



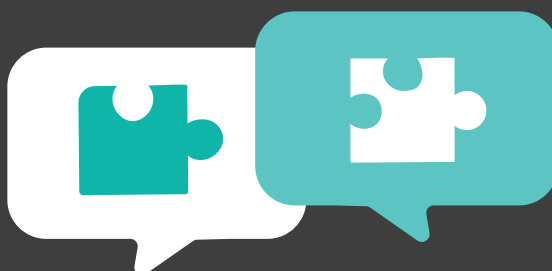
**NATIONAL ADVOCACY  
SERVICE**

**FOR PEOPLE WITH  
DISABILITIES**



**Patient  
Advocacy  
Service**

INFORMATION | SUPPORT | EMPOWERMENT



# Annual Report 2021



# Contents

|   |           |
|---|-----------|
| Foreword by Chairperson .....                                 | 2         |
| Easy to Read Summary of Annual Report.....                    | 4         |
| <b>1. Our Highlights 2021</b> .....                           | <b>15</b> |
| 1.1 NAS Highlights 2021.....                                  | 15        |
| 1.2 Patient Advocacy Service Highlights 2021 .....            | 16        |
| <b>2. Vision, Mission &amp; Values</b> .....                  | <b>17</b> |
| <b>3. Our Remit</b> .....                                     | <b>18</b> |
| 3.1 National Advocacy Service Remit .....                     | 18        |
| 3.2 Patient Advocacy Service Remit .....                      | 19        |
| <b>4. Our Services</b> .....                                  | <b>22</b> |
| 4.1 Responding to Covid-19's Ongoing Impact .....             | 22        |
| 4.2 National Advocacy Service Work in 2021 .....              | 24        |
| 4.3 Patient Advocacy Service Work in 2021 .....               | 25        |
| 4.4 Complexity of Work by Our Services.....                   | 27        |
| 4.5 Key Issues for Our Services .....                         | 29        |
| 4.6 Who Engaged with the National Advocacy Service .....      | 32        |
| <b>5. Our Standards Work</b> .....                            | <b>35</b> |
| 5.1 Ongoing Development of the Patient Advocacy Service ..... | 35        |
| <b>6. Our Policy Work</b> .....                               | <b>36</b> |
| 6.1 Stakeholder engagement .....                              | 36        |
| 6.2 Public Consultations and Submissions .....                | 37        |
| <b>7. Raising Awareness of Our Services</b> .....             | <b>38</b> |
| 7.1 Promoting the National Advocacy Service .....             | 38        |
| 7.2 Promoting the Patient Advocacy Service.....               | 39        |

## Foreword by Chairperson



**2021, the second year of the Covid-19 pandemic, was another hugely challenging year for everyone in our society.**

The pandemic, its restrictions and ongoing disruptions to healthcare services in Ireland continued to have a particularly detrimental impact on the people supported by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

In my first year as Chairperson of NAS, I saw the many traumatising and life changing experiences faced by the people we support. I also witnessed the hugely important advocacy provided by our Services to these people when they needed our help the most.

For NAS, face-to-face meetings remained limited and many service providers were focused on the safety of their residents, which meant they were unable to engage properly with our advocates.

There has been a 50% increase in enquiries and cases over the last five years for NAS. However, the Service continued to work with limited resources in 2021. The Service has not received funding for any new permanent posts since 2011. The number of people on the waiting list to access NAS services stood at 158 by the end of 2021.

The Patient Advocacy Service, in just its second full year of operation, also faced difficulties as hospital patients were unable to communicate with their loved ones and meetings with hospitals were postponed, leaving people waiting for months to discuss their complaints. Staff from both our Services also continued to work from home.

Despite the many challenges we faced during the year, our Services continued to operate as normal, with our staff demonstrating determination, empathy and adaptability to embrace new technologies such as video calls and text messaging.

Indeed, in 2021 the Patient Advocacy Service signed a Memorandum of Understanding with the HSE outlining their joint commitment to further improve support services for people who wish to make a complaint about the care they have received in public acute hospitals. The remit of the Patient Advocacy Service was also extended to include support for people in HSE-operated nursing homes.

All of these important steps forward will help our organisation to build its capacity and effectiveness and will ensure we can continue to help people across Ireland, upholding their human rights and supporting them to have their voice heard.

**“Despite the many challenges we faced during the year, our Services continued to operate as normal, with our staff demonstrating determination, empathy and adaptability...”**

This Annual Report provides a detailed breakdown of all the key data covering the work of NAS and the Patient Advocacy service in 2021. The report describes the issues our advocates encountered during the year, many of which continued to be altered due to the pandemic.

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 2021.



**Rosemary Smyth,**  
Chairperson of NAS Board

Covid-19 continued to have a negative impact on the lives of people across Ireland in 2021, including the people we support. While the situation has improved significantly for many of us in 2022, we must ensure that those people who lost their lives are remembered, that the challenges the HSE and health services continue to deal with are recognised, and that we continue to learn from the mistakes that were made.

## 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 or a HSE nursing home.



## 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.





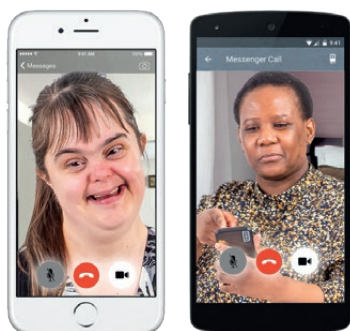
## Covid-19 and our Work

Covid-19 in 2021 changed the ways that NAS and the Patient Advocacy Service could do its work.

Lockdown in the first half of 2021 meant it was hard to meet people face to face.

Services wanted to keep residents and staff safe.

The Patient Advocacy Service had delays in getting information. There were also delays in having meetings.



## New Ways of Working

NAS and the Patient Advocacy Service worked in new ways during 2021.

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.

This meant they could get the advocacy support they needed.



## NAS Work in 2021

NAS Advocates worked on 1,006 cases supporting people with disabilities with their advocacy issues in 2021.

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 to 2,827 people in 2021.

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

1,890 people called this number in 2021.



## Patient Advocacy Service work in 2021

The Patient Advocacy Service provided support to 1,205 people in 2021.

Advocates worked on 3,382 complaint issues for the people they supported.

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

|  |   |
|--|---|
|  | <p>In May 2021, the Patient Advocacy Service began to support residents of HSE-operated nursing homes.</p> <p>The Patient Advocacy Service has a website and it was visited by over 12,100 new users in 2021.</p>   |
| <br> | <p><b>Key Issues for NAS in 2021</b></p> <p>NAS dealt with a lot of important issues for people with disabilities in 2021.</p> <p>The biggest issues were around capacity building, housing, residential and healthcare settings, decision making, social care and health.</p> <p>NAS helped people with disabilities to work on these issues to try and make things better.</p>                                  |
|   | <p><b>Key Issues for the Patient Advocacy Service in 2021</b></p> <p>The Patient Advocacy Service worked on important issues for people in 2021.</p> <p>These top complaint issues were people feeling their anxieties were not listened to, not being able to visit hospitals, difficulty phoning healthcare units, calls not being returned and hospital staff not communicating care plans to the patient.</p> |



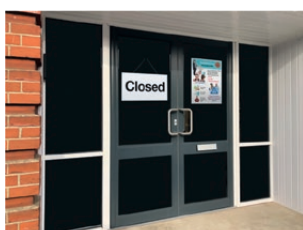
## Who Contacted Us?

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 going on the website or through hospitals.

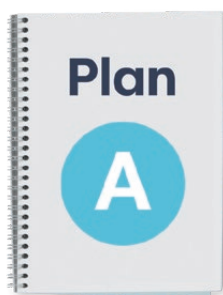


## Other Important Work in 2021

NAS and the Patient Advocacy Service wrote 4 new reports in 2021 called 'Advocacy Matters: Impact of Covid-19'.

These reports told people about the work NAS and the Patient Advocacy Service did during the Covid-19 time.

The reports told people how hard the Covid-19 time was for the people NAS and the Patient Advocacy Service support.



The reports told people how important advocacy support is for people in difficult times.

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 mental health services and home standards for home support services are important for the people they support.

NAS managers spoke at important meetings about disability issues.



## Telling People About Us

NAS and the Patient Advocacy Service took 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.

The Patient Advocacy Service had a regional advertising campaign in 2021.

This meant going on the radio and writing in newspapers to tell people about how they could support them.

## **NAS Case Study: Paul's Story about Move from an Inappropriate Placement**

My name is Paul and I am in my 40's. I also have an intellectual disability. I love music and spending time with my friends.

I was living in a nursing home. I did not need to be there because I did not have any nursing needs. I was not happy living in the nursing home.

Covid-19 meant that my advocate could not come to see me at the nursing home. We talked on the phone and on video calls. My advocate also talked to my family to learn more about where I would like to live.

My advocate talked to the HSE disability managers and told them about me. My advocate asked them to find me somewhere new to live that would suit me better.

Covid-19 meant that talking to the HSE disability services took a lot of time but my advocate did not give up. A meeting was finally organised to discuss my issue. With the support of my advocate, I was offered a place to live in a residential service near where my family live.

It took some more time before I could move because of Covid-19. I was really excited to move to my new home. I am happy with my new home. I feel more settled.



## **Patient Advocacy Service Case Study: Adam's story about Appointment Cancellation**

My name is Adam. I contacted the Patient Advocacy Service about a medical condition I have that was causing me a lot of pain. I need regular treatment but I had not got any treatment since the middle of 2020.

Many of my hospital appointments have been cancelled. My hospital doctor told me that this was because I needed to have my Covid-19 vaccine and my treatment could not happen at the same time. My hospital doctor did not help me to get my Covid-19 vaccine and said this was the job of my GP.

I spoke to an advocate in the Patient Advocacy Service who took the time to really listen to my concerns. The advocate gave me the chance to tell my story and helped me understand my options. My advocate explained the HSE's complaint process. They told me what department in the hospital to contact as the delays to my treatment were affecting my quality of life.

I contacted the hospital department. They told me that a mistake had been made. I was a high-risk patient who needed to get a vaccine as soon as possible. My name had been missed on the list. My advocate helped me to make a complaint. I received my vaccine and got an appointment for my treatment. I am making my complaint to the hospital so that this does not happen to anyone else.



# 1. Our Highlights 2021

## 1.1 NAS Highlights 2021



NAS also provided empowerment advocacy support or information in **2,827** instances.



NAS opened **447** new cases and closed **458** cases, having achieved outcomes for clients.



NAS staff engaged in **181** promotional events and presentations in disability services and other services throughout Ireland.



The NAS national phone line received **1,890** calls in 2021.



The NAS website was visited by over **6,300** new users in 2021.

Some of the biggest issues for people with disabilities worked on by NAS advocates in 2021 related to capacity building; housing and accommodation; residential and healthcare settings; decision making and social care.



## 1.2 Patient Advocacy Service Highlights 2021



**1,054** of the enquiries were short-term, such as providing people with information by phone and referrals to other support services.



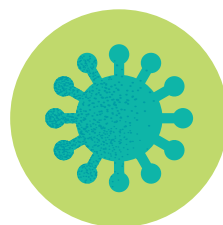
**151** of the enquiries were given full 1-1 advocacy support, including supporting people with written correspondence and attending meetings with them.



The Patient Advocacy Service carried out **586** promotions in 2021, including presentations and offers of leaflets and posters.



The Patient Advocacy Service website was visited by over **12,100** new users in 2021.



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



The Patient Advocacy Service closed **1,153** contacts in 2021. **49** of those were carried forward from 2020, the rest were opened and closed in 2021.

Some of the biggest complaint issues for people in public acute hospitals worked on by the Patient Advocacy Service's advocates were visiting being unavailable, difficult phoning healthcare units, and staff not communicating care plans.



## 2. Vision, Mission & 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. The Patient Advocacy Service is an independent, free and confidential Service that provides information and support to people who want to make a complaint about an experience they have had in a public acute hospital or HSE-operated nursing home, and in the aftermath of patient safety incidents.

### Core Values

Our Strategic Plan 2018-2023 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 preference. 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. Our Remit

### 3.1 National Advocacy Service Remit

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.

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.

### 3.2 Patient Advocacy Service Remit

The Patient Advocacy Service is commissioned and funded by the **National Patient Safety Office in the Department of Health (DoH)**. The Patient Advocacy Service is fully independent of the HSE.

The 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 process in relation to the care they have experienced in a public acute hospital or HSE-operated nursing home, and in the aftermath of a patient safety incident.

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

In May 2021, the Patient Advocacy Service expanded its remit to provide advocacy support to residents of HSE-operated Nursing Homes.

The Service is now also providing advocacy services to:

- Users of HSE Funded Nursing Homes;
- Users of nursing homes operated under arrangement pursuant to S.38 of the Health Act 2004.

The service will support those who wish to make a complaint through the HSE 'Your Service, Your Say' complaints process about the care they have received in their Nursing Home.



## NAS Case Study

### Paul's Story: Move from Inappropriate Placement

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My name is Paul, I am in my 40's and I have an intellectual disability. I love music and socialising with my friends. I was supported by a NAS advocate because I was inappropriately living in a nursing home when I had no nursing needs.

Due to Covid-19 restrictions on visits to the nursing home, I spoke to my advocate on the telephone and video calls. The advocate also spoke to my family to understand my will and preference.

I wasn't happy in the nursing home and staff there said my behaviour was challenging to deal with at times.

My advocate contacted HSE disability services several times to explain that my placement was inappropriate and asked for them to find alternatives for me.

The impact of Covid-19 meant the HSE were slow in responding to the request but my advocate didn't give up and a meeting was finally organised to discuss my issue.

With the support of my advocate, I was offered a placement in a residential service close to where my family live.

I was really excited to transfer to my new home but the Covid-19 restrictions meant the move was further delayed. Despite this setback, my advocate and my family did not give in and continued to raise the issue with disability services. Funding was eventually secured and the move was completed.

I am happy with my new home. I feel more settled.



## Patient Advocacy Service Case Study

### Angela's Story: Issues Regarding Hospital Care

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My name is Angela and I contacted the Patient Advocacy Service because I had a number of concerns around the care provided to my mum who passed away in hospital during the Covid-19 pandemic. I wanted to access my mum's records and to make a formal complaint about the poor level of care she had received.

My mum had been admitted to hospital but I was not allowed to visit her due to the Covid-19 restrictions. A decision was made to discharge her, but I was not contacted by patient services and there was no discharge plan in place.

My mum's condition worsened and she was re-admitted to hospital. In the days that followed I tried to contact the hospital to find out what was going on, but my calls were not returned.

Late one evening, I was contacted by the hospital to inform me that mum was seriously ill. However, when I arrived at the hospital, she had passed away.

The advocate I spoke to in the Patient Advocacy Service explained the HSE's Freedom of Information policy and supported me to write a letter to the hospital requesting my mother's records. Once I received the records, the advocate helped me to review them.

With the advocate's support, I submitted a letter of complaint to the HSE, requesting a clinical review of my mum's care and a meeting between the hospital and my family. However, my request was not granted and I felt the complaint response did not fully deal with my issues.

My advocate supported me to pursue the complaint by requesting an internal HSE review. As a result, the hospital offered a meeting where I was given an apology and recommendations for improvement were initiated. I am satisfied that my concerns have been listened to.



## 4. Our Services

### 4.1 Responding to Covid-19's Ongoing Impact

Covid-19 restrictions and disruptions continued to have a significant impact on the services provided by **NAS** in 2021, particularly during the periods of lockdown in the first half of the year. Health and social care service providers remained focused on the safety of their residents and staff which meant fewer opportunities to engage meaningfully with NAS. This led to a reduction in enquiries into NAS from third party referrers over that period. Face-to-face meetings with both staff and residents were still limited, which had an impact on enquiries into NAS.

The Patient Advocacy Service was also affected by the Covid-19 crisis. It often proved difficult to progress complaints and gain access to freedom of information requests. Meetings were regularly postponed, leaving families waiting for months to discuss review findings or complaint issues.

Despite these challenges, our services continued to deliver high quality advocacy support in 2021. Our staff worked effectively from home, with blended working introduced where possible. Both NAS and the Patient Advocacy Service utilised our national phone lines and online methods of enquiry (email, website) and we further embraced innovative ways of working such as video calls, emailing and text messaging.

By using these technologies, NAS advocates were 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.

When restrictions began to lift in 2021, 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, and assessments where face-to-face engagement was essential often took place in outdoor settings, including walks in public areas.

The Patient Advocacy Service also continued to support users of its service during the pandemic through its national phone line and online forums. 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. The Service also provided valuable links for people who have had difficulty in accessing information from their care settings.



## Launch of 'Advocacy matters: Impact of Covid-19' Reports

NAS and the Patient Advocacy Service launched our 4 new 'Advocacy Matters: Impact of Covid-19' reports in autumn/winter 2021. The reports focus on the work carried out by both Services during the pandemic, particularly during the period from March 2020 - March 2021, outlining the support we provided and the positive outcomes this advocacy helped to achieve.

The aim of the reports was to show the hugely detrimental impact the Covid-19 pandemic, its restrictions and the subsequent disruptions to healthcare services in Ireland have had on the people we support. They also conveyed the key role that advocacy plays in supporting people who may be vulnerable in Irish society, particularly during periods of crisis. The reports covered the following themes:

- Report 1: [Advocating for People in Residential & Day Services during the Covid-19 Pandemic](#)
- Report 2: [Advocating for People Regarding Access to Justice & Decision-making during the Covid-19 Pandemic](#)
- Report 3: [Advocating for People Regarding Health & Social Care during the Covid-19 Pandemic](#)
- Report 4: [Advocating for People Living in Nursing Homes during the Covid-19 Pandemic](#)

The reports make it clear that we must ensure that the voice, will and preference, and human rights of people are always recognised.

Given the ongoing impact of the Covid-19 virus, they stress the need for health and social care services to learn from people's negative experiences, using their feedback to continue to improve their service delivery.

The NAS and the Patient Advocacy Service organised two online webinars (the first in October and the second in December) to launch the 'Advocacy Matters' reports. In total, over 270 people, from 120+ separate organisations, attended the two events. These included representatives from the Department of Health, the HSE, CIB, HIQA (Health Information and Quality Authority), government departments, advocacy and community organisations and political representatives.

An aspect of the webinars that proved particularly engaging for those in attendance was the use of videos featuring audio interviews with people who have been supported by NAS and the Patient Advocacy Service telling their own stories. Feedback from attendees was that these videos were very powerful and emotional, and helped to convey the human side of advocacy work.

Both launch events received significant national print media coverage, including 2 articles on the RTE news website ([first event/second event](#)), 2 articles in the [Irish Examiner](#) and an article in the [Irish Times](#). NAS National Manager, Louise Loughlin, was also interviewed on Cork's C103, Limerick's Wired FM, Clare FM and Kildare FM.

## 4.2 National Advocacy Service Work in 2021

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

Amy, who was supported by a NAS advocate in 2021.

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 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.

NAS has consistently had a waiting list of people wishing to access its services over the last number of years. At the end of December 2021, 158 people were on the waiting list.

NAS has received some funding for temporary posts but has not received funding for any new permanent posts since 2011, this is despite an increase of over 50% in the number of enquiries and cases since 2015. This means that people who are already isolated and in vulnerable situations are left waiting a long time for access to advocacy. This is despite references to advocacy in HIQA and Mental Health Commission publications and the importance of access to advocacy in the [Ombudsman's Wasted Lives report](#).

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

- NAS provided full representative advocacy to 1,006 people in 2021. 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 2,827 instances of such support in 2021.

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 1,006 full representative advocacy cases in 2021, 559 cases had been open from 2020, while 447 new cases were opened in 2021.

Combining both ways that NAS advocates help people, NAS provided advocacy support in 3,833 pieces of work in 2021, an increase on 2020 when the figure was 3,755 pieces of work.

## 4.3 Patient Advocacy Service Work in 2021

**“Thank-you for being empathic and patient.”**

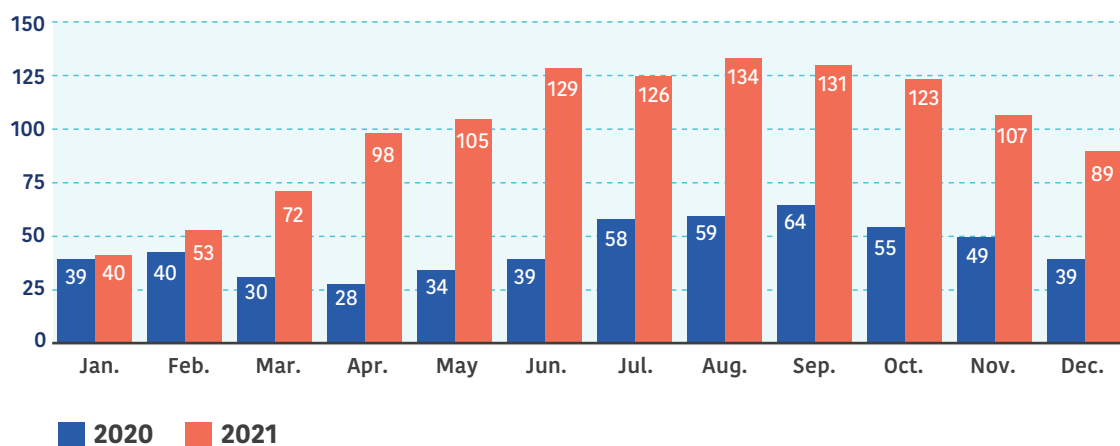
James, who was supported by the Patient Advocacy Service in 2021.

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.

2021 was the second full year of service delivery for the Patient Advocacy Service. In 2021, the Service received 1,205 new complaint enquiries, of which 3,382 separate complaint issues were identified. This was an increase of 125% on 2020 when we received 535 complaint enquiries. The table below shows the numbers of new contacts by month in 2021, compared with 2020.



## Patient Advocacy Service 2020/2021 - New Contacts by Month



Despite the ongoing impact of Covid-19, the number of new contacts to the Service continued to increase throughout 2021. This was due to a regional advertising campaign from April – July 2021 to raise awareness of the Service among the public across Ireland. The campaign significantly increased the number of new contacts to the Service.

Of the 1,205 new contacts received by the Service, 1,054 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.

151 new contacts were given full 1-1 advocacy support. This work involved supporting people to write correspondence, attending meetings with the person, and helping them to have their concerns heard.

313 of the people supported by the Patient Advocacy Service in 2021 had issues impacted by Covid-19. This is a much higher number than in 2020 when 154 of the individuals supported had issues impacted by Covid-19.

In 2021, the Patient Advocacy Service expanded its remit to provide advocacy support to residents of HSE-operated Nursing Homes. This expansion took place in May 2021 which meant there was limited time to promote the new remit to nursing home residents and their families. However, the service received 36 new complaint enquiries in relation to HSE-operated nursing homes.

## Total Combined NAS and Patient Advocacy Service Work<sup>1</sup>

| Year | NAS Work | Patient Advocacy Service Cases | Total Pieces of Work |
|------|----------|--------------------------------|----------------------|
| 2015 | 2,145    | N/A                            | 2,145                |
| 2016 | 3,741    | N/A                            | 3,741                |
| 2017 | 3,628    | N/A                            | 3,628                |
| 2018 | 3,941    | N/A                            | 3,941                |
| 2019 | 4,485    | 65                             | 4,550                |
| 2020 | 3,755    | 535                            | 4,290                |
| 2021 | 3,833    | 1,205                          | 5,038                |

## 4.4 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 2021, 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. Through advocacy plans, the complex work of 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 number of cases with between 2 and 7 issues has risen from 495 cases in 2018 to 686 cases in 2021.

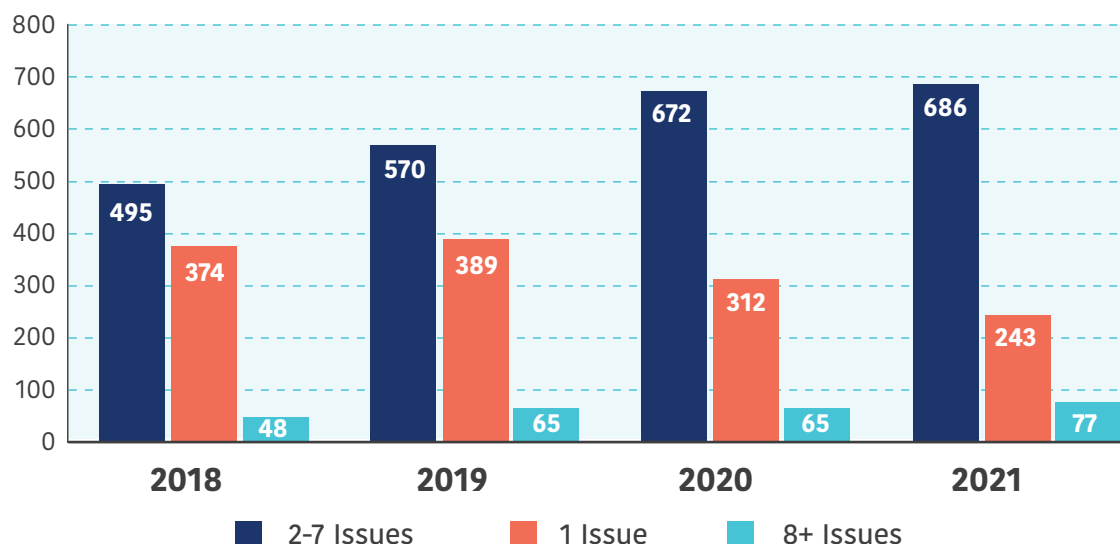
Of the 1,006 full representative advocacy cases in 2021, 243 (24%) had one issue, 686 (68%) had two to seven issues and 77 cases (8%) had eight issues or more.

The increase in the number of issues per full, representative advocacy case is due to several factors:

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

<sup>1</sup> 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 casework in 2019, 2020 and 2021.

## NAS Advocacy Issues Per Case Nationally



## Complexity of Patient Advocacy Service Work

The **Patient Advocacy Service** uses the Healthcare Complaints Analysis Tool (HCAT)<sup>2</sup>, developed by the London School of Economics and Political Science, to categorise all the complaint issues that are presented. 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 1,205 advocacy contacts in 2021. Of these contacts, 344 were outside the remit of the Service.

There were 651 contacts that had between 1 and 5 complaint issues, 151 contacts that had between 6 and 10 complaint issues, and 28 contacts that had between 11 and 15 complaint issues. There were also a further 10 contacts with 16-27 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 2021 and how serious and complex some of their complaint issues were. Some contacts involved several different complaints at several different levels of severity.



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

## 4.5 Issues for Our Services

### Issues for NAS in 2021

Due to the ongoing impact of the Covid-19 pandemic, many of the issues normally present in NAS casework continued to change in profile in 2021. 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.

Housing and accommodation remained among the most significant issues worked on by advocates, but they made up a smaller percentage of the overall issues than in previous years. In 2019, housing accounted for 16% of all recorded issues. In 2020, this figure was 14%, while in 2021 it stood at 13%.

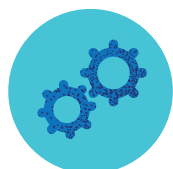
Issues relating to residential and healthcare settings also came to the fore in 2021, along with issues around decision making and social care. In a general sense, isolation came up as an issue frequently due to the Covid-19 restrictions. Some other issues which have emerged include:

- Ward of Court hearings in the High Court were delayed and subsequently took place online
- Delayed court hearings in parenting with a disability
- Suspended access to children in care for disabled parents
- Delayed transfers from residential settings
- Delays in assessment and provision of new home support and personal assistance services
- 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
- Access to Covid-19 vaccination, where families prevented access to the vaccine contrary to the will and preference of the person with a disability
- Lack of access to home support and personal assistant services due to staffing issues in service providers





## National Advocacy Service Issue Categories in 2021



Capacity Building  
**18%**



Housing  
**13%**



Residential &  
Healthcare Settings  
**13%**



Decision Making  
**12%**



Social Care  
**8%**



Health  
**9%**



Access to Justice  
**5%**



Parenting with a  
Disability  
**6%**



Family and  
relationships  
**5%**



Financial Issues/  
Matters  
**5%**



Complaints  
**2%**



Safeguarding  
**4%**

\*These figures are a percentage of all the instances of one of the issues that arose in a case in 2021. In some instances, a case had more than one of these issues present.

## Issues for the Patient Advocacy Service in 2021

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).

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 chart below shows the top issues identified by severity rating.



**The complaint issues received by the Patient Advocacy Service in 2021 are broken down as follows:**

| Severity Level    | No. of Complaints/Issues | Types of Complaints  |
|-------------------|--------------------------|--|
| <b>Severity 1</b> | 822                      | <ul style="list-style-type: none"> <li>• Staff spoke in a condescending manner</li> <li>• Phone calls not returned</li> <li>• Difficult phoning healthcare unit</li> </ul>   |
| <b>Severity 2</b> | 1,936                    | <ul style="list-style-type: none"> <li>• Anxieties acknowledged, not addressed</li> <li>• Visiting unavailable</li> <li>• Complaint not responded to</li> <li>• Rude behaviour</li> </ul>  |
| <b>Severity 3</b> | 628                      | <ul style="list-style-type: none"> <li>• Unable to access specialist care</li> <li>• Staff ignored severe distress</li> <li>• Discharge without sufficient examination</li> <li>• Patient left with unexpected disabilities</li> </ul> |

### **The top 5 complaint issues in 2021 were:**

- 1.** Anxieties acknowledged, not addressed
- 2.** Visiting unavailable
- 3.** Difficulty phoning healthcare unit
- 4.** Staff did not communicate care plan
- 5.** Phone calls not returned



## 4.6 Who Engaged with the National Advocacy Service

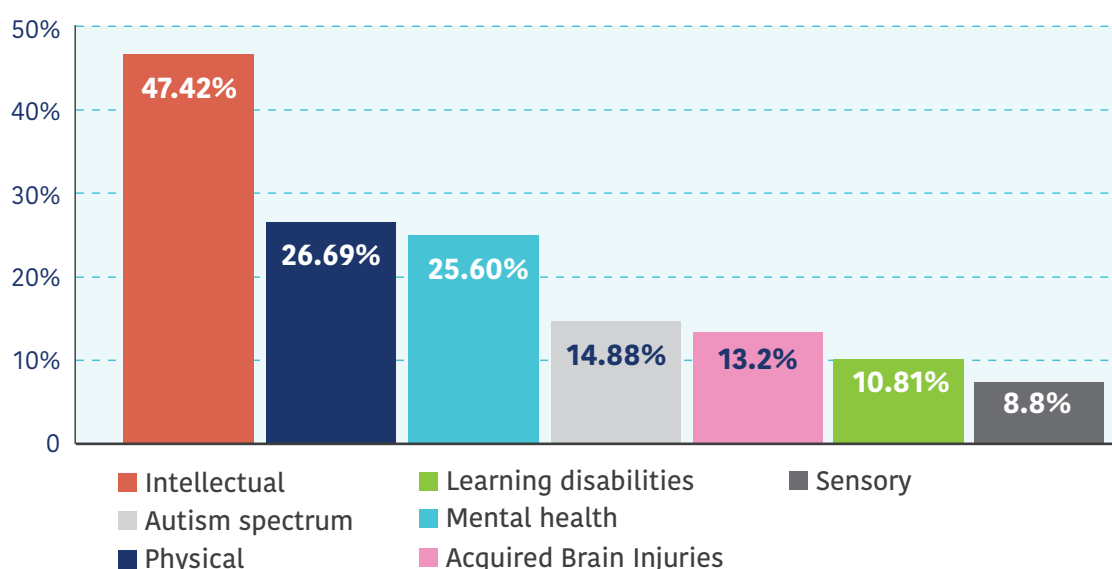
NAS has a particular remit to provide advocacy services to people in particularly vulnerable situations, but the service worked with a diverse range of people in 2021 experiencing many different types of disabilities.

As has been the case for several years, 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. People with physical disabilities also continued to be a significant element of NAS work in 2021.

The number of people with acquired brain injuries (ABIs) remained consistent as an element of NAS casework, at 13% of cases in 2021. The number of people with ABIs in 2020 was also 13%, in 2019 it was 12% and 2018 it stood at 8%.

Most notably, 2021 continued to show that a significant portion 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 and the type of disability represented.

### Disability Type Reported - % of all Clients 2021



## NAS Case Study

### Deirdre's Story: Safeguarding Issues

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My name is Deirdre and I'm in my thirties. I live in a residential service and I have a physical and intellectual disability. I had an issue with a member of my family during the Covid-19 pandemic.

My family member wanted me to sign a legal form allowing them to discharge me from my accommodation, but I didn't want to leave.

A staff member from the residential service put me in touch with an advocate from NAS and explained what had happened. The Advocate helped me understand the implications of signing the form and helped me to get legal support.

My advocate put me in contact with the HSE Safeguarding and Protection Team and a safeguarding plan was put in place to protect me and my rights. According to the plan, if restrictions were lifted and visits resumed, the visits were to take place in a public area of the residential service.

This would give me space to meet my family member privately, but it was close enough for staff to make observations and intervene if anything happened or I became upset.

Thanks to my advocate, I have been able to stay in my residential service. I now have the time, space, and support I need to make sure my own views are listened to and protected.



## Patient Advocacy Service Case Study

### **Adam's Story: Complaint Regarding Appointment Cancellation**

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My name is Adam. I contacted the Patient Advocacy Service about a medical condition I have that was causing me a lot of pain. I require regular treatment for the condition, but I hadn't received any treatment since the middle of 2020. Several of my hospital appointments have been cancelled.

My hospital consultant said the cancellations had occurred because I was due to get my Covid-19 vaccination and the two treatments could not take place at the same time. My consultant did not seek to prioritise my vaccination and said this was the role of my GP.

I spoke to an advocate in the Patient Advocacy Service who took the time to really listen to my concerns. The advocate gave me the chance to speak openly and helped me understand the options open to me.

My advocate explained the HSE's complaint process and the timelines involved. They advised me to contact the Risk Management Department in the hospital as the delays to my treatment were affecting my quality of life.

I contacted the department and was told an error had occurred. I was recognised as a high-risk patient requiring urgent referral for vaccination, but my name had been missed off the list. With the support of my advocate, I made a formal complaint.

Following the complaint, I received my vaccination, and my treatment was rescheduled. I am pursuing my complaint with the hospital to try and ensure this does not happen to anyone else.



## 5. Our Standards Work

**“My advocate showed so much professional integrity in pursuing my rights.”**

Claire, who used the Patient Advocacy Service in 2021.

Over several years NAS has carried out significant work to develop its robust policies and quality working standards. In 2021, this included using its experience and knowledge of the sector to further develop the Patient Advocacy Service and align its professional and advocacy standards with those of NAS.

### 5.1 Ongoing Development of the Patient Advocacy Service

Despite the ongoing impact of the Covid-19 pandemic, in 2021 the Patient Advocacy Service took important steps forward to build its capacity and effectiveness. In February 2021, the initial term of the Patient Advocacy Service contract was extended by a period of 16 months, from June 2021 to the end of October 2022. This was followed by two key actions:

#### **Signing of MoU between HSE and Patient Advocacy Service**

In April 2021, the Patient Advocacy Service and the Health Service Executive (HSE) signed a Memorandum of Understanding (MoU) pledging to work together to further improve support services for people who wish to make a complaint about the care they have received in public acute hospitals.

The MoU sets out the commitment of both organisations to cooperate to ensure that people receive a timely, compassionate and comprehensive response to their complaints.

The MoU recognises that every person has the right to make a complaint about the service they have received in HSE public acute hospitals. In the MoU, the HSE recognises the important role that independent patient advocacy can play in the complaints process, while the Patient Advocacy Service commits to helping people to improve their understanding of the HSE's complaints processes, 'Your Service Your Say' and the Incident Management Framework.

## Expansion of Remit to Nursing Homes

From May 2021, the Patient Advocacy Service expanded its remit to provide advocacy support to residents of HSE-operated Nursing Homes.

The Service is now also providing advocacy services to:

- Users of HSE Funded Nursing Homes;
- Users of nursing homes operated under arrangement pursuant to S.38 of the Health Act 2004.

The service will support those who wish to make a complaint through the HSE ‘Your Service, Your Say’ complaints process about the care they have received in their Nursing Home.

# 6. Our Policy Work

“Thanks for listening to me, it’s good to have someone on my side. You are very kind.”

Patrick, who was supported by a NAS Advocate in 2021.

## 6.1 Stakeholder engagement

### Engagement with external statutory bodies on COVID-19 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.

The service continued building positive working relationships with the HSE National Office of Human Rights and Equality Policy and National Quality Improvement Division, and the HSE Open Disclosure Office.

NAS contributed to various HSE activities related to Covid-19 including:

- A chapter on Assisted Decision-Making in a publication for HSE 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
- HSE Quality Improvement Division Webinar on Supporting the consent process for the vaccination programme against Sars-CoV-2 (Covid-19)

### The Service was engaged at a national level in other fora:

- Nursing Home Expert Report Group Implementation Reference Group
- National Care Experience Programme Steering Board
- HSE Project Group on Patient Engagement Framework
- National Inpatient Experience Survey Programme Board
- HSE Disability National Consultative Forum to plan recommencement of non-Covid disability services
- Department of Health Nursing Home Report Reference Group membership
- Steering Committee on the Post-Partum Haemorrhage Quality Improvement Initiative (NPEC)
- HSE Disability National Consultative Forum to plan recommencement of non-Covid disability services

## 6.2 Public Consultations and Submissions

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

- Public consultation on draft legislation to update the Mental Health Act 2001 – June 2021
- Review of the Quality Framework for Mental Health Services in Ireland – August 2021
- Code of Practice on the Use of Seclusion and Restraint in Inpatient Mental Health Services – September 2021
- Draft National Standards for Home Support Services Consultation – September 2021
- Royal College of Surgeons in Ireland (RCSI) Pilot Study to map Health Services Available to Adults with Cerebral Palsy in Ireland – September 2021
- Interim Regulatory Reform in Nursing Homes – September 2021
- Serious Patient Safety Incident Bill – September 2021
- CRA – Have Your Say: Supports for Parents with Children in Care – September 2021
- Joint Committee on Disability Matters, Public Meeting – October 2021
- Stakeholder Consultation on Implementation of Health and Social Care Standards, HIQA Corporate Plan Feedback – November 2021
- Equality Act Review – December 2021
- Joint Committee Disability Matters Public Meeting – December 2021

## 7. Raising Awareness of Our Services

**“The support I received from my advocate had a big impact on my quality of life.”**

Joanne, who was supported by an advocate from the Patient Advocacy Service in 2021.

**The Covid-19 pandemic and the subsequent restrictions continued to have a significant impact on outreach and promotional work carried out by NAS and the Patient Advocacy Service in 2021. Covid-19 restrictions meant that public gatherings 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 2021.**

### 7.1 Promoting the National Advocacy Service

The NAS website received 6,468 visitors in 2021, of which 6,337 were new users. The website received an average of 40-50 visits per day on weekdays.

As face-to-face meetings were not possible, NAS increased its use of social media in 2021.

- ▶ The Service’s Facebook page increased by 12%, from 1,720 followers at the start of 2021 to 1,928 at the end of 2021.

Also in 2021, NAS advocates, senior advocates and regional managers took part in 181 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 December 2021, NAS and the Patient Advocacy Service launched their 2020 Annual Report. The report included several updates on key activities of NAS and the Patient Advocacy Service during the year, including the impact of the Covid-19 pandemic on the Services. Supporting the launch of the report, the Services published a video featuring Minister for Social Protection, Heather Humphries, who welcomed the report.



## 7.2 Promoting the Patient Advocacy Service

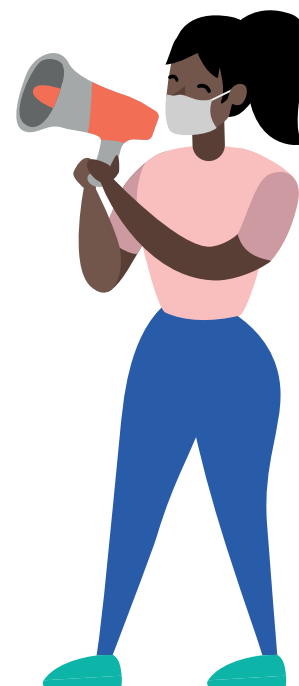
Following the curtailment of its promotional and advertising plans in 2020, the Patient Advocacy Service carried out significant work in 2021 to promote its Service among key stakeholders and the wider public across Ireland.

A key element of this work was a regional advertising campaign which ran from April 2021 – July 2021. The campaign involved radio and print adverts that targeted local media in all 26 counties in Ireland. The aim was to ensure as many people as possible, including those considered hardest to reach, were aware of the Service and the support it provides. The regional ad campaign led to a 125% increase in the number of new cases received by the Service.

The Service also increased its use of social media in 2021. In support of the advertising campaign, a social media marketing campaign was run on Facebook and Google Ads:

- ▶ The Service's Facebook page, regarded as the key platform for engaging the public, increased by 20%, from around 2,100 followers at the start of 2021 to over 2,500 at the end of 2021.
- ▶ The use of a Google Ad to promote the Service proved particularly effective. The Google Ad was promoted from the start of April 2021 to the end of the year. It was clicked on 4,400 times and led to 456 direct calls to the Service.

As a result of increased interaction and engagement across the Service's social media platforms, visitors to the Patient Advocacy Service website gradually increased over the course of the year. The site had 12,213 users in 2021, of which 12,144 were new users. This was nearly twice the number of new visitors to the website that we received in 2020.







NAS is funded and supported by the Citizen's Information Board (CIB)



The Patient Advocacy Service is funded and supported by the Department of Health (DoH)

**National Advocacy Service for  
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Patient Advocacy Service**

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