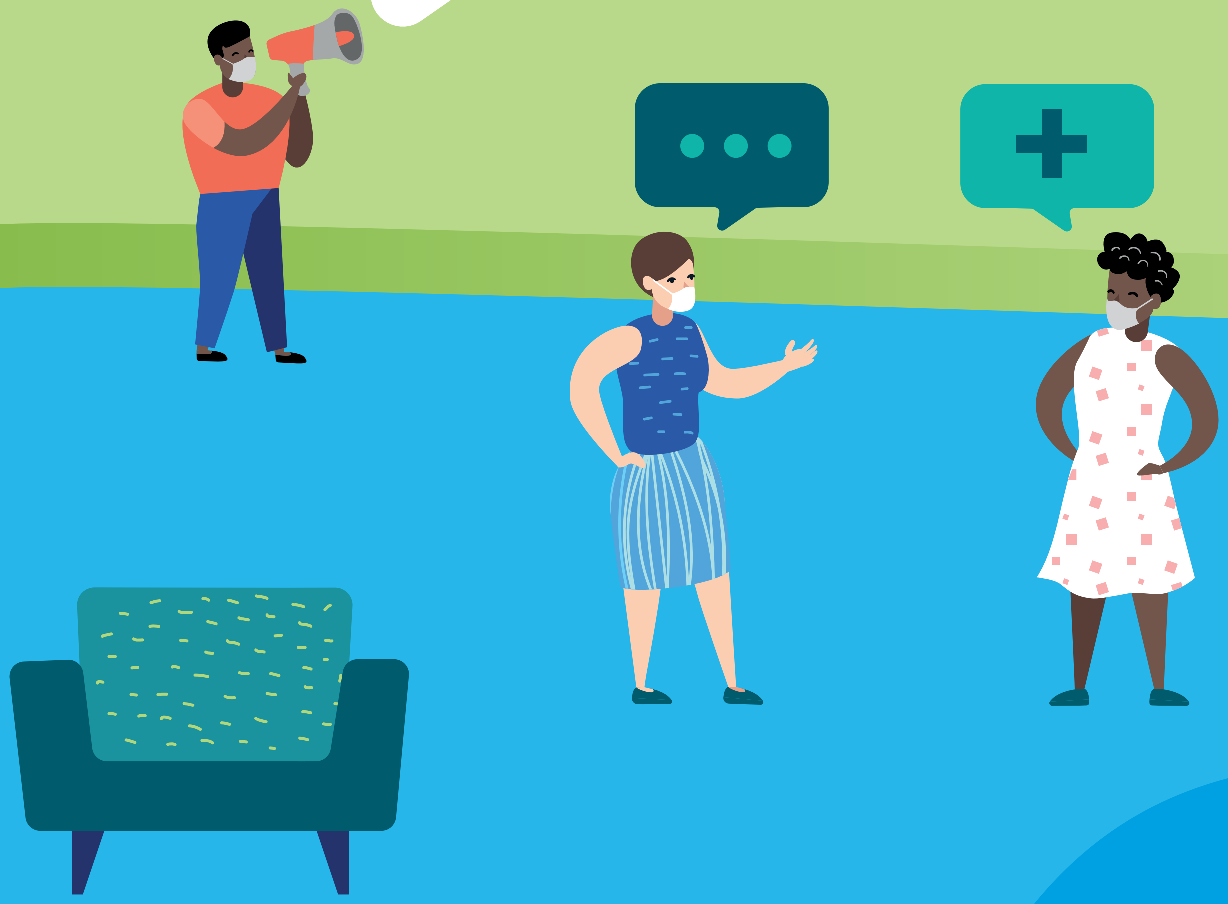
NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

Patient Advocacy Service
INFORMATION | SUPPORT | EMPOWERMENT

# Advocacy Matters:

## Advocating for People Regarding ‘Access to Justice’ & ‘Decision-Making’ During the Covid-19 Pandemic



October 2021

# Contents

# About this Report

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

It is the second of four reports which outline our observations and experiences in providing independent advocacy to people who required our support during the Covid-19 pandemic, particularly during the period from March 2020 - March 2021. Each report will look at a different theme.

This report, theme two, explains the issues people faced in relation to ‘access to justice’ and ‘decision-making’ during this traumatic period. It focuses on our work, outlining the support we provided and the positive outcomes this advocacy support helped to achieve. It shows the key role that advocacy services play in supporting people who may be vulnerable in Irish society, particularly during periods of crisis.

Having Access to Justice is a basic principle of the rule of law of Ireland. In the absence of access to justice, people with disabilities are unable to have their voice heard, exercise their basic human rights, challenge discrimination or hold decision-makers accountable.

Decision-Making is the right of every person, including people with disabilities, to have their voice, will and preference heard in any decisions about their own lives.

Established in 2011, the National Advocacy Service for People with Disabilities (NAS) is an independent, free and confidential service, funded and supported by the Citizens Information Board. NAS provides representative advocacy to people with disabilities across Ireland, to ensure that their will and preferences are sought and heard in decisions that affect their lives.

NAS also hosts the Patient Advocacy Service, established in October 2019, which is commissioned and funded by the Department of Health. This free, independent and confidential Service provides information and empowerment advocacy to people who want to make a formal complaint through the HSE ‘Your Service, Your Say’ complaints policy in relation to their care in a public acute hospital or a HSE operated nursing home and in the aftermath of a patient safety incident.

The vision of NAS is one where people with disabilities can exercise their rights, with dignity, autonomy, equality and independence at the core. NAS recognises the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities[1] (UNCRPD).

Both NAS and the Patient Advocacy Service recognise the rights of all people to support, guidance and information when issues arise in relation to their care and treatment which may lead to their wish to complain about their treatment or care or seek answers in the aftermath of a patient safety incident.

**Please note, all statistics presented in this report are specifically looking at the period March 2020 – March 2021. They report on emerging and ongoing issues, resulting from the Covid-19 pandemic, which impacted on the lives of people with disabilities supported by NAS.**

# Key Recommendations in this Report

- NAS should be adequately funded and resourced to ensure that it can continue to support people with disabilities to have their will and preference in decision making upheld.
- Every person should be supported to make their own informed decision in relation to the Covid-19 vaccine and Do Not Attempt Resuscitation (DNARs) orders.
- It is imperative that health and social care providers engage with advocacy support for the person, particularly in cases where people may not be able to directly communicate their will and preferences.

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[1] United Nations Convention on the Rights of People with Disabilities **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html**

- It is also hugely important that the Irish government ensures the Assisted Decision-Making (Capacity) Act 2015[2] is commenced and the Decision Support Service fully established. Matters such as a person's capacity to make decisions, or give their informed consent are of paramount importance, and the human rights of the person must be at the centre of these processes.
- Heath and Social care services must act according to the HSE Consent Policy[3] and the Principles of the Assisted Decision-Making (Capacity) Act, recognising the person's rights under the UNCRPD, all of which state that no other person can give consent or make decisions on another person's behalf without legal authority to do so and recognise a person's right to be supported with decision-making.
- In decisions regarding medical care, it is important that guidance is sought from the relevant clinical team to also support the person in establishing their will and preference. Decision making for those who communicate differently should be based on medical guidance to uphold the person's human right to health and life.
- A co-ordinated approach is required for people with disabilities who are also experiencing homelessness. Local Authorities must ensure people with disabilities are supported to engage in an accessible way in the housing process. Appropriate and accessible accommodation must be made available to ensure that their needs are met.

# Key Conclusions in this Report

- NAS and the Patient Advocacy Service have upheld people's rights, ensuring their voices are heard and they have fair and equal treatment and access to services. They ensured that decisions were taken with due consideration for a person's will and preference.
- Next of Kin has no legal basis for anyone to make a decision on behalf of another person unless they have specific legal authority to do so. However, often decisions are made on this basis about people with disabilities, those who are elderly or ill.
- NAS and the Patient Advocacy Service is fully aware that families' concerns should be listened to, but not at the expense of the person's own right to choose for themselves.

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[2] Assisted Decision-Making (Capacity) Act 2015 **https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html**

[3] National Consent Policy **https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consentnational-consent-policy-hse-v1-3-june-2019.pdf**

- NAS supported people with disabilities who were at risk of having their views overlooked or ignored altogether when it came to key decisions about their lives.
- NAS works with people to ensure their right to meaningful and appropriate inclusion in legal processes is upheld, such as parents with a disability who may be engaged in legal childcare proceedings. Advocates strive to ensure the parent is supported to understand and fully participate in the process.
- At times during the pandemic, Court hearings were only available in emergency cases and Advocates were unable to support people to attend court. It was also difficult for people to meet face-to-face with legal representatives in advance of proceedings.
- NAS provided advocacy support to those who were being made a Ward of Court and subjected to Ward of Court proceedings. Restrictions and infection control measures resulted in lengthy delays to the wardship process, medical reviews and capacity assessments. Advocates ensured that people were kept fully informed on matters and received information in an accessible format. Our work during the pandemic has helped to ensure that the voice of the person has been considered by the Court in the Wardship process.
- NAS has supported people with disabilities in relation to safeguarding issues, regarding issues such as abuse and financial concerns. These actions included linking with solicitors in relation to Ward of Court and legal aid, supporting access to psychology and counselling services, reviewing of wills and linking a person with the Probate Office.
- NAS has supported people with disabilities at risk of homelessness or living in accommodation supported by homeless services. As the pandemic took hold, external supports such as home help care agencies were unable to go into homeless services. Advocates helped people to move into accommodation that was more comfortable, accessible and appropriate to their disability support needs.
- The UNCRPD recognises the rights of persons with disabilities to access adequate housing through public housing programmes. Safe and secure housing is a fundamental right for people with disabilities. It also their right to have meaningful participation in their community.

# Impact of Covid on Our Services

Before focusing on the issues Covid-19 has caused for people in relation to Access to Justice and Decision-Making, it is important to note the impact of the virus on the services provided by NAS and the Patient Advocacy Service.

The emergence of the Covid-19 virus in March 2020 meant it was impossible for the two services to continue their normal way of office working, including meeting people face-to-face. Overnight, they moved to working from home, a situation which continues over one year later.

However, while some organisations struggled to respond effectively to operational changes, NAS and the Patient Advocacy Service manage national phone lines and online methods of enquiry (email, website). This has ensured that both Services have continued to advocate for people to ensure that their voices are heard when decisions are being made on public health grounds, and to advocate with them and for them to have access to services and supports at this challenging time.

In addition, particularly at the beginning of the pandemic lockdown, NAS provided support beyond their remit by helping people to access services such as shopping, GPs and pharmacies, as well as Covid-19 pandemic unemployment payments.

Meeting the people we support face-to-face also proved challenging as Advocates could not spend time with them to observe and understand their will and preference fully. Responding to these difficulties, Advocates utilised alternative methods of communication such as, phone calls, video calls, emailing and text messaging. To continue with the provision of advocacy for some people, particularly those who communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) Advocates had to rely on the support of families and service providers to aid with continued communication. Despite these communications challenges, NAS worked with the person to ensure their will and preference were carried out.

The Patient Advocacy Service has also continued to provide advocacy support and information to users of its service during the pandemic through its national phone line and online forums. It provided long arm support to people around difficulties they experienced with their home-based care, whether living in their own home or community setting, including providing access to information.

# Decision Making & Access to Justice: Responding to the Impact of Covid

> **"The Advocate spent hours gathering the information required and put so much effort into every part of my case. Without the advocate's help, I probably would have made the wrong decision".**
>
> Jane, who was supported by NAS in 2020 to make her own decision about her care

NAS has a particular remit to work with those who may be isolated from their community of choice or mainstream society, those who may communicate differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication) and those who have limited informal or natural supports. NAS and the Patient Advocacy Service uphold the person's rights, ensuring fair and equal treatment and access to services.

**Advocates make certain that decisions are taken with due consideration for a person's unique preferences and perspective, will and preference.**

The Services empowerment and representative advocacy involves professional, trained experts in advocacy dealing with specific issues and working with an individual until that issue reaches conclusion. Independent, empowerment and representative advocacy is directed by the people who use it. Where the person communicates differently, the Advocate is still directed by the person.

In ordinary times, the people NAS works with face rights restrictions and have poorer access to health, education and employment. They have difficulties in accessing justice and decision making and are more likely to experience discrimination.

People with disabilities and those accessing health and social care supports are a very diverse group and some within this group face even greater marginalisation. These include those experiencing mental health issues, those from different migrant or ethnic groups, and those who communicate differently.

During the Covid-19 pandemic, these issues were further exacerbated for people with disabilities when it came to issues surrounding their right to make their own decisions, and their right to access justice in Ireland.

In relation to decision making, NAS and the Patient Advocacy Service have found that

**people with disabilities are often not informed of or included in making decisions made about their own lives. This became particularly evident during the pandemic when NAS became aware that many decisions were being made on behalf of people with disabilities.**

In these cases, the individual's independent voice was not being heard and there had been no attempt to do so. The will and preference of individuals was not being upheld in a decision-making process. In the HSE's 'Effective Participation in Decision-Making for People with Disabilities and Families: Planning for Ordinary Lives in Ordinary Places'[4] it stresses that the person with a disability has the right to participate in decisions made about their lives. The person's voice, and choice, their will and preference, should be heard in the decision-making process and they should be given control over the decisions made about their lives.

The right of people with disabilities to be involved in decision making is also underpinned in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Assisted Decision Making (Capacity) Act 2015[5].

Of the people NAS supported from March 2020 - March 2021, 41% of people with decision-making issues impacted by Covid-19 were living independently in the community with support, and 37% were living in residential services. This demonstrates the need for the valuable work carried out by NAS to uphold the rights of people with disabilities.

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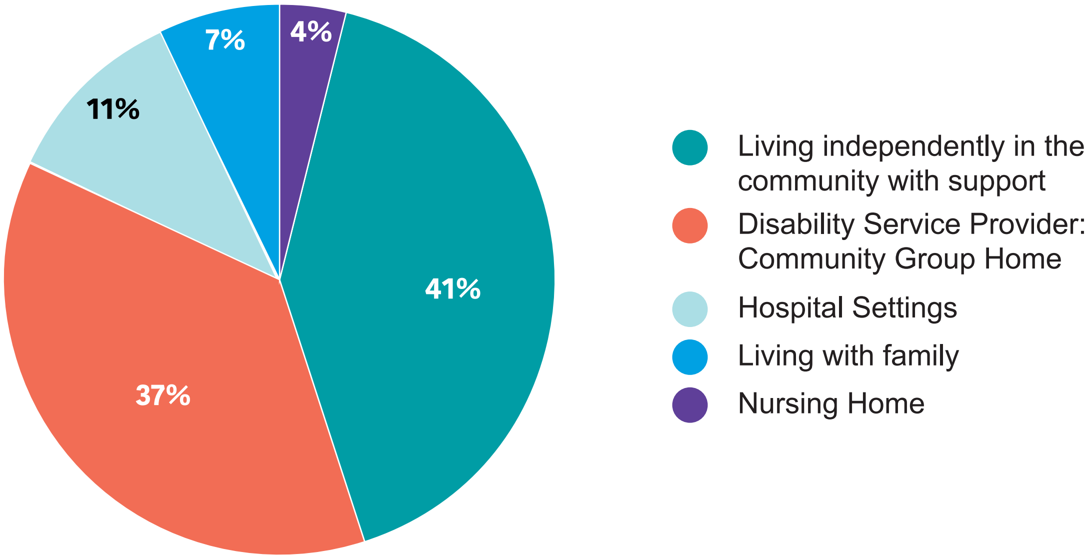
[4] Effective Participation in Decision-Making for People with Disabilities and Families: Planning for Ordinary Lives in Ordinary Places **https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-implementation-for-hse-staff.pdf**

[5] Assisted Decision Making (Capacity) Act 2015 **http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html**

## Location of People who Experienced Decision Making Issues due to Covid-19



Advocates helped to ensure people's will and preference was upheld when making decisions about consenting to the Covid-19 vaccine.

**Advocates were particularly concerned that some family members were making decisions on behalf of the person with a disability and people in nursing homes, despite having no legal authority to do so.**

**They also provided support when it came to Do Not Attempt Resuscitation (DNARs) orders in hospitals and nursing homes, when no attempt was made to ascertain a person's own views and wishes , and family members were asked to make decisions on their behalf.**

NAS recognised that this was not in line with the HSE consent policy[6] and breached the rights of the person.

An important part of NAS advocacy practice is to uphold the rights of people with disabilities to get access to justice, as set out in Article 13 of the United Nations Convention on Rights of Persons with Disabilities[7] (UNCRPD).

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[6] National Consent Policy **https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf**

[7] United Nations Convention on Rights of Persons with Disabilities **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-13-access-to-justice.html**

NAS frequently supports people to engage with the legal system and ensure their right to meaningful and appropriate inclusion in legal processes is upheld.

NAS is aware that for many people with disabilities, accessing justice and engaging with the legal system can be difficult. Advocates work to ensure the person is not excluded from processes and their voice is heard by decision makers.

NAS frequently provides independent advocacy support to parents with a disability who may be engaged in legal childcare proceedings under the Child Care Act 1991[8] and helps to ensure the parent is supported to understand and fully participate in the process.

NAS also provides support to those who may be a Ward of Court and are the subject of Ward of Court proceedings under the Lunacy Regulation (Ireland) Act[9]. A person is made a Ward of Court/wardship when, following medical assessments, they have been deemed to lack decision-making capacity by the President of the High Court and appointed a committee/general solicitor to manage their affairs. Advocates help to ensure the person's voice is supported and represented to the President of the High Court when key decisions are being made.

Advocates have continued to provide support in this area throughout the pandemic. In some cases, this work was adapted to remote support, until it was safe to resume face-to-face support.

# Decision Making: Next of Kin

Every person under Irish law, including a person with a disability, has the right to make their own decisions. This is underpinned in the United Nations Convention on the Rights of the Persons with Disabilities (UNCRPD), which Ireland ratified in March 2018. Article 3 of the convention says there must be 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'[10].

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[8] Child Care Act 1991 **http://www.irishstatutebook.ie/eli/1991/act/17/enacted/en/html**

[9] Lunacy Regulation (Ireland) Act 1871 **http://www.irishstatutebook.ie/eli/1871/act/22/enacted/en/print.html**

[10] United Nations Convention on Rights of Persons with Disabilities, Article 3 **https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html**

The HSE's document 'Consent: A guide for health and social care professionals'[11] clearly outlines that when "treating or caring for people (this involves anything from helping people with dressing to carrying out major surgery), you must make sure you have that person's consent to what you propose to do. This respect for people's rights to determine what happens to their own bodies is a fundamental part of good practice". The need to have the person's consent for all decisions is also present in the Irish Constitution. The person must be presumed to have capacity to make decisions.

It is clearly outlined in the HSE's National Consent Policy[12] that no other person can give or refuse consent on behalf of another adult unless they have the legal authority to do so such as an enduring power of attorney or the person is a Ward of Court. Someone who is listed as a Next of Kin is the person to be contacted in case of emergency, however this does not give the next of kin authority to make decisions or give consent on the person's behalf.

A Power of Attorney[13] is a legal process set up by the person themselves that allows for decisions to be made on their behalf by an appointed person. An Enduring Power of Attorney[14] is an agreement made with a person and their appointed person and only takes effect when the person no longer has the capacity to make decisions.

If these legal processes are not in place, and there is a concern for a person's capacity to make their own decisions, there may be an application for the person to be made a Ward of Court. The Ward of Court System in Ireland is set out by the Lunacy Regulation Act 1871[15]. Making someone a Ward of Court should be a last resort and should only be considered when every other option has been explored and exhausted. If the person is made a Ward of Court, a committee will generally be appointed to oversee the personal care of the person and manage the finances of the person. The Ward of Court system also removes all decision-making authority from the person and limits their autonomy.

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[11] Consent: A guide for health and social care professionals, pg. 6 **https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/guidehealhsocialcareprof.pdf**

[12] National Consent Policy **https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf**

[13] Powers of Attorney Act 1996 **http://www.irishstatutebook.ie/eli/1996/act/12/enacted/en/html**

[14] Enduring Powers of Attorney Regulations 1996 **http://www.irishstatutebook.ie/eli/1996/si/196/made/en/**

[15] Lunacy Regulation (Ireland) Act 1871 **http://www.irishstatutebook.ie/eli/1871/act/22/enacted/en/print.html**

The Assisted Decision Making (Capacity) Act 2015 (ADM)[16] provides for a new statutory framework to support decision-making by adults who may need support when making certain decisions. When fully commenced, this Act will repeal the Lunacy Regulation Act. The ADM will ensure the person is included in the decision-making process and can continue to exercise their right to make their own decisions.

Over the course of the pandemic, NAS and the Patient Advocacy Service heard of instances when a next of kin or family member was making decisions on the person's behalf in relation to the Covid-19 vaccine and Do Not Attempt Resuscitation (DNARs).

NAS is also aware of cases when rushed decisions were made on behalf of the person in response to the pandemic. Some families made the decision to remove the person with a disability from residential services without the person's consent. People with a disability have been moved to a new service with little or no transition planning for the person.

There have also been cases involving disproportionate restrictions in residential services that limited the rights and autonomy of the person and were not in line with the current public health guidelines. When providing people with advocacy support, NAS and the Patient Advocacy Service always ensures that the person is included in the decision-making process and assumes capacity of the person to make their own informed decisions.

# Decision Making: Consenting to the Covid-19 Vaccine

> **"Thank you so much for all that information, you made my issue so much easier to understand. It is great that your service exists to help people"**
>
> James, who was supported by a NAS Advocate in Autumn 2020

NAS and the Patient Advocacy Service supported people with disabilities, people in nursing homes, service providers and their families with the consent process and the Covid-19 vaccine. One of our core values is to ensure that the rights and will and preference of a person are respected.

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[16] Assisted Decision Making (Capacity) Act 2015 **http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html**

As per the principles of the Assisted Decision-Making (Capacity) Act 2015, families are a key component in the circle of support to establish the will and preference of the person who may not be able to give clear direction. Advocates are fully aware that family concerns should be listened to, but not at the expense of the person’s own right to choose for themselves.

In decisions regarding medical care, it is important that guidance is sought from the relevant clinical team to support the person in establishing their will and preference and for the person to understand all the relevant information so they can make an informed decision. For those who communicate differently, decision making should be based on the will and preference of the person where it may have been previously expressed and also on medical guidance, to uphold the person’s human right to health and life.

In the early stages of 2021, NAS and the Patient Advocacy Service anticipated that there would be some additional issues that would arise from the national vaccine roll-out. The two services are already very familiar with issues around decision making and consent for people with disabilities or others who may be in vulnerable situations, such as those who are very ill or those living in nursing homes.

NAS and the Patient Advocacy Service have extensive experience when it comes to protecting the rights of a people in relation to issues surrounding next of kin. Next of kin as a concept does not provide a legal basis for anyone to make a decision on behalf of anyone else, unless they have specific legal authority to do so. NAS, in particular, has many years of experience in supporting people to ensure that family members do not make decisions on their behalf.

NAS was invited by the HSE to participate in **webinars** with the HSE National Office for Human Rights and Equality Policy about the Covid-19 vaccine consent and decision-making process. NAS was part of the expert panel, presenting at these events. NAS shared their expertise in relation to consent and how best to ensure that the rights of a person with a disability are respected. Advocates are highly skilled at establishing will and preference and this was a key facet of supporting people with vaccine administration. Advocates developed additional knowledge, understanding and expertise in this area to ensure they could fully support people and services.

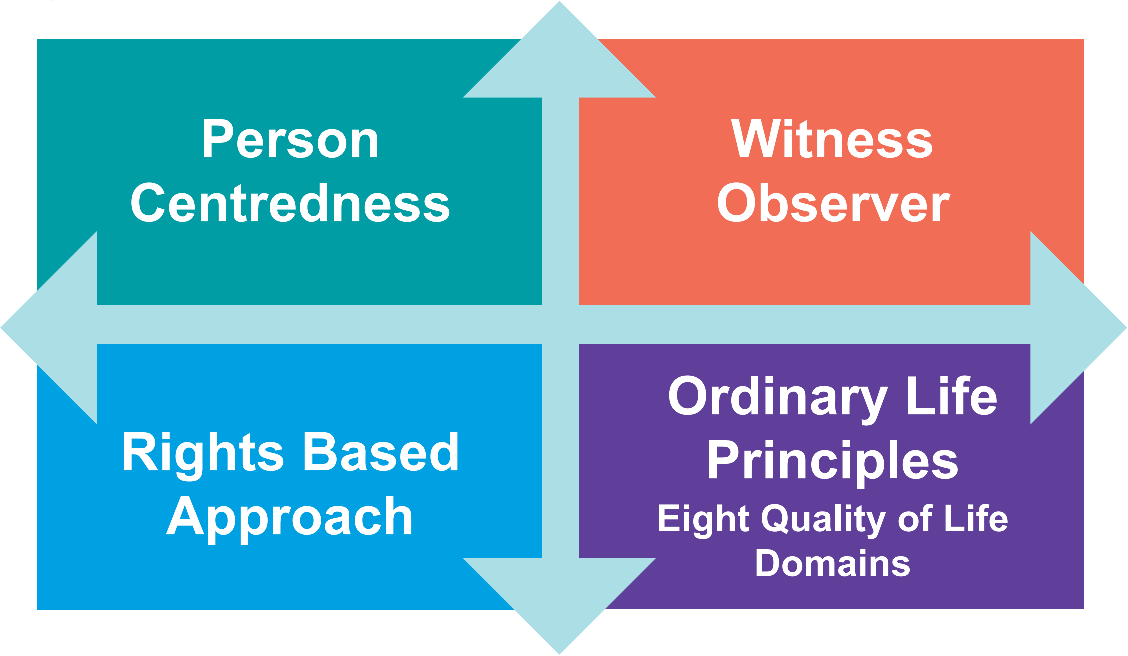
NAS and the Patient Advocacy Service identified cases where family members or next of kin sought to direct service providers not to give the vaccine to a person with a disability and those living in nursing homes.

The issue was that this instruction would be based on their own opinion, rather than the opinion of the person themselves.

In response, Advocates provided support in cases where families wished to make decisions on behalf of the person receiving the vaccine. NAS supported service providers to ascertain the person’s choice in relation to giving vaccine consent or not. In most of these cases, service providers were looking for advice and information about how to support a person with a disability, who communicated differently (through behaviour and gestures or assistive technology as opposed to verbal or written communication).

Advocates’ expertise in the use of the four approaches in working with people who communicate differently proved very effective. The **four approaches** are a set of internationally recognised tools that help to identify and ascertain what a person’s will and preference are, particularly if they communicate differently. These four approaches are: Witness Observer; Person-Centred approach; Rights Based Approach and the Ordinary Life Principles (Eight Quality of Life Domains) (fig.1).

Figure 1



Advocates liaised with service providers, providing guidance, information and advice on how adopting the use of such approaches could support the consent process. They supported the person with a disability to exercise their right to have their own will and preference recognised and heard.

Advocates worked closely with service providers to ensure that people with disabilities were provided with appropriate information on what the vaccine was for and why it was being administered. They supported services to make sure the information was accessible, and that people were given the time they required to fully understand. This ensured that people with disabilities were appropriately informed and could make an informed decision.

As per the guidance outlined in the HSE National Consent Policy, and in line with the principles of the Assisted Decision Making (Capacity) Act 2015, NAS and the Patient Advocacy Service operates from a basis that capacity is always assumed unless it is proven otherwise, or when all efforts to support the person to understand have been exhausted. Advocates were at the forefront in supporting disability services to guide people with disabilities through the decision-making and consent process.

**At times this became a contentious issue, particularly given the societal belief that next of kin confers an authority which it does not. There is much confusion about next of kin and decision making in Ireland, which compounded issues around consent and vaccines. This posed a considerable challenge to service providers who aim to include families in the journey of the person in their care.**

Despite these issues, Advocates adhered to a person-centred process to ensure that a true indication of the person’s decision could be reached.

NAS is still dealing with enquiries and cases on this issue. Some services are refusing to uphold the person’s will and preference in deference to family wishes and out of fear of litigation. Quite often, when these issues have arisen, the service provider contacts NAS for guidance.

In one example, an Advocate had been supporting a person with a disability who communicated differently. The person’s family decided that the person was not to receive the vaccine. The service provider was concerned about repercussions of possible legal action by the person’s family if they supported the person to get the vaccine. The Advocate worked with the service provider to highlight the efforts they had already made were in keeping with the National Consent Policy and that they had used all approaches to elicit the will and preference of the person to support the person’s own decision to get the vaccine.

## John’s Story: Covid-19 Vaccine

My name is John and I live in a residential service. I have a learning disability and I also communicate differently, through gestures.

I was offered the Covid-19 vaccination and staff in my residential service were trying to find out if I should be given it.

However, instead of identifying how they could communicate with me directly to learn my view, they spoke with my family to ask for their consent. My family did not want me to receive the vaccination.

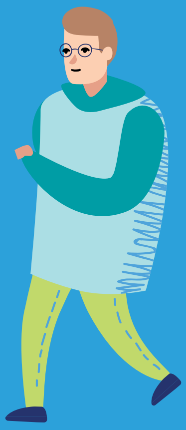
The residential service staff decided to contact NAS to identify how they could communicate with me more effectively. The NAS Advocate explained that my will and preference should be taken into account in the decision-making process. My Advocate advised that they were seeking consent from a family member instead of getting it from me.

To address this, the Advocate developed a guide outlining the steps the service needed to follow. Due to the Covid restrictions they couldn’t meet in person, so the Advocate arranged a video call to present the guide to the service.

The guide covered points like how to make sure my views were listened to when making decisions about the vaccine and if I wanted to take it. The guide spoke about supporting me with my decision even if my family and the service didn’t agree with it.

As a result of this guide, my Advocate and staff in the residential service were able to work together to find out my views and what would be best for me.

I got the vaccine which was my decision. The residential service changed how they approach getting a person’s views about the vaccination. They have also committed to reviewing their policy around other decisions such as money management.



# Access to Justice for Parents with a Disability

> **“I felt enabled, empowered, in control. I felt able to make sense of it and make considered decisions through a difficult process. Thank you so much.”**
>
> Angie, who was supported by NAS in 2021

Many of the people supported by NAS are parents with a disability whose children are in care or are in the process of legal childcare proceedings under the Child Care Act 1991[17]. Tusla, the Child and Family agency, has a statutory duty to promote the welfare of children who are not receiving adequate care and protection. If they feel a child needs care and protection or is at risk, they may seek an order from the court to place the child in care.

NAS supports parents to prepare for meetings with Tusla and other professionals involved in the care of their children. They also support them to prepare for and attend legal consultations with their Solicitors and court appearances.

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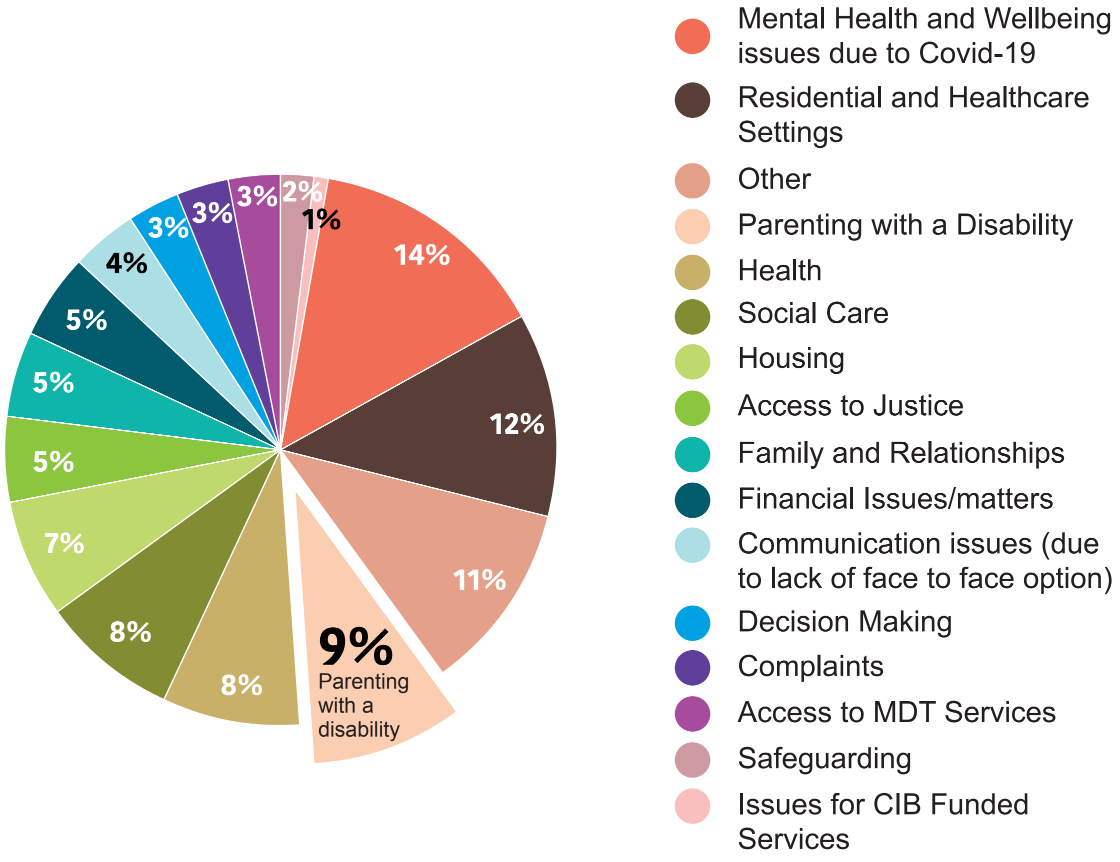
[17] Child Care Act 1991 **http://www.irishstatutebook.ie/eli/1991/act/17/enacted/en/html**

## Issues Impacted by Covid-19 Experienced by People NAS Supported

### March 2020 - March 2021



NAS data from March 2020 - March 2021 shows that 9% of issues reported by people impacted by Covid-19 who accessed the Service's support were related to parenting with a disability.

The support and preparation provided by NAS often involves ensuring that these complicated proceedings are fully explained in a manner that the person with a disability can understand. This is often a lengthy process.

These proceedings were hugely affected by the pandemic and the lockdowns. At several points throughout the Covid-19 pandemic, court hearings were only available in emergency cases and Advocates were unable to support people to attend court. It was also difficult for parents to meet face-to-face with legal representatives in advance of proceedings.

This impacted on the parent's ability to understand all the implications of decisions. NAS has noted long delays for people in progressing court cases during this period which has caused considerable stress and upset for people with disabilities, their children and their families.

As the pandemic became a more long-term issue, involving several lockdowns, court proceedings moved online via video link. Teleconferences were also utilised by Tusla to speed up these proceedings. Although these appeared to be creative solutions to an otherwise challenging time, Advocates found that these mechanisms caused difficulties for some people with disabilities.

One Advocate noted that the person they were supporting could not engage with an annual review meeting for their children, as it was to be done via teleconference due to Covid restrictions.

The parent could not cope with so many voices over the phone and found it extremely disconcerting as they could not see the person who was speaking. As a result, the parent could not attend the meeting. The Advocate made numerous requests in writing to Tusla for a copy of the minutes of the meeting for the person so they could be fully informed of any decisions made at the meeting. The Advocate wanted to ensure that the person was afforded as much information as possible to ensure so their rights were respected within the process.

NAS has also continued to engage with legal teams as part of childcare proceedings to ensure that the right to access to justice is upheld for the person with a disability. Advocates have worked with legal services and child protection services to make sure the person could engage in the legal process in a meaningful and appropriate manner.

During the pandemic, the supports that NAS provides to parents with a disability have changed and developed. NAS has supported people to engage in remote access visits with their children using video calls. Advocates have noted that a lack of smart technology in some foster carers' homes has led to situations where some parents have only been able to contact their children by telephone. This has caused great distress for parents, particularly those with babies and young children.

As face-to-face access had been suspended during the pandemic, many people supported by NAS said that they had found it difficult to engage with alternative access arrangements put in place by Tusla. These access arrangements attempted to safeguard children in care due to Covid-19, but they did not afford the right of the parent with a disability to have access to their children in care.

NAS was informed of children not engaging with technologies such as FaceTime or video calls, especially where children had disabilities themselves, such as Autism or Attention Deficit Hyperactivity Disorder (ADHD). This meant it was impossible for the parent to get a real sense of how their child was doing and to make decisions around their care, due to lack of information and updates on how their child was progressing.

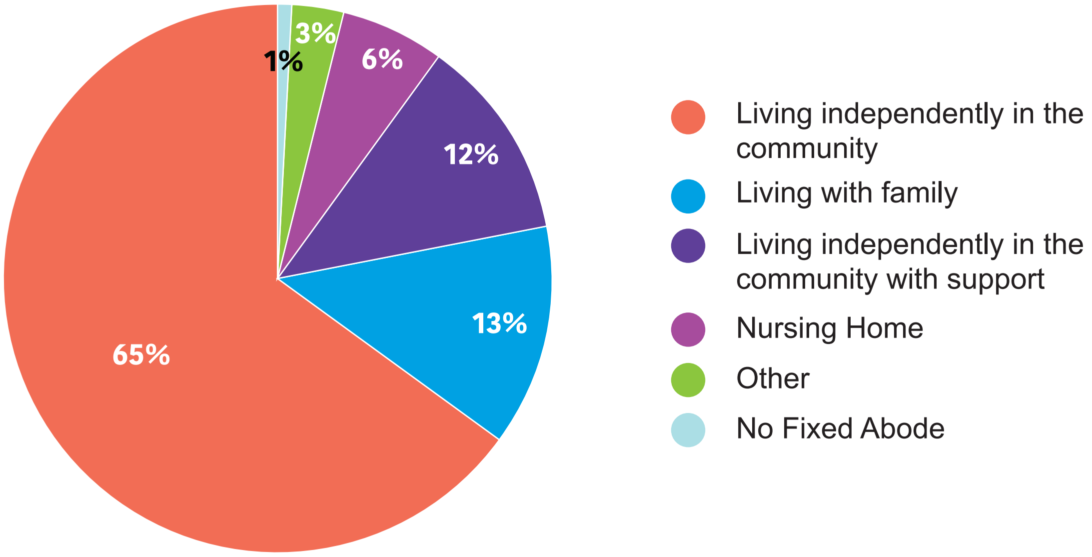
NAS engaged with Social Work Teams on these matters, highlighting the emotional impact they had on the parent with a disability, particularly those parents who were living alone and had to deal with feelings of isolation. They also highlighted the emotional loss for the child in care, as they too were experiencing further loss or absence from their parent due to the Covid-related restrictions.

Some Advocates reported that after some lockdowns were eased, much needed face-to-face access visits for parents did not always come back on stream. In these instances, NAS supported the person by ensuring contact was made with Tusla Social Work services to rectify this issue as swiftly as possible.

It was frequently reported to NAS that lockdown experiences were extremely isolating for people, taking a significant toll on their mental health. This was made worse by the absence of contact or restricted access to their children. Advocates spoke to social work teams to highlight the additional impact upon parents with a disability with children in care.

NAS data shows that 65%, the majority of people parenting with a disability who were impacted by Covid-19, lived independently in the community.

## Issue: Parenting with a Disability Impacted by Covid-19 (Location of the Person)



In one case, NAS supported a young parent with a disability. The person had their child in care as part of a private arrangement with family, but issues arose around the person seeing their child due to the Covid-19 restrictions. Video calls were the only permitted means for the person to make contact, but the child was not able to engage properly. The calls did not work, and their relationship was adversely affected. The Advocate sought additional arrangements to improve the relationship between the parent and child, including planned activities that would interest the child on the video calls. They also worked to ensure that face-to-face access visits were planned once the lockdown restrictions were eased.

A significant issue faced by parents with disabilities during the pandemic involved accessing free legal aid. NAS noted lengthy delays accessing free legal aid across the country led to extensive waiting lists. This caused additional distress to people with disabilities who had children in care.

NAS is also aware that community-based family supports such as family resource centres have been disrupted for parents with disabilities. In the early stages of the pandemic, these essential supports were stopped to comply with public health guidance. NAS supported a parent who faced childcare proceedings following several months of parenting their children without these supports.

## Ciara’s Story: Parenting with a Disability

My name is Ciara, I am in my forties, and I live with mental health difficulties. I have been seeking unsupervised access to my children, who are living in foster care, through the courts for the past two years.

I contacted NAS for support and my Advocate has been helping me to prepare for court dates and supporting me to link in with my legal team.

When the Covid-19 restrictions were introduced in March 2020, my court dates were adjourned for several months. As a result, I have not had access to my children for nearly a year.

When a court date was eventually scheduled, I was unable to have the support of my Advocate in Court due to restrictions on numbers being present in the Court House. I found this difficult as I often feel very anxious in court and my Advocate helps me to feel calm, prepared and supported in Court.

The Judge recommended that a Voice of the Child Report be carried out to progress the case. This is when an expert is appointed to find out and convey the child’s views. However, due to the Covid restrictions, the Report cannot be completed as the professional employed to carry it out is unable to do face-to-face work at this time.

Covid-19 has meant that my case has gone on for a lot longer than I thought it would. I feel that I am missing out on an opportunity to develop a relationship with my children due to the many delays with the case and I feel disconnected from them.

# Decision Making and Do Not Attempt Resuscitation (DNARs)

NAS and the Patient Advocacy Service have supported people in nursing homes, disability service providers and acute settings regarding matters such as advanced healthcare planning, end of life planning and DNARs. A do not attempt resuscitation (DNAR) is a written order stating that resuscitation should not be attempted if an individual suffers a cardiac or respiratory arrest (HSE Consent Policy[18]).

NAS and the Patient Advocacy Service were aware of discussions around ethical decision making in hospitals as fears grew about the pressure the pandemic would place on the acute hospital system across Ireland.

NAS was particularly concerned about developments in the UK about the lack of an individual decision-making approach for each person with a disability in relation to DNAR orders. These decisions made in the UK can often be reflected in Ireland. During the pandemic's first wave, it was reported that decisions around DNAR orders were being made by medical professionals and care providers. According to reports[19], they advised that people living in services under their care were not to be resuscitated, however no individual assessments of the person's health had been made.

These blanket decisions in the UK were condemned and reviewed. NAS and the Patient Advocacy Service ensured that they were vigilant at the initial stages of the pandemic in Ireland, so this unacceptable practice did not take place. Both Services advocated for all people to be included in decision making such as DNAR orders no matter what their disability, age or illness was.

Advocates in NAS and the Patient Advocacy Service reviewed and discussed the Department of Health's 'Ethical Framework for Decision-Making in a Pandemic'[20] (March 2020) document and the impact this may have on advocacy practice and the people we advocate for. Advocates also attended webinars around Advanced Healthcare Planning to ensure they could provide appropriate support to services and people throughout the pandemic.

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[18] National Consent Policy **https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf**

[19] **https://www.theguardian.com/society/2021/mar/18/blanket-do-not-resuscitate-orders-imposed-on-english-care-homes-finds-cqc**

[20] Ethical Framework for Decision-Making in a Pandemic **https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/**

**The Services were informed by medical professionals of decisions made in nursing homes and other residential settings during the pandemic about whether people should be offered resuscitation and acute medical treatment. Advocates spoke to family members who said they had been contacted by services to make decisions on DNARs.**

**This practice is not in line with the HSE Consent Policy, which states that no other person can make decisions on another's behalf. It is also not in line with the UN Convention on the Rights of Peron's with Disabilities (UNCPRD) which states that every person with a disability has the right to autonomy and to make their own decisions about their life. Although the Assisted Decision-Making (Capacity) Act (2015) has not yet been fully commenced, people must be supported to make decisions about their life in keeping with the principles of the act and in line the HSE's National Consent Policy.**

The Patient Advocacy Service was contacted by family members who had loved ones in both nursing homes and hospitals. After reviewing files of loved ones that had died, family members raised concerns that there was a DNAR on their family member's file. The families have concerns about their loved one's ability to give this direction without support and noted that it was in contradiction with their knowledge of their loved one's will and preference.

In another case, NAS supported two services with the issue of DNAR orders and end of life decision-making for people with intellectual disabilities. NAS provided information and guidance to the services about their role in supporting the rights of people with disabilities with matters such as advanced healthcare planning and end of life care planning. NAS provided guidance regarding Cardiopulmonary Resuscitation (CPR) and DNAR Decision-Making during the Covid-19 Pandemic and discussed the guidance with the services, explaining how this can be used in practice to support people with these matters that had not been addressed prior to the Covid crisis. It was apparent to NAS during this time that guidance on matters such as DNARs and end of life planning was available, but services did not always seem to be aware of these. NAS positively impacted on people using these services by ensuring it kept them at the centre of decisions being made that effect their lives and they upheld their rights to be supported by the service with decision-making.

NAS was also working with a person who was a Ward of Court and their service provider had made an application to the Wards of Court office for guidance on the person's end of life plan and if a DNAR should be in place for the person. The Advocate was concerned that the service would consider the DNAR for the person with no clinical guidance and felt a blanket approach to decision-making was being taken without the inclusion of the person. The Advocate made this representation to the service provider to reconsider on ethical grounds, and they subsequently sought medical guidance and no DNAR was put in place.

As per the HSE Consent Policy, discussions about DNAR's must also include healthcare professionals to co-ordinate decision making process. The Advocate discussed ethical considerations in decision-making with the service.

# Decision Making for People who are Wards of Court

> **"My Advocate went out of her way to keep me informed of her research. She gave so much of her time to me and my concerns. It gave me the confidence I needed to make decisions."**
>
> Theresa, who was support by NAS through a decision-making process

Wardship arises when a person is deemed by the courts to be unable to look after their affairs and has somebody appointed to do so on their behalf. An application for Wardship can be made to the Courts when there are concerns that a person does not have capacity to manage their affairs.

For an adult to be taken into Wardship, the President of the High Court must be satisfied "on the basis of the medical evidence available that the person should be deemed to lack capacity and is incapable of managing his/her own affairs"[21].

Throughout the Covid-19 pandemic, NAS has continued to provide advocacy support for people with disabilities who are going through the Wardship process to be made a Ward of Court. NAS has also supported people who are already a Ward of Court. NAS case work has shown that the predominant issue that arose for people in relation to Wardship during the pandemic was procedural delays.

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[21] **https://www.courts.ie/wardship-adults**

In particular, Covid-19 restrictions and infection control measures resulted in delays for medical reviews and capacity assessments for people. A reduction in the Court Service's operations, combined with an increase in the number of wardship applications during the pandemic, also led to lengthy delays in the wardship process.

Where people experienced delays, NAS ensured that each person was kept fully informed on matters and that the reason for any delay was fully explained to them. Advocates also ensured that people received information in an accessible format.

At various times throughout the pandemic, such as when level 5 restrictions were in place, face-to-face meetings were not permissible for Advocates. Advocates continued, where possible, to keep in contact with people by telephone and WhatsApp.

Unfortunately, in some cases where people communicated differently the use of telephone or video technology was not appropriate and Advocates could not provide the same level of advocacy supports as they had prior to the pandemic. In these cases, Advocates continued to engage with all relevant third parties to progress the case for the person and communicated with the person through their family and/or service provider where appropriate. Once face-to-face meetings were possible again, Advocates linked directly with the person to ensure they were at the centre of the decision-making process.

Advocates have undertaken significant work during the pandemic to help ensure that each person's voice was heard and given consideration by the Court at Wardship hearings and reviews. In particular, NAS supported people at remote hearings with their Solicitor and where appropriate, an Independent Visitor or Guardian Ad Litem, to help ensure their right to access justice was upheld. The role of the independent visitor is to meet the prospective Ward of Court, assess the current situation and provide a report to the President of the High Court.

Advocates have also submitted reports to Court in advance of hearings to have the person's voice and will and preference heard and represented in the decision-making process. As many court hearings and reviews moved to a remote forum during the pandemic, Advocates supported people to express their voice and will and preference at these hearings. In some other cases during the pandemic, Advocates have attended remote hearings on behalf of the person and represented the person's will and preferences directly to the President of the High Court.

The extensive work carried out by NAS during the pandemic has contributed to the voice of the person being heard by the Court in the Wardship process.

# Access to Justice and Safeguarding

Safeguarding is concerned with the protection of a person's health, well-being and human rights. It ensures that the person is enabled to live a life that is free from harm, abuse and neglect.[22] Supporting people with disabilities and those living in nursing homes, who are involved with safeguarding concerns, is work NAS and the Patient Advocacy Service are involved with on an ongoing basis.

Within each HSE Community Health Organisation (CHO), there is an established HSE Safeguarding and Protection Team for people who might be in vulnerable situations. These teams work to ensure the welfare of people with disabilities, those who are older or those in a vulnerable position, is protected and concerns are responded to and investigated, and a Safeguarding Plan is in place to support the person.

Throughout the Covid-19 pandemic, Advocates have continued to identify and work on safeguarding issues arising for the people they support. Safeguarding concerns made up 2% of the overall issues impacted by Covid-19.

These issues were at their highest when level 5 restrictions were in place with visiting restrictions and service closures. Advocates apply the NAS Disclosures, Observations and Suspicions of Abuse policy, which reflects the HSE's Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures[23], when supporting a person involved with a safeguarding concern.

The most reported safeguarding issues for people related to their finances. The rights of people with disabilities to access their own money was not being fulfilled. In one case, NAS supported a person who reported that a member of their family would take their money from their bank account. The Advocate reported this issue to the HSE Safeguarding social worker, with the consent of the person. The Advocate supported the person at the meeting with the HSE Safeguarding and Protection team and ensured that the person's wishes and voice were included in the development of the Safeguarding plan.

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[22] **https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/creating%20a%20safeguarding%20culture.pdf** Pg.39

[23] Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures **https://www.hse.ie/eng/services/publications/corporate/personsatriskofabuse.pdf**

Another area where Advocates provided support during the pandemic was in domestic abuse cases. In one case, a person had been dealing with violence in their home for a long period of time. The pressures of the Covid-19 restrictions further contributed to safeguarding incidents. The Advocate worked with the person to establish their will and preference and the person stated that they would like to leave the home to live independently. The person is now living independently with support.

Safeguarding concerns also arose in relation to physical abuse in residential services. In one case, NAS supported a person who had been assaulted by a fellow resident. The service provider moved the person at short notice and with no safeguarding plan in place. The person made a complaint and the Advocate ensured that the person's voice and rights were represented at meetings. The person was moved back into their home and arrangements were made to ensure that no further safeguarding concerns were present.

People who communicated differently who faced safeguarding issues were also adversely affected further by the pandemic. Their Advocate often could not meet with them face-to-face and could not spend time with them to observe and fully understand their will and preference. In these instances, NAS made a referral to the HSE's safeguarding team. Advocates also relied on the support of the staff in services during this time to aid with continued communication.

Despite these communications challenges, NAS and the Patient Advocacy Service worked to ensure the financial rights and safety of people were upheld. They worked with the person to ensure their will and preference were carried out. They also communicated with residential services, providing them with information on protocols and guidance documents available.

# Homelessness: Accessing Justice and the Right to Housing

> **"I want to thank you for all your help and professional integrity in pursuing my rights and dealing with a complex system. You [the NAS Advocate] are an asset to your organisation."**
>
> Michael, who was supported by a NAS Advocate in early 2021

NAS is aware that many people with disabilities are at risk of homelessness or live in accommodation supported by homeless services. The Service's work on this issue has increased significantly in recent years.

Enquiries to NAS have often highlighted the lack of appropriate services and opportunities for progression to secure long-term accommodation with supports for people with intellectual disabilities and/or autism who are homeless.

NAS works with many people with disabilities who are living in inappropriate accommodation while they wait for social housing on Local Authority housing lists. NAS frequently supports people to navigate the local authority housing system and ensure the person's will and preferences are heard and considered.

As the Covid-19 pandemic took hold in Ireland, crowded homeless accommodations were identified as an area of public health concern due to the risk of infection and the inability to control and minimise the spread of infection in this type of congregated accommodation.

External supports such as home help care agencies were unable to go into homeless services and this had a big impact on people with disabilities requiring these supports.

A Covid-19 response was quickly developed by the Dublin Region Homeless Executive (DRHE) and local authorities. However, NAS heard from people they supported that appropriate measures to support people were not taken outside of Dublin.

People told NAS that in the early stages of the pandemic they were moved into other types of vacant accommodation to protect the health of people living in services and ensure social distancing and other public health measures could be practised effectively. NAS statistics show that 2% of people it worked with throughout this period stated they had "No fixed abode".

NAS supported people to move into accommodation that was more comfortable, accessible and appropriate to their disability support needs. However, NAS understands that in some cases issues arose for people who moved to unfamiliar settings and were being supported by unfamiliar staff members.

NAS also supported people who were at risk of homelessness during the pandemic. As day services closed, some people with disabilities found themselves at home with family members on a full-time basis. Due to the pressure of the Covid 19 restrictions, this led to some difficulties in the home environment. Advocates supported people who transitioned into homeless accommodation during this time to access services and find long-term accommodation.

In one case, a person who was homeless contacted the Patient Advocacy Service to make a complaint about how they were treated in two different hospitals. The person needed medical treatment for injuries suffered. The first hospital did not triage the person, so they left. The person went to a second hospital and decided to leave as they felt they were not being treated well by staff and had not received any examination. The following day the person attended a scheduled appointment in the hospital and their treating doctor gave them the medical attention they needed.

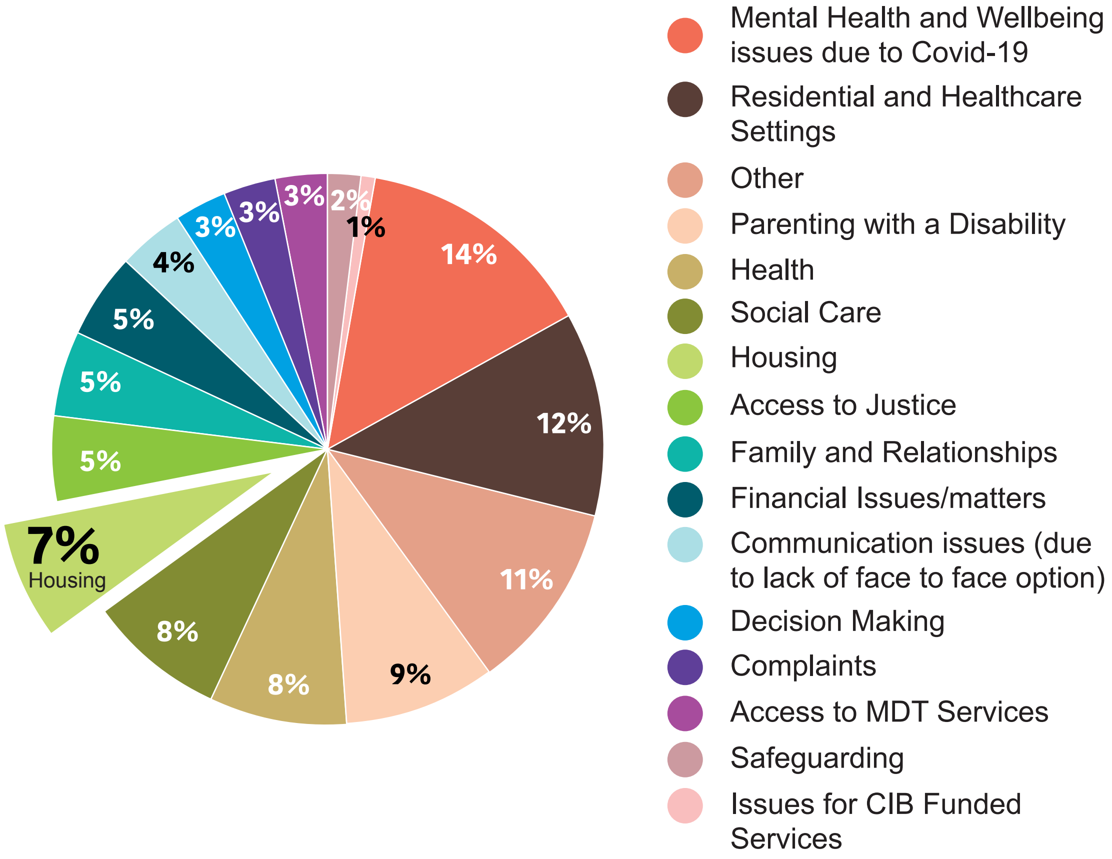
NAS also supported a person living in emergency accommodation by ensuring that their will and preference was considered during planning meetings to discuss their placement and ensuring that the person was kept informed and updated after each meeting. NAS wrote to the Disability Manager informing them of the person’s situation and requesting that they be prioritised. Without the support of NAS, the person would not have had an independent person advocating on their behalf during meetings and would not have been kept fully informed on what was discussed during the meetings.

**While certain housing options were put on hold during the pandemic, NAS continued to support people experiencing homelessness and seeking access to social housing and advocate on their behalf.**

Advocates linked with various professionals, such as local authorities, housing associations, and the Residential Tenancies Board, and provided letters of support for the person to be prioritised and housed as a matter of urgency, and ensuring the person’s will and preferences were heard by the decision-makers.

7% of people supported by NAS whose lives were impacted by Covid-19 reported housing as an issue. In NAS work, housing can include issues such as homelessness and risk of homelessness, rent and arrears, inappropriate residential placements, lack of choice in residential placements, and local authority social housing.

## Issues Impacted by Covid-19 Experienced by People NAS Supported
(March 2020 to March 2021)



The statistics highlight a sharp increase in the issue of housing during the early months of the pandemic. NAS heard of issues such as people being unable to view properties due to Covid 19 restrictions.

In one case, NAS supported a person with a disability to liaise with the local authority around their right to access social housing. The person was living in overcrowded accommodation with family and waiting for their own home. When the pandemic hit, the person was in another country. During this time, the local authority offered the person a home but withdrew the offer when notified they were abroad. The person was advised they would be removed from the list pending an investigation. It was difficult for the person to return to Ireland due to the Covid restrictions on travel.

The Advocate supported the person to make representations to the Department of Social Protection of their efforts to return home to Ireland. With the Advocate's support the person was supported to move into a new home with additional home care supports in place.

## Helen’s Story: Homelessness

My name is Helen, I am in my forties and I have a physical disability. I was living in a homeless hostel.

I have mobility issues and it was difficult for me to meet anyone outside of the hostel without support. As a result, I was isolated from the community and I found it quite difficult to cope.

I contacted NAS for support to get an assessment through Primary Care to access appropriate mobility aids that would allow me to be more independent in the community.

I shared a room in the hostel with another person and I had been on the local authority list for housing for several years.

When the Covid-19 crisis hit, it was clear that the hostel, with room sharing and communal spaces, would be a great risk for the people living there if there was a virus outbreak occurred. It would be very difficult to contain and I was worried about what could happen.

The homeless service acted quickly and soon everyone in the hostel was moved out into apartments that had been made vacant due to the lack of tourism in the city centre. I had my own two-bedroom apartment and staff on site to support my needs.

This was a much more comfortable environment and I felt much safer. I was happy to have my own personal space but I was still nervous about what would happen when the crisis passed.

During this time, I was contacted by the local authority, who had been working to provide secure accommodation to those in homeless accommodation. I was delighted and a few weeks later I viewed my new property and accepted the offer.

I am now living happily in my new home and getting appropriate supports in the community from the Primary care team after my Advocate supported me to link in for assessment and support with my mobility issues.

# Conclusions and Recommendations

NAS provides a crucial means of support for people with disabilities to ensure the persons voice is heard. The Patient Advocacy Services also offers an important means of support for people who have had a negative experience regarding their care in a HSE-funded public acute hospital or a HSE-operated nursing home and wish to make a formal complaint to the HSE.

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

The support offered by both services is of huge importance. In normal times, the people that NAS works with face rights restrictions and have poorer access to health, education and employment. They have difficulties in accessing justice and decision making and are more likely to experience discrimination. However, during the Covid-19 pandemic, these issues were made significantly more difficult for people with disabilities.

NAS has found that people with disabilities are often not informed of, or included in making, decisions made about their own lives. This became particularly evident during the pandemic when many decisions were being made on behalf of people with disabilities. The individual’s independent voice was not being heard and there had been no attempt to do so.

This included cases where some family members were making decisions on behalf of a person with a disability and people in nursing homes, despite having no legal authority to do so, such as when it came to consenting to the Covid-19 vaccine. The Patient Advocacy Service also found that there were cases of Do Not Attempt Resuscitation (DNARs) orders in hospitals and nursing homes, when no attempt was made to ascertain a person’s own views and wishes, and family members were asked to make decisions on their behalf.

In terms of access to justice, NAS is aware that engaging with the legal system can be difficult for many people with disabilities. NAS works with people to ensure their right to meaningful and appropriate inclusion in legal processes is upheld.

One area of this work is advocacy support for parents with a disability who may be engaged in legal childcare proceedings, when Advocates strive to ensure the parent is supported to understand and fully participate in the process. During the pandemic, these proceedings were hugely affected.

Court hearings were only available in emergency cases and Advocates were unable to support people to attend court. It was also difficult for parents to meet face-to-face with legal representatives in advance of proceedings.

NAS has supported people to engage in remote access visits with their children using video calls, and it has helped people overcome the challenges caused by video links and teleconferences. Advocates have engaged with legal teams and child protection to ensure that the rights of the parent are upheld, and they could effectively engage in the legal process.

NAS also provides support to those who may be a Ward of Court and are the subject of Ward of Court proceedings. During the pandemic, restrictions and infection control measures resulted in lengthy delays to the wardship process, medical reviews and capacity assessments. Advocates ensured that people were kept fully informed on matters and received information in an accessible format. They also continued, where possible, to keep in contact with people by telephone and WhatsApp. Their extensive work during the pandemic has ensured that the voice of the person has been considered by the Court in the Wardship process.

In addition, NAS has supported people with disabilities in relation to safeguarding issues, such as abuse and financial concerns. These actions included linking with solicitors in relation to Ward of Court and legal aid, supporting access to psychology and counselling services, reviewing of wills and linking a person with the probate office.

NAS has also supported many people with disabilities at risk of homelessness or living in accommodation supported by homeless services. As the pandemic took hold, external supports such as home help care agencies were unable to go into homeless services and this had a big impact on people with disabilities requiring these supports. Advocates helped people to move into accommodation that was more comfortable, accessible and appropriate to their disability support needs. They also continued to support people experiencing homelessness to access social housing.

Based on the extensive work and findings of NAS and the Patient Advocacy Service over the past year of the pandemic, it is clear that independent advocacy is a crucial part of decision-making support for people with disabilities.

Without the support of NAS and the Patient Advocacy Service, many people were at risk of having their views overlooked or ignored altogether when it came to key decisions about the lives. It is imperative that health and social care providers engage with advocacy support for the person, particularly in cases where people may not be able to directly instruct their will and preferences.

It is also hugely important that the Irish government ensures the Assisted Decision-Making (Capacity) Act 2015 is commenced and the Decision Support Service fully established. Matters such as a person’s capacity to make decisions, or give their informed consent are of paramount importance, and the human rights of the person must be at the centre of these processes.

Heath and Social care services must act according to the HSE Consent Policy and the Principles of the Assisted Decision-Making (Capacity) Act, recognising the person’s rights under the UNCRPD, all of which state that no other person can give consent or make decisions on other person’s behalf without legal authority to do so and recognise a person’s right to be supported with decision-making.

In line with the principles of the Assisted Decision-Making (Capacity) Act, NAS also recognises that families are a key component in the circle of support to establish the will and preference of the person who may not be able to give clear instruction. NAS is fully aware that families’ concerns should be listened to, but not at the expense of the person’s own right to choose for themselves.

In decisions regarding medical care, it is important that guidance is sought from the relevant clinical team to also support the person in establishing their will and preference. Decision making should be based on medical guidance to uphold the person’s human right to health and life.

A co-ordinated approach is required to respond to the precarious situations that people with disabilities who are also experiencing homelessness may find themselves in. Appropriate and accessible accommodation must be made available to ensure that their needs are met.

The UNCRPD recognises the rights of persons with disabilities to access adequate housing through public housing programmes. It also recognises the right to meaningfully participate in their community. Safe and secure housing is fundamental to achieving this right. Local Authorities must ensure people with disabilities are supported to engage in an accessible way in the housing process and that offers of housing are suitable for the needs of the person.

Now the initial crisis of the pandemic has passed, it is crucial that people are supported to make their own decisions about issues affecting their lives. Every person, including people with disabilities, has the right to have their voice, will and preference heard. As outlined in Irish law, it is also fundamental that people are able to exercise their basic human rights, challenge discrimination or hold decision-makers accountable.