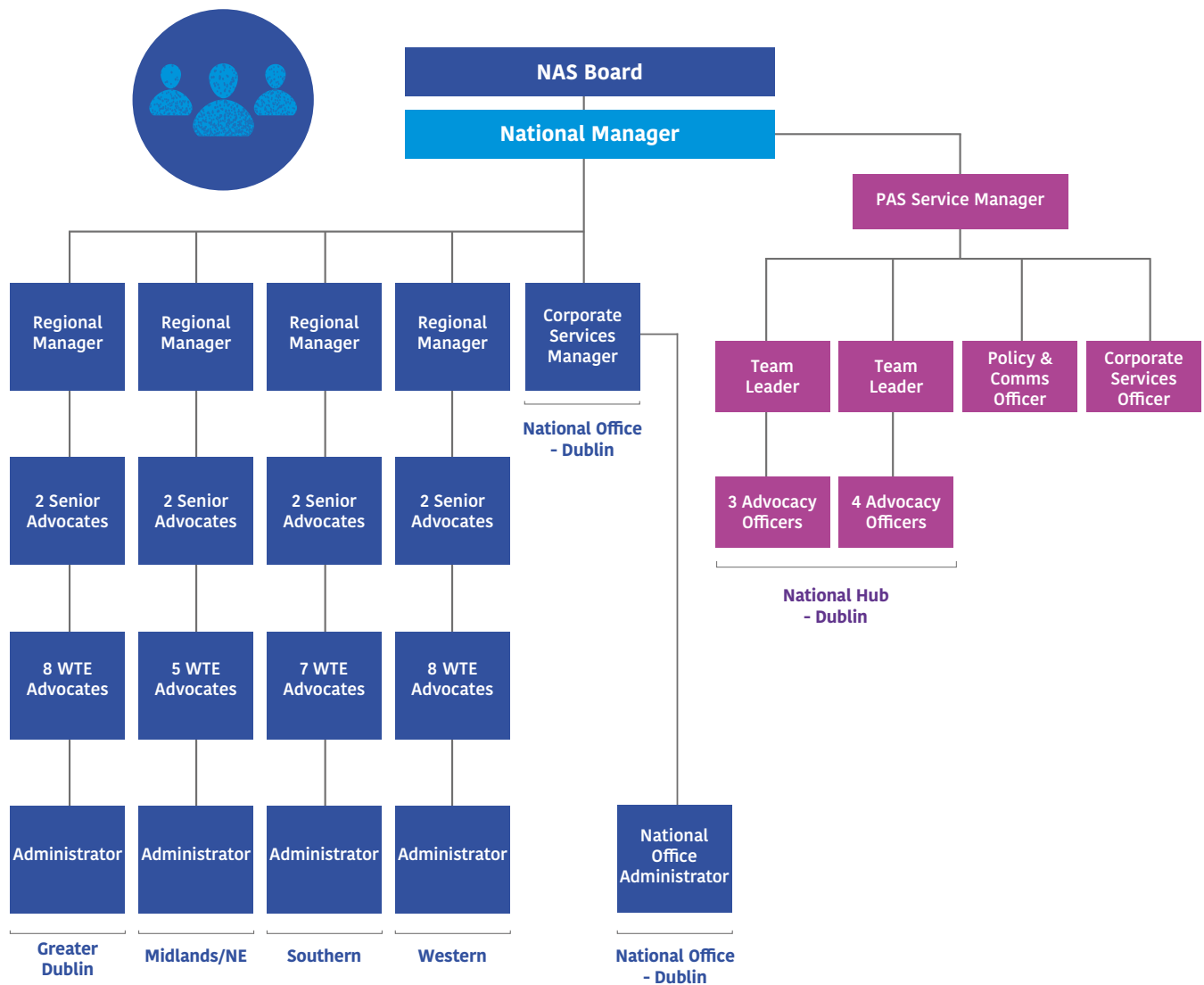
**“Thank you. I wouldn’t be here
without you standing beside me.”**

Christopher, who used the NAS service in 2019



This section outlines work in 2020 in relation to the second key enabler in the NAS Strategic Plan: building capacity and effectiveness.

2020 NAS/Patient Advocacy Service Organisational Structure



WTE = Whole Time Equivalents.

10.1 Resources

Human Resources

NAS had the following approved posts in 2020:

- ▶ National Manager
- ▶ Corporate Services Manager (started in November 2020)
- ▶ 4 Regional Managers
- ▶ 8 Senior advocates
- ▶ 28 Advocates
- ▶ 5 Administrators

However, it should be noted that throughout 2020 NAS had a lower number of staff members than in 2019.

This was due to:

- ▶ The completion of 2 x Advocacy Project Officer roles over 2018 and 2019
- ▶ The loss of temporary Advocate posts
- ▶ The delayed recruitment of 3 posts in order to comply with headcount requirements

The Patient Advocacy Service had the following approved posts in 2020:

- ▶ Service Manager
- ▶ Corporate Services Officer
- ▶ Communications Officer
- ▶ 2 Advocacy Team Leads
- ▶ 6 Advocacy Officers

The Patient Advocacy Service continued to expand its staff, recruiting two new team members in July 2020, a Policy and Communications Officer and a Corporate Services Officer. This brought the total number of staff members to ten.



10.2 Training and Development

Despite the impact of the Covid-19 pandemic, NAS and the Patient Advocacy Service made it a priority to provide their teams with opportunities for continuous professional and personal development.

As a result of Covid-related restrictions, face-to-face meetings and presentations could not take place. Instead, new online technologies were utilised and training was delivered via online webinars and video calls.

Advocates from both Services attended online training and events on a wide range of topics in 2020, ensuring they were equipped to work at a high standard. This training also ensured they could address new and emerging needs as they arose, including those issues caused by the Covid-19 pandemic, and they were able to best meet the needs of the people they supported.

Each regional team in NAS undertook a practice development session every six weeks, while six of the advocacy team for the Patient Advocacy Service

completed the Open Training College's diploma in patient advocacy and complaints.

Some of the key topics covered by NAS advocates included: Advocacy During Covid-19; Self Care for Advocates; Advocacy in a Covid World; Housing Law; Suicide Prevention; Disclosures, Observations and Suspicions of Abuse Policy; and Bereavement Support for People with Intellectual Disabilities

Advocacy officers for the Patient Advocacy Service took part in training that included: Effective Advocacy in the Time of Covid, Consent in Relation to the Covid-19 Vaccination, Safeguarding and Exploring Anxiety and Suicide Prevention.

10.3 Organisation Operational Highlights

The operation of the services provided by both NAS and the Patient Advocacy Service underwent a swift and significant change in March 2020. Due to the impact of the Covid-19 pandemic, office working was no longer possible. Overnight, on 12 March 2020, both Services quickly moved all staff to remote working from home.

For NAS, the Service has a dispersed workforce which is familiar with working in relative isolation from colleagues. The Service was also equipped with laptops which enabled this response.

Both services manage national phone lines and online methods of enquiry (email, website). This meant they were able to continue to provide people with advocacy support at this challenging time. They have also embraced innovative new ways of working such as video calls, emailing and text messaging.

A management response incorporating internal communication with staff was critical in sustaining the organisation and morale throughout this period.

Some of the actions taken include:

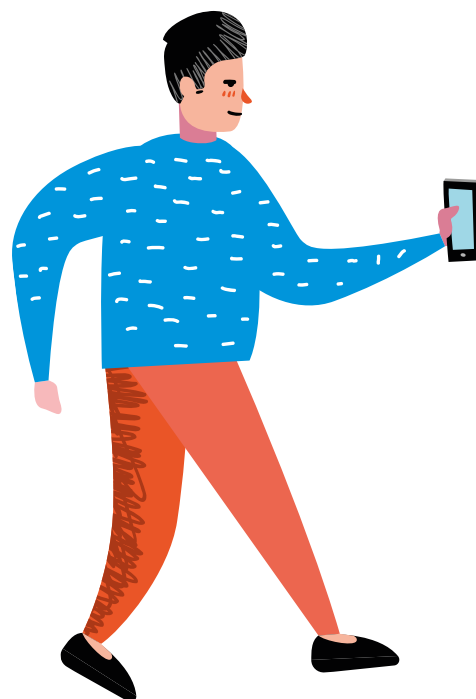
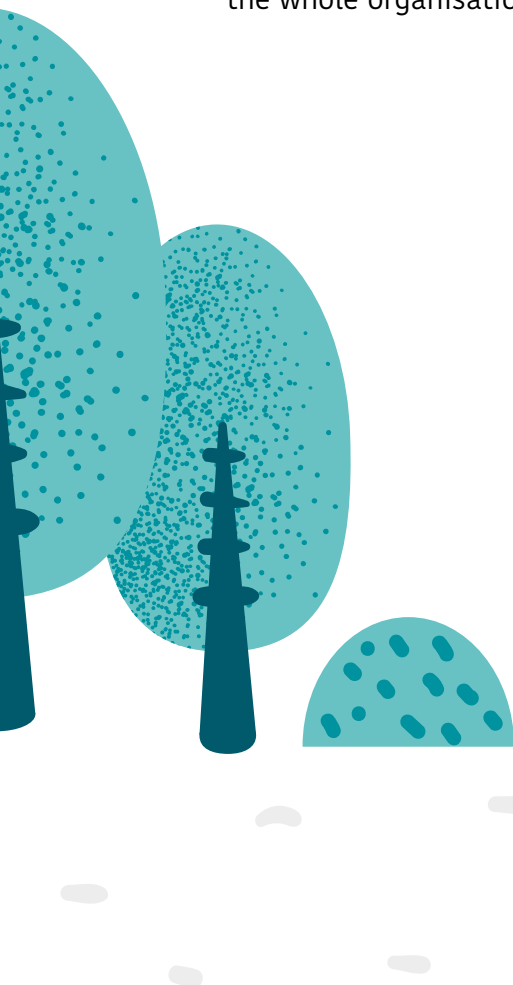
- ▶ Business Continuity Plan developed, reviewed and updated.
- ▶ Covid specific Risk Register developed.
- ▶ Covid Response Plan developed.
- ▶ Regular communication from the National Manager to all staff at each change to the lockdown restrictions.
- ▶ Regular virtual team meetings across regional teams (increased from once per month to weekly and then fortnightly).
- ▶ Cross regional practice development sessions increased.
- ▶ Covid response team formed representing all parts of the organisation.
- ▶ Quarterly newsletter.
- ▶ End of year virtual get together for the whole organisation.

Unfortunately, NAS was in a significant recruitment campaign just as the country locked down. As a result, we lost vital weeks of service delivery hours due to delayed recruitment. This contributed to the reduction in initial enquiries in 2020.

Another factor that significantly contributed to the reduction in initial enquiries were the NAS moved to remote working which meant it was not possible for NAS Advocates to meet people face-to-face to fully observe and understand their will and preference. In addition, third party referrers lacked the capacity to make enquiries to NAS due to their focus on the Covid response.

Both NAS and the Patient Advocacy Service completed all recruitment by virtual means in 2020. Induction during Covid-19 was a challenge as new staff members did not get to meet, connect or socialise with their colleagues in person,

However, both Services have responded to the challenge and have been highly innovative through further development of peer support, peer to peer mentoring for new staff and increased shared learning and resources.



10.4 Organisation Corporate Governance

There were some changes in NAS directors in 2020:

- ▶ Appointments of Tony Ward and John Roycroft
- ▶ Retirement of Noel Beecher, Diarmuid O' Corrbui and Nuala O' Doherty, Chair of NAS Board

NAS Directors completed training on The Charities Governance Code in November 2020.

The Board of NAS met 7 times in 2020, as well as providing additional ad hoc support when required.

There are 3 sub committees of the Board:

- ▶ HR subcommittee – 7 meetings
- ▶ Finance Audit and Risk Committee – 7 meetings
- ▶ Policy and Communications Committee – 2 meetings

NAS also completed, or participated in, a number of projects in 2020:

- ▶ Securing funding, new premises, lease and fit out and ICT of new national office for NAS and the Patient Advocacy Service.
- ▶ Participation in CIB return to the workplace group.
- ▶ Roll out and implementation of new staff handbook.
- ▶ Completed project for ECMS upgrade plan.
- ▶ Transition to new telephony software for national line.
- ▶ Review, training, transition and implementation of new Thrive financial software.



11. Conclusion from the National Manager of the National Advocacy Service

No-one could have anticipated the onset of the Covid-19 pandemic at the start of 2020, and we certainly could not have foreseen the impact on our lives when it came to working from home, social distancing and the many restrictions we learned to live with.

People with disabilities have been particularly badly affected by both the virus and the State's response.

Over half of all Covid 19 deaths in 2020 were in nursing homes. Whilst nursing homes are primarily for older people, there are many people under 65 in nursing homes with complex disabilities. Older people, particularly the older old, were especially vulnerable to the most severe impact of Covid-19.

In particular, the cessation of day services, transport services, home support and PA hours severely curtailed the independence of many disabled people living in their own homes. This led to increased dependence on family members, isolation from all contacts, fear of infection and significant impacts on people's mental health. NAS also lost several people we worked with due to Covid-19. We send our condolences to their loved ones.

There were challenges too for the services provided by both NAS and the Patient Advocacy Service. In March 2020, all our staff moved to working from home, while face-to-face meetings were restricted and service providers moved their focus to the protection of residents and staff. This made it difficult to progress much of our case work.

We responded by adapting and improving our services to ensure we were able to continue to provide high levels of quality, professional advocacy support. This was challenging to do at very short notice for the whole organisation. However, we responded quickly and soon meetings were taking place with the people we support by virtual means, using video calls and messaging services.

“...we continued to uphold the rights of the people we support, ensuring their voice, will and preference was heard, they were aware of the entitlements, and they had an Advocate there to express their wishes during meetings with Services about their care.”

As a result, we continued to uphold the rights of the people we support, ensuring their voice, will and preference was heard, they were aware of the entitlements, and they had an Advocate there to express their wishes during meetings with Services about their care. We also made service providers aware of their obligations to those people in their care.

There is no doubt, however, that for those who are very isolated, or have communication differences (those who do not communicate verbally), it has been extremely challenging to provide good quality advocacy support.

For NAS, there was a reduction in enquiries in 2020, but this was related to the Covid-19 pandemic. The Patient Advocacy Service also experienced dips in enquiries during the year, particularly during periods of lockdown.

Overall, NAS provided more complex casework with fewer resources than in the previous year, while awareness of and contacts to the Patient Advocacy Service continued to increase.

Looking to the future, the Covid-19 virus remains with us, but we will continue to adapt and develop our services in response to any changes. We will continue to work with key stakeholders across the disability and patient advocacy sectors in 2021 to provide the highest level of service to people in Ireland.



Louise Loughlin

National Manager of the National Advocacy Service
for People with Disabilities (NAS)



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