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Foreword by Chairperson

Welcome to the 2022 Annual Report for the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service. 2022 was a challenging year with significant changes both for our services and wider society. It was the 3rd year of the Covid-19 pandemic.

The issues associated with the pandemic, its restrictions and its disruptions to health services across the country continued to disproportionately impact people that access both our services.

2022 again demonstrated the significant need for our services. NAS continue to operate under significant pressure and there was a large demand across the country for our services. In the past year, our waiting list has grown from 161 to 250. Despite this, our Service has not received funding for any new permanent posts since 2011.

The Patient Advocacy Service saw an increase of 54% in service enquiries in 2022, in response to this and in line with our contractual obligations we have continued to build capacity and effectiveness in 2022. We have also grown the service by opening offices in Galway and Cork and expanded our remit to provide support for residents of nursing homes.

This period also saw a dramatic reduction in Covid-19 cases and the lifting of almost all restrictions. While these were immediate changes for many in society, the shift back to "normal" life was slower for a lot of the people who access our services and the residual impact will require significant management for some time to come.

Alongside this, NAS Advocates worked on a wide range of other issues during 2022. We continued to see people contacting our services with issues related to housing, residential and healthcare settings and decision-making. I note that issues like these are directly linked to someone's ability to live a meaningful and full life within their communities. The interactions between advocates and people that access our services are vital as they underline to the person the importance of their human rights. Communication was a significant theme reported by Advocates working in the Patient Advocacy Service in 2022. People seeking advocacy reported problems such as people's anxieties not being addressed, lack of capacity for visiting, poorly communicated healthcare plans, people having difficulty phoning healthcare units and staff speaking to people in a condescending manner. These are important issues and have detrimental effects on people's lives when they are not addressed.

It is the experience of our Advocates that people who seek advocacy support do so because they have exhausted all other options. In 2022, our Advocates worked tirelessly to ensure that the voices of people with disabilities were heard, will and preferences were upheld and that people's voices are protected and listened to.

This Annual Report is broken into two sections. Section one provides detailed information on all the work of the NAS service in 2022. Section two details similar information related to the Patient Advocacy Service.

In 2022, our Advocates worked tirelessly to ensure that the voices of people with disabilities were heard, will and preferences were upheld and that people's voices are protected and listened to.

Both Sections highlight key data around the number of enquiries received by our services, the number of cases worked on by our Advocates and the complexity of the cases we worked on. This document illustrates the wide range of people that we work with and the types of issues they face. It provides an insight into how NAS Advocates work with people through several case examples.

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 ongoing 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 to providing professional advocacy services throughout 2022.

Rosemary Smyth

Rosemary Smyth, Chairperson of NAS Board

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 nursing home. They also help people after a patient safety incident.

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.

Who Supports the Patient Advocacy Service?



Rialtas na hÉireann Government of Ireland 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. They also help people after a patient safety incident.



This is called empowerment advocacy.



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

NAS Work in 2022



NAS Advocates worked on 1,577 cases supporting people with disabilities with their advocacy issues in 2022.



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 709 people in 2022.

NAS has a telephone number people can call for help with their issue on 0818 07 3000



1,367 people called this number in 2022.

Patient Advocacy Service work in 2022



The Patient Advocacy Service provided support to 1,859 people in 2022.



Advocates worked on 6,101 complaint issues for the people they supported.



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



In October 2022, the Patient Advocacy Service began to support residents in private nursing homes.



The Patient Advocacy Service has a website and it was visited by over 22,000 new users in 2022.



The Patient Advocacy Service has a telephone number people can call for help with their issue on 0818 293003

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Key Issues for NAS in 2022

NAS dealt with a lot of important issues for people with disabilities in 2022.



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 2022



The Patient Advocacy Service worked on important issues for people in 2022.



The top complaint issues were people feeling their anxieties were not listened to, not being able to visit hospitals, questions not answered, hospital staff not communicating care plans to the patient and staff being rude.

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 themselves or through hospitals and nursing homes.

Other Important Work in 2022



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 carried out a lot of work about the Assisted Decision Making (Capacity) Act and the Decision Support Service.



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 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 work both services do.

The Patient Advocacy Service had a national advertising campaign in 2022.



This meant going on the radio and writing in newspapers to tell people about how they could support them. National Advocacy Service Annual Report 2022

National Advocacy Service Highlights 2022

NAS provided

3,576 instances of advocacy in 2022. NAS received

initial enquiries in 2022.

The Service provided full representative advocacy support in **868** cases and full empowerment support in a further **709** cases.

NAS opened **1,022** new cases, of which **697** were empowerment advocacy cases and **325** were representative advocacy cases.

NAS closed 747 cases, of which 343 were empowerment advocacy cases¹ and 404 were representative advocacy cases², having achieved outcomes for those we support.

NAS staff engaged in **212** promotional events and presentations in disability services and other services throughout Ireland.

The NAS national phone line received **1,367** calls in 2022.

The NAS website had 11,814 individual site visits with 7,050 different users in 2022. Some of the biggest issues for people with disabilities which were worked on by NAS advocates in 2022 related to capacity building; housing and accommodation; residential and healthcare settings; decision making and social care.

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 seek 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, which is funded by the Department of Health, 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 nursing home, and in the aftermath of patient safety incidents.

^{1.} Empowerment advocacy supports a person to take action on their issue themselves. From a NAS perspective this may involve working with the person to explore fully what is the issue itself, suggesting some actions they may take to progress their situation, signposting them to various services (e.g. legal) or complaint mechanisms, providing a template letter, etc.

^{2.} Independent, representative advocacy empowers and is directed by the people who use it. It is person centred, accountable, accessible, impartial and independent of service providers, families and other supports. It 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.

Core Values

Our Strategic Plan 2018-2023 establishes the following five core values that underpin the work of NAS.

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.



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3. 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.



Case Study

Brenda's Story: Building Capacity

My name is Brenda, I grew up in foster care, I am a wheelchair user and I also have an intellectual disability. When I made an enquiry to NAS to seek an advocate, I was homeless and living in emergency accommodation. People were making decisions about where I should live without my input or involvement.

When I met my advocate, we discussed where I would like to live and what kind of staff support I would need. My Advocate came with me to a monthly planning meeting with all of the professionals involved in finding me somewhere to live. My advocate helped me to express my will and preference. My advocate also kept me up to date with the various placements I was being offered. She was very informative.

My Advocate met me before each meeting and I had an opportunity to provide any updates or information that I wanted to pass on to the professionals. After each meeting, my advocate also contacted me to recap on everything that happened at each meeting. I was also encouraged to attend some of the meetings by my advocate, which I had never done before. I found this very empowering and I was supported to tell everyone there what I wanted.

Unfortunately, there were several delays in providing me with an appropriate placement. My Advocate wrote to the Disability Manager on my behalf several times, highlighting the difficulties I was experiencing and my right to a safe and secure home.

After approximately 18 months, I was provided with a suitable placement. My Advocate supported me with the transition to my new home and ensured that all of my questions and queries were addressed before I moved. I now live happily in my own secure home and have all the staffing supports I need to live a full and meaningful life.



Susan's Story: Delayed discharge, inappropriate settings, exclusion from decision making, social care, residential placements

My name is Susan, I have an intellectual disability and have lived with my family all my life. I have a mental health diagnosis which means that sometimes when I am stressed, I will shout. I was prescribed medication for my mental health, however my family believed that the medication was not right for me, so I did not take it. My family brought me to the hospital as they felt that I might have a different condition and that this needed exploration and treatment. My family did not want to take me home from the hospital until I had all the necessary tests. They also contacted an Advocate as they were worried that I was not getting the right treatment.

When I met with my advocate, I explained that I found it hard to understand why I was in the hospital. I missed my friends and family. It was not possible to meet people or do my usual activities as Covid restrictions meant I could not leave the hospital temporarily.

I had a lot of different tests at the hospital and was diagnosed with a neurological disorder that could be managed with medication. My family did not accept this diagnosis and said that I could not come home until they were confident everything else was ruled out. My clinical team felt all appropriate tests had been carried out and that I should be discharged. At this stage, I had been in the hospital for more than six months. I told my advocate that I wanted to get out of the hospital and go back to my day service. Being in the hospital made me feel bored and lonely. I did not like to use technology, so I found it hard to maintain links with the outside world.

My Advocate spoke to my family about what I wanted and went to care planning meetings to support my will and preference. The hospital wanted to discharge me as I was not ill, but my family said I could not come home as they felt I was unwell. They disagreed with my diagnosis and they felt they could not manage my symptoms.



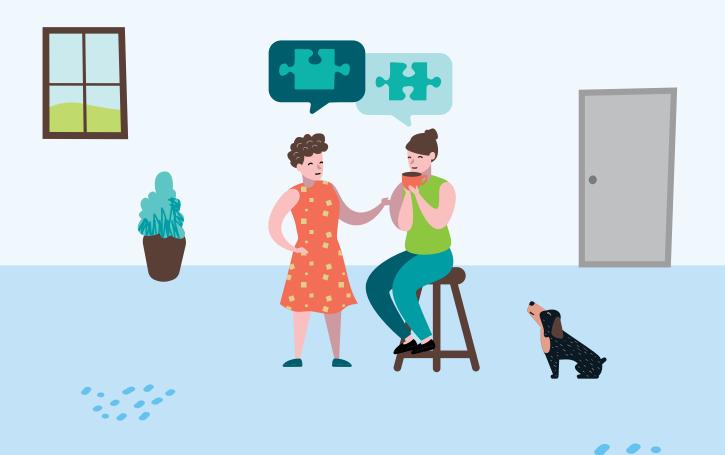
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My Advocate continued to support my wishes to return to my usual life and routine. My Advocate argued that I should not be moved to a step-down unit, but that instead I should be supported to move to a suitable longer-term home in the community, with people I knew.

My Advocate supported me to get information about services that might suit me. My hospital Social Worker made several referrals for me and I was offered a home by my day service provider. My Advocate spoke with me about the new home and I was happy to visit and then trial it. I moved into a shared house with some people that I already knew.

I am now very happy and living in my new home with people that I like and have things in common with. I have also returned to my day service and can visit my family whenever I wish.

My Advocate supported me so that I was heard in discussions about my future. My advocate kept me informed during the whole process and supported me in my decision-making. I was in the hospital for ten months and during this time, my Advocate communicated my wishes and managed complex conversations with officials in hospital and with services in the community as well as with my family.



4. Our Service

4.1 National Advocacy Service Work in 2022

"I wish to thank you from the bottom of my heart for all the good advice and help you gave me."

- Aaron, who was supported by NAS in 2022

NAS provides services to adults over 18 with disabilities. The range of issues which advocates have to support people 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 reviews 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 practices and knowledge.

NAS has identified that as our work has become more complex and is provided to more people, we need 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 with a disability who meet the criteria for our services have access to advocacy.

The criteria for accessing NAS services are outlined in our access and eligibility criteria policy, which is an internal document used in NAS operations. The policy is designed to ensure that NAS can uphold its remit of providing advocacy services for people with disabilities. To access NAS services a person must meet the criteria outlined in this policy. The policy ensures that our resources are utilised most fairly and efficiently and that those who most need our service can access it. The document focuses on a range of relevant issues including quality of life, risk of harm to a person's health, issues accessing services, lack of natural supports, and some other factors. 24

The number of people on the waiting list to access NAS services went from 161 (January 2022) to 250 (at the end of December 2022). While such a waiting list looks rather small when compared to waiting lists for other public services, behind these numbers lie individuals with disabilities who are facing significant barriers and who are experiencing personal suffering. The lack of resources available to NAS to deliver its services is also making waiting list management both more difficult and more time-consuming.



Total National Waiting List at the End of Each Month

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 to the Service since 2015. This means that people who are already isolated and in difficult situations are left waiting a long time for access to advocacy.

This is despite the recommendation³ to provide people with a statutory entitlement to independent advocacy attention made in the Joint Committee on Disability Matters, Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2023 Pre-Budget <u>Submission</u>,⁴ and the importance of access to advocacy noted in the <u>Ombudsman's Wasted Lives report</u>.⁵

^{3.} Point 4.4 of Joint Committee on Disability Matters Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2023 Pre-Budget Submission.

^{4.} <u>https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/</u> reports/2023/2023-02-23_report-on-aligning-disability-services-with-the-united-nations-convention-onthe-rights-of-persons-with-disabilities_en.pdf

^{5. &}lt;u>https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf</u>

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

- Overall, NAS received a total of 3,021 initial enquiries in 2022. This figure has grown since 2021, when there were 2,827 initial enquiries.
- NAS provided full representative advocacy to 868 people in 2022. This work involved extended engagement with individuals, ensuring that their will and preferences were heard, understood, and taken into account. 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.
- Of the 868 full representative advocacy cases in 2022, 543 cases had been open from 2021, while 325 new cases were opened in 2022.
- In addition, NAS also provided short-term or empowerment advocacy support and information support to 709 people in 2022. These instances 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 supporting referrals to other services.

Combining both ways that NAS advocates assist people, NAS provided advocacy support in 3,576 pieces of work in 2022, slightly lower than the 2021 figure of 3,833 pieces of work. It should be noted that due to the growing complexity of cases, the higher number of advocacy issues results in these cases staying active for longer. 26

4.2 Launch of Casebook

NAS and the Patient Advocacy Service published our first joint <u>Casebook</u>⁶ document in December 2022.

The Casebook contained a selection of the many advocacy cases worked on by both NAS and the Patient Advocacy Service over the past couple of years, including during the Covid-19 pandemic. It is a source of information for anyone who wants to find out more about the work and impact of both services.

It provides an insight into how independent, professional advocacy can positively impact on people's lives and protect their human rights. It illustrates the diverse range of people who access advocacy services in Ireland and the many issues covered by both NAS and the Patient Advocacy Service.

The case examples in this publication demonstrate how our Services help breach gaps in systems, ensure best practice across public services and promote positive systemic changes. They show how our advocacy work has a positive impact both for individuals and in communities across Ireland.

4.3 Preparation for Assisted Decision Making (Capacity) Act 2015

NAS staff placed a lot of focus in 2022 on preparing for the commencement of the Assisted Decision Making (Capacity) Act 2015. This preparation involved a wide range of activities which included:

- NAS senior management attending a range of in person and online training events for relevant services and organisations to educate them on the role of NAS in the Assisted Decision Making (Capacity) Act 2015.
- NAS engaged in a call for submissions from the Oireachtas Joint Committee on Children, Equality, Disability, Integration and Youth. In <u>this</u> <u>submission</u>,⁷ NAS provided an overall commentary on the content of the Bill, detailed feedback on any relevant heads of bills and a comprehensive list of recommendations based on its feedback.

^{6.} https://advocacy.ie/app/uploads/2022/12/NAS-PAS-Case-Study-Book-Final-Web.pdf

^{7. &}lt;u>https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_children_equality_disability_integration_and_youth/submissions/2022/2022-04-08_submission-louise-loughlin-national-manager-national-advocacy-service-for-people-with-disabilities_en.pdf</u>

Some of these recommendations included:

- ► That the Bill includes a clear definition of Advocacy.
- ► That the Bill provides people with a statutory right to Advocacy.
- That "Independent Advocates" need to be recognised as "interveners" under the Act.
- That "Independent Advocate attached to an organisation" should be included as a person in the list of persons whose views are to be considered by an intervener when he or she is intervening concerning a relevant person.
- That independent Advocates are given the right under this bill to attend court, access documents, data and other information regarding people they support.
- That more robust references be made to the role of an advocate under head 26 concerning decision-making regarding property affairs. Also, financial and property professionals should be obliged by the Act to engage with independent advocates.
- That NAS disagreed with the deletion in the Act of the application of the Advanced Healthcare Directives provisions, to those detained under the provisions of the Mental Health Act.
- NAS built relationships with the Decision Support Service through engagement and submissions.
- NAS contributed to the HSE Human Rights and Equality offices development of E-Learning resources for the Assisted Decision Making (Capacity) Act 2015.
- NAS National Manager sat on the HSE Assisted Decision Making (Capacity) Act 2015 oversight implementation group.
- NAS built internal capacity to deal with the commencement of the Act by carrying out detailed analysis of our Case Management Systems to make changes and amendments to its structure so that we can accurately report on our work in line with the changes brought about from the Act. NAS also developed a practice guide for all staff to provide detailed information on how the Act would impact their work.

4.4 Complexity of NAS Work

The number of issues per advocacy case for NAS has continued to increase year on year. This was also the case in 2022, 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, all the while ensuring that each issue is worked through at a pace that works best for the person.

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 advocates is managed and focused. Cases 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. The number of cases with between 2 and 7 issues has risen from 495 cases in 2018 to 926 cases in 2022.

Of the 1577 advocacy cases in 2022, 576 (37%) had one issue, 926 (58%) had two to seven issues and 75 (5%) 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 (UNCRPD) among service providers.
- Increased awareness of future obligations on service providers because of the Assisted Decision Making (Capacity) Act 2015.
- Embedding of HSE Safeguarding Policy.
- Increased knowledge of NAS among disabled people and their representatives.
- Increased knowledge and skills in NAS staff.
- Increased complexity of process around accessing disability services e.g., home care, Personal Assistance hours etc.



NAS Advocacy Issues Per Case Nationally

In recognition of the fact that NAS casework has consistently grown in complexity, NAS developed a Complex Case Review Forum. This is a new method of reviewing and dealing with particularly complex cases. It will involve a meeting of several NAS staff who will be briefed on a complex anonymised case. They will then pool their experiences, knowledge and expertise and provide possible options to progress the case.

4.5 Key Issues for NAS in 2022

The issues associated with delivering the NAS service in 2022 were similar to previous years. NAS staff were still working through many of the residual impacts of Covid-19 and the associated restrictions during this period. As has been reported by NAS in previous publications and by other organisations, the impact of Covid-19 and the associated restrictions on people with disabilities were disproportionate to the rest of the population and many of the people we advocated for were working through issues that arose as a result of Covid-19 throughout 2022.

These issues were most evident in residential and healthcare settings. In these settings, people reported to advocates negative experiences stemming from isolation and loneliness. Some of the main issues which have persisted from 2021 and were still being dealt with in 2022 include:

- Delayed transfers from residential settings.
- Delays in assessment and provision of new home support and personal assistance services.

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- 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 services in different locations.
- Access to Covid-19 vaccination, where third parties prevented access to the vaccine, contrary to the will and preference of the disabled person.
- Lack of access to home support and personal assistant services due to insufficient numbers of staff in many service providers.

NAS advocates have also noted that people in residential and healthcare settings that are under-65 are still living in and being placed in nursing homes. They also have reported many other issues associated with living in these settings, which are continuing to occur, for example, compatibility issues with other residents, not having autonomy over their own lives and not being able to access their own money and communities.

Housing was another key issue that arose for people that access NAS services. NAS advocates have worked with people across the spectrum of housing needs. There are some consistent trends that appear across the country that impact the people we advocate for. These include a lack of accessible and suitable rental accommodation, lack of accessible and suitable social housing, lack of accessible emergency accommodation and difficulties in accessing PA support. This is not an exhaustive list, but just some examples of the types of issues that are reported across the disability sector that are evident in NAS casework.

In 2022, 39% of all cases were related to housing and accommodation-related issues, while 36% of all cases were related to residential and healthcare settings. These are significant figures and represent a large portion of the work of NAS advocates and the needs of people that access our services.

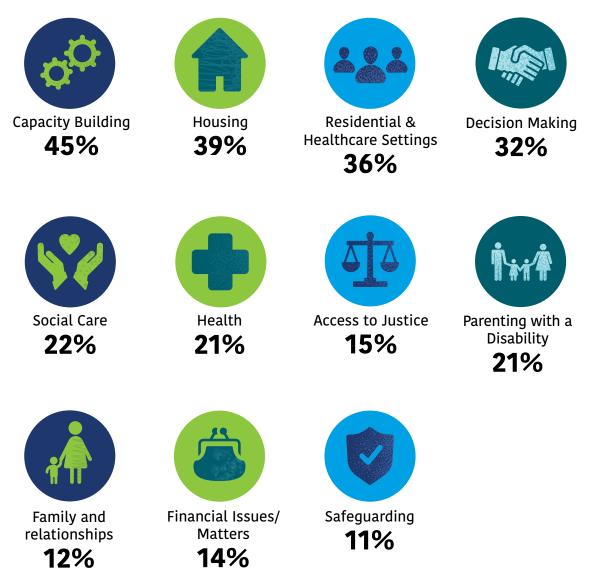
These figures have changed: In 2021, 46% of cases were related to housing, whereas in 2020 this figure was 45%. While for residential and healthcare settings, in 2021 43% of cases were related to housing and in 2020 this figure was 37%.

The issue of financial matters is an area which NAS has highlighted as a growing concern in our casework. People NAS support have reported problems like difficulties accessing bank accounts, and not having autonomy over their own money, these issues significantly impedes people's rights and quality of life. 14% of all cases in 2022 were related to financial issues and there is a need for active work to progress these systemic issues.



National Advocacy Service Issue Categories in 2022

Area Requiring Support



*Each figure here is independent and represents the total percentage of NAS cases that were linked to the associated issue. For example, 45% of the 1577 that NAS advocates worked on in 2022 were related to capacity building.

4.6 Who Engaged with the National Advocacy Service

NAS has a remit to provide advocacy services to people in particularly difficult situations. The service worked with a diverse range of people in 2022 who have many different types of disabilities.

As has been the case for several years, intellectual disability⁸ continued to make up the largest cohort of people NAS supports, at 47% of cases. People with intellectual disabilities who engage with NAS are mainly living in residential services or attending day services.

People with physical disabilities⁹ also continued to be a significant cohort of those NAS supported in 2022 at 24%. While people with mental health difficulties also feature heavily in NAS casework, with 25% of those NAS supports having some form of mental health difficulty¹⁰.

The number of people with acquired brain injuries¹¹(ABIs) continues to play a significant role in NAS casework, maintaining the figure of 13% of cases in 2022. This was the same as 2021 and is an increase from the 8% figure seen in 2019.

A trend which has continued in NAS service delivery for 2022 is that a significant element of NAS work is with people who have multiple disabilities. For example, a person seeking advocacy may have an intellectual disability and also a physical disability, or mental health issue. Generally speaking, people who have multiple disabilities will often have more complex issues or will experience more difficulty trying to navigate multiple systems of support, which requires them to be provided with a higher level of advocacy input.

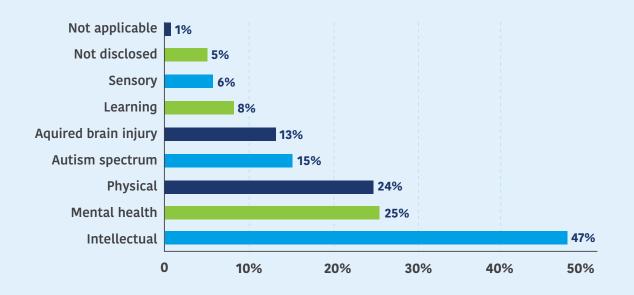
The table on the next page outlines the percentage of advocacy cases where a type of disability was present.

^{8.} An Intellectual disability is "a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. The disability originates before the age of 18." (American Association of Intellectual and Developmental Disabilities, 2014).

^{9.} A physical disability is a physical condition that affects a person's mobility, physical capacity, stamina, or dexterity.

^{10.} Mental Health Difficulties includes persons with psychosocial disabilities including those who regardless of self-identification or diagnosis of any mental health condition, face restrictions in the exercise of their rights and barriers to participation on the basis of an actual or perceived impairment. (This is from the UN High Commission on Human rights in 2017).

¹¹. Acquired brain injury (ABI) refers to any damage to the brain that occurred after birth.



4.7. Financial Overview

The National Advocacy Service for People with Disabilities (NAS) is fully funded by the Citizens Information Board. NAS also hosts the Patient Advocacy Service which is funded by the Department of Health.

The Citizen Information Board budget allocation for NAS in 2022 was €2,973,054. This generated an underspend of €190,242 which was returned to CIB in 2023. CIB advised in September 2022 the budget was to be re-profiled. This resulted in a reduction in the budget of €131,853 for NAS for 2022.The reason for the underspend in NAS funding is due to restrictions associated with how funding can be utilised and difficulties associated with predicting staffing levels and associated costs on an annual basis. The budget allocation provided for 48 FTE positions across the country. This level of funding has not changed in over ten years, despite a substantial increase in demand for the NAS service which has led to ongoing increases in enquiries to the service and a growth in our waiting list.

The Patient Advocacy Service received €1,291,811 from the Department of Health in 2022. This funding was used to provide for 18 FTE positions across the country to support delivery of the advocacy service to people seeking to make a complaint about an experience they had in a Public Acute Hospital or Nursing Home and also providing support after a patient safety incident.

Full details of our annual accounts can be found here.¹²

¹². https://advocacy.ie/app/uploads/2023/07/National-Advocacy-Service-for-people-with-Disabilities-fully-Signed-financials-2022.pdf

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Case Study

Canice's Story: Capacity Building

My name is Canice and I live in a residential setting. I have a history of depression and suffer from anxiety. I rang the National Line of the National Advocacy Service as I had an issue where I lived. I felt that I was being bullied by the residential manager and this person was also the complaints officer. I do not consider myself to be a confident person, and I don't like confrontation. I stopped using the services where I stayed and avoided meals and activities. I was making up excuses for my absence because I did not want to meet the person or tell others how I was feeling.

When I met my Advocate I was very clear and said that whilst I did not want the issue to escalate I did want the person to know how I was feeling. I did not want to advance the issue to a formal complaint, so I asked my Advocate not to obtain a copy of the complaints policy.

My Advocate supported me in setting out my concerns and my feelings over several meetings. With the support of my Advocate, I arranged a meeting with the manager. In this meeting, I expressed my concerns and spoke about the times I felt the manager had bullied me.

While the manager did not acknowledge bullying me, the manager did clarify some outstanding questions that I had in relation to comments they had made. The manager apologised that I felt the way I did, and we both agreed to talk about issues before they escalated in the future. My Advocate highlighted the concern that the manager was also the complaints officer and an alternative name was then provided to me if I had concerns in the future.

After this, I returned to attending activities and eating meals at the centre. I have a person in the service that I can contact if I have concerns in the future. My relationship with the manager has greatly improved and I feel respected and heard. I feel able to live the life I want and that I can now access all the services available to me, due to the support I received from my Advocate.



Margaret's Story: Finances

My name is Margaret, I am a 61-year-old woman, I have a physical disability and I live in a nursing home. I got in touch with NAS via an enquiry form. The reason I contacted NAS was that I wanted to have access to the money that I had each week after the deduction of the fair deal scheme. The nursing home would give this only by request and only in cheque format as the nursing home finances were cashless. The only way I could access my money was by being supported by my PA service to lodge the cheque in my bank and waiting 5 days for the cheques to clear, which made life difficult for me.

My Advocate supported me to explore the options of different bank accounts and providers. I told my Advocate that my will and preference was not to use an ATM card to complete my banking. I was supported by the Advocate and my Social Worker to organise a meeting with my preferred bank to discuss what account would suit me best, discuss my wish not to use an ATM card and seek clarity on bank fees. Once I brought these questions to the Bank's customer service, my Social Worker supported me to arrange for my social welfare to be paid into my account and a standing order set up to pay fair deal scheme invoices.

These meetings with my Advocate were very helpful as they allowed me to gather information about accounts, consider the options available and decide what account suited. After accessing NAS Advocacy services, I was able to access my own money in a way that was more in line with my will and preference.

5. Our Policy Work

"Thank you for all your efforts and for taking the stress off me. Long may you continue with your great work. Thank you for all you have done."

- Ciara, who was supported by a NAS Advocate in 2022.

5.1 Stakeholder engagement

Engagement with external statutory bodies:

The experience and expertise of NAS has contributed to a wide range of statutory bodies, public debates and discussion and organisational working groups and forums. NAS has provided insights into the role of advocacy and the importance of ensuring that a person's will and preference, voice and experience are central components in policy discussions.

NAS has continued to build strong working relationships with our funding organisation CIB, the HSE National Office of Human Rights and Equality Policy and National Quality Improvement Division, HIQA, the Court Service, the HSE Open Disclosure Office, the Joint Oireachtas Committee on Disability Matters, the Department of Health, the Department of Justice, the Department of Social Protection and the Department of Children, Equality, Disability, Integration & Youth, and the Decision Support Service.

Some examples of our engagement with external bodies include:

- Appearance before the Joint Oireachtas Committee on Disability Matters -October 13th "Considering a Right's Based Approach to Disability in Mental Health".
- Delivered presentations on the Assisted Decision Making (Capacity) Act 2015 to a wide range of external stakeholders including: Department of Social Protection Staff, HSE Staff, Irish League of Credit Unions, Judicial Council.
- Worked with the HSE Human Rights & Equality Team on an E-learning module regarding the Assisted Decision Making (Capacity) Act 2015.
- Worked with HIQA to contribute to the development of an Advocacy E-learning module.

- Chairing a panel and presenting at Law Society/DCU conference on Police Custody for vulnerable persons.
- Membership of the following groups:
 - ► National Care Experience Programme Steering Group
 - ► HSE ADM Implementation Oversight Group
 - ▶ HSE Under 65 Stakeholder Reference Group
 - ▶ HSE National Disability Consultative Forum
 - NWIHP Clinical Advisory Group and Clinical Guidelines Group
 - Safeguarding Ireland Committee

5.2 Public Consultations and Submissions

- Decision Support Service Consultation: Feedback on Draft Code of Practice for Designated Healthcare Representatives January 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Healthcare Professionals January 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Advanced Healthcare Directives for Healthcare Professionals – January 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Financial Service Providers January 2022
- Submission to the Joint Oireachtas Committee on Children, Equality, Disability, Integration and Youth on the General Scheme of the Assisted Decision-Making (Capacity) (Amendment) Bill 2021 – February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Court Friends – February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Decision Making Representatives – February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for General Visitors – February 2022



- Decision Support Service Consultation: Feedback on Draft Code of Practice for Independent Advocates February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Special Visitors February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Attorneys February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Co-Decision Makers February 2022
- Decision Support Service Consultation: Feedback on Draft Code of Practice for Decision Making Assistants February 2022
- Medical Council Research Strategy Survey April 2022
- Attended Mental Health Commission Focus Group on the revised rules and code of practice on the use of seclusion, mechanical restraint and physical restraint in approved centres August 2022
- Department of Health Public Consultation on Home Support Regulations August 2022
- A Public Consultation on a draft Policy Framework for Open Disclosure in the Irish Health Sector September 2022



6. Raising Awareness of Our Service

"Many thanks for your kindness & thank you for hearing me."

- Ronan, who was supported by a NAS Advocate in 2022.

6.1 Promoting the National Advocacy Service

In 2022, NAS advocates, Senior Advocates and Regional Managers took part in 212 outreach events. This included large scale marketing events such as the National Ploughing Championship, 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 led to increased enquiries.

The NAS website received 11,814 individual visits by 7,050 unique users.

NAS increased it's use of social media in 2022:

- The Service's Facebook page grew from 1,888 followers at the start of 2022 to 2,066 at the end of 2022.
- The Service's Twitter page grew from 1,774 followers at the start of 2022 to 2,009 at the end of 2022.
- The Service's LinkedIn grew from 549 at the beginning of 2022 to 879 at the end of the year.





National Advocacy Service for People with Disabilities & Patient Advocacy Service

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