NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

Patient
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Advocacy Matters:

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

Executive Summary
October 2021

Executive Summary

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. It entitles people to exercise their basic human rights. Decision-Making is also the right of every person to have their voice, will and preference heard in any decisions about their own lives.

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.

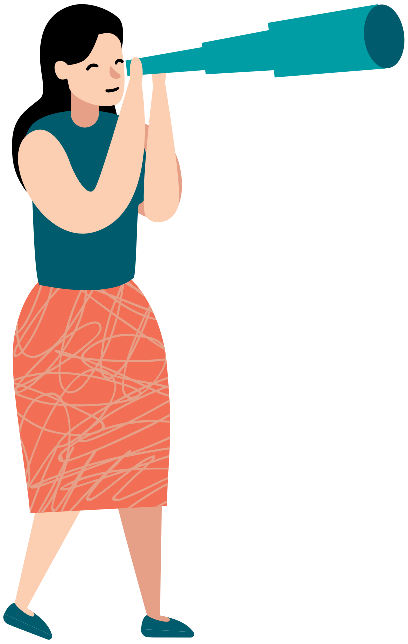
In terms of access to justice, NAS is aware that engaging with the legal system can be difficult for many people with disabilities. NAS works with people to ensure their right to meaningful and appropriate inclusion in legal processes is upheld.

In response to the challenges posed by the pandemic, NAS and the Patient Advocacy Service have adapted and improvised their services to ensure they have been able to continue to deliver high-quality advocacy to people with disabilities. Almost overnight, both Services moved from office to home working, while also embracing innovative new ways of working such as phone calls, video calls, emailing and text messaging.

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.

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. It is also fundamental that people are able to exercise their basic human rights, challenge discrimination or hold decision-makers accountable.



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

Findings:

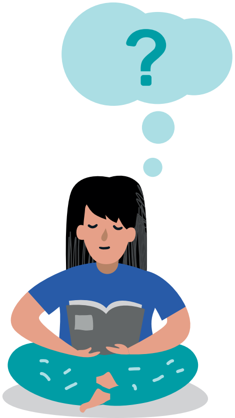
In ordinary times, the people with disabilities face rights restrictions and have difficulties in accessing justice and decision making and are more likely to experience discrimination. During the Covid-19 pandemic, these issues were further exacerbated for people with disabilities when it came to issues surrounding their right to make their own decisions, and their right to access justice in Ireland.

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 by family members, despite having no legal authority to do so. The will and preference of individuals was not being upheld in a decision-making process. This demonstrates the need for the valuable work carried out by NAS to uphold the rights of people with disabilities.

Areas Advocates have provided support in decision making and access to justice include:

- Decisions about consenting to the Covid-19 vaccine
- Do Not Attempt Resuscitation (DNARs) orders in hospitals and nursing homes
- Parents with a disability who may be engaged in legal childcare proceedings
- Those who are a Ward of Court and are subject of Ward of Court proceedings

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



Decision Making: Next of Kin

Findings:

Every person under Irish law, including a person with a disability, has the right to make their own decisions. 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.

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.

When providing people with advocacy support, NAS and the Patient Advocacy Service always ensure 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

Findings:

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.

NAS was part of an expert panel at **webinars** hosted by the HSE National Office for Human Rights and Equality Policy about the Covid-19 vaccine consent and decision-making process. NAS shared their expertise in relation to consent and how best to ensure that the rights of a person with a disability are respected.

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. NAS supported service providers to ascertain the person's choice in relation to giving vaccine consent or not. This ensured that people were appropriately informed and could make an informed decision. They supported the person to exercise their right to have their own will and preference recognised and heard.

Access to Justice for Parents with a Disability - Findings

Findings:

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[1]. NAS supports parents to prepare for meetings with Tusla, the Child and Family agency, 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. 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.

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.

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 which has caused considerable stress and upset for people with disabilities, their children and 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. Advocates found that these mechanisms caused difficulties for some people with disabilities.

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

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. 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.

NAS was informed of children not engaging with technologies such as FaceTime or video calls, especially where children had disabilities themselves. 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.

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.

NAS noted lengthy delays for parents with disabilities in 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.

Decision Making and Do Not Attempt Resuscitation (DNARs)

Findings:

NAS and the Patient Advocacy Service have supported people in nursing homes, service providers and acute settings regarding matters such as advanced healthcare planning, end of life planning and DNARs.

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 policies and legislation which state that no other person can make decisions on another's behalf.

Family members who had loved ones in both nursing homes and hospitals raised concerns that there was a DNAR on their family member's file. The families had 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.

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 and the Patient Advocacy Service ensured that the person was kept 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.

Decision Making for People who are Wards of Court

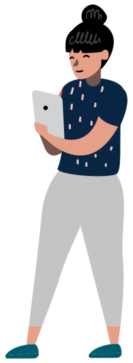
Findings:

Wardship arises when a person is deemed by the High Court to be unable to look after their affairs and has somebody appointed to do so on their behalf.

NAS has provided 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 in relation to Wardship during the pandemic was procedural delays.

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, also led to lengthy delays in the wardship process.

Advocates have submitted reports to Court in advance of hearings to help have the person's voice and will and preference heard and represented in the decision-making process. This helped to ensure that each person's voice was given consideration by the Court at Wardship hearings and reviews. 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.



Access to Justice and Safeguarding

Findings:

NAS and the Patient Advocacy Service support people with disabilities and those living in nursing homes with safeguarding concerns. Advocates have continued to identify and work on safeguarding issues arising for the people they support. The pressures of the Covid-19 restrictions further contributed to safeguarding incidents such as people's finances, and physical and domestic abuse cases.

People who communicated differently who faced safeguarding issues were 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. NAS and the Patient Advocacy Service worked to ensure the financial rights and safety of people was upheld. They worked with the person to ensure their will and preference were carried out.

Homelessness: Accessing Justice and the Right to Housing

Findings:

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.

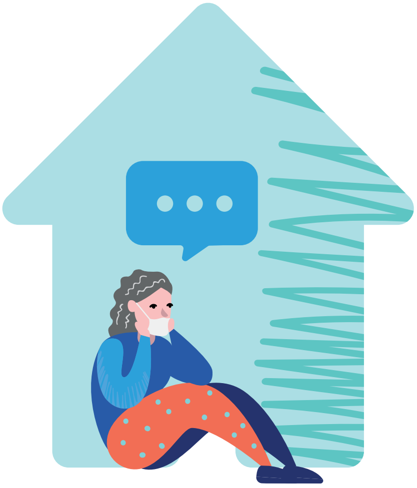
A Covid-19 response was quickly developed by the Dublin Region Homeless Executive (DRHE) and local authorities. However, NAS heard from people they supported that appropriate measures to support people were not taken outside of Dublin.

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 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. This led to some difficulties in the home environment. NAS supported people who transitioned into homeless accommodation during this time to access services and find long-term accommodation.

While certain housing options were put on hold during the pandemic, 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. However, NAS understands that in some cases issues arose for people who moved to unfamiliar settings and were being supported by unfamiliar staff members.

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.



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.
- 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[4], 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

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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**

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

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.
- 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.