

National Advocacy Service for People with Disabilities and the Patient Advocacy Service

Casebook





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



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



An Roinn Sláinte
Department of Health

Contents

NAS Case Studies

1. Parenting with a Disability	4
2. Access to Finances	6
3. Choice and Autonomy on Where to Live	8
4. Support with Decision-Making	10
5. Consensual Adoption	12
6. Capacity Building	14
7. Health	15
8. Residential and Healthcare Settings	17
9. Family and Relationships	19
10. Health	21
11. Decision-Making and Capacity Building	23
12. Housing	25
13. Housing	27
14. Quality of Life	29
15. Parenting with a Disability	31
16. Housing	33

Patient Advocacy Service Case Studies

17. Complaint re Care in a Public Acute Hospital	35
18. Complaint re Care in a Public Acute Hospital	37
19. Complaint re Access to Care	39
20. Complaint re a HSE-Operated Nursing Home	40
21. Complaint re Care in an Acute Hospital	42

Foreword



Welcome to our first casebook. This publication contains a selection of the many advocacy interventions worked on over the past couple of years, including during the Covid-19 pandemic, by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

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

NAS, which is funded by the Citizens Information Board (CIB), focuses on ensuring the rights of people with disabilities are upheld. We provide people with disabilities across Ireland with an independent, professional and free advocacy service that helps people to have their voices heard, make decisions and live their lives independently.

The Patient Advocacy Service, which is commissioned by the Department of Health (DoH) and delivered by NAS, provides support to people who wish to make a complaint to the HSE about their care in a Public Acute Hospital or a HSE-operated Nursing Home. From 01st November 2022, the Service has also been providing advocacy support to people who wish to make a complaint about their care in private nursing homes.

As you read the case examples in this publication, you will notice that advocacy interventions generally come when people need specific and tailored information or support. You will be shown the different forms of advocacy, including empowerment and representative advocacy, and you will see that these situations are often very emotionally charged for both the people receiving advocacy and our Advocates. We cover issues related to parenting with a disability, housing, healthcare, and much more.

I hope that these case examples demonstrate what our Services do, how important advocacy is, and how we have a positive impact in communities across the country. Advocacy helps breach gaps in systems that leave people in difficult situations, it ensures best practice across public services, and it promotes positive systemic changes when necessary.

Finally, I would like to thank anyone who has accessed either NAS or the Patient Advocacy Service over the past year. I wish to extend my thanks to the CIB for their continued endorsement of NAS and their ongoing support of our work. I would also like to thank the DoH for their guidance and support of the Patient Advocacy Service.

On behalf of the Board, I would like to thank the work ethic and dedication of all the staff of NAS and the Patient Advocacy Service for providing high-quality professional advocacy services.

Thank you.



Rosemary Smyth

Chairperson of the National Advocacy Service for People with Disabilities (NAS), which delivers the Patient Advocacy Service.

Note to Reader: all case studies included in this document have gone through a rigorous anonymisation process which involves changing identifying elements of the case to protect the anonymity of the person and advocate involved. This means that the location, age, gender and name of the people in these stories are likely to have been changed.



1. Parenting with a Disability



Context:

Olga is a woman in her thirties who has a mild learning difficulty and a history of mental ill health with limited natural supports. During a mental health crisis, Olga's young child was taken into the care of the Child and Family Agency, Tusla, and placed with a relation. At the same time, Olga lost her rented accommodation and became homeless. Olga sought advocacy support from the National Advocacy Service, at the suggestion of her legal team, as she was involved in complex family court proceedings while a decision was made about the long term care of her child.



Actions by the Advocate:

The Advocate and Olga agreed that the Advocate would support Olga at court hearings and any consultations with her legal team, to ensure that Olga understood the legal process and could fully instruct her solicitor and otherwise participate in the courts process.

The Advocate supported Olga to seek reports from her key workers in her rehabilitation program, her homeless accommodation and her mental health team, to show the progress Olga was making in terms of her recovery and her efforts to secure housing. The Advocate accompanied Olga to meetings with her solicitor, supporting her to review social work reports and other court documents. The Advocate and Olga's legal team worked together to ensure that the information provided to Olga was in plain English and could be easily understood by Olga.

While Olga had excellent English, it was not her first language. The Advocate helped ensure that all important documents were clear and accurate so that Olga could understand all the information and make an informed decision on how she wished to proceed. The Advocate assisted Olga to debrief after meetings with her legal team to help with Olga's understanding of the information and supported her to seek any necessary clarifications from her solicitor.

Olga's legal team understood the need for reasonable accommodation and worked hard to present information in an accessible way, assisted by the Advocate. At the Advocate's suggestion, the solicitor made time to meet with Olga a few days prior to each court hearing to review documents in a quiet office, with adequate time for Olga to work through the lengthy reports and ask questions if required. The Advocate also met with Olga following each court hearing to review the outcome, the decision of the Judge and the next steps in the process with her.



Outcome:

At the close of this case, Olga consented to a short-term Care Order. She understood this would provide her child with security while she sought housing and continued to demonstrate her recovery and maintain her positive mental health. Olga will also use this time to continue to build on her relationship with her child, and will be supported toward family reunification by Tusla. Olga knows she can seek support from the National Advocacy Service again when the review of the Care Order is due.



2. Access to Finances



Context:

The National Advocacy Service received an enquiry from Clara who was unable to access her online banking due to the introduction of increased online security measures by her bank.



Actions by the Advocate:

The Advocate met with Clara and learned that she was no longer able to access her online banking as the bank had increased their strong customer authentication security measures which timed out before Clara was able to enter required codes. Clara told the Advocate that she has a disability that requires additional time to manage using technological devices.

Up to the introduction of the bank's new security measures, Clara had independently accessed her own monies and was sad to lose her autonomy in this important area of her life. Clara now needed to ask other people to support her when accessing her banking and she did not want to have to rely on this option in the long-term.

The Advocate and Clara agreed an advocacy plan which would seek to make Clara's online banking accessible and agreed to firstly make contact with her local bank branch, detailing her issue and asking if the bank could resolve the problem.

Together, the Advocate and Clara wrote to the bank branch manager and also visited the branch in person to discuss Clara's issue. The bank manager agreed to look into the problem but they did not come back to Clara or her Advocate with any update.

With Clara's agreement, the Advocate escalated the issue to the bank's internal complaints department. At the same time, the Advocate, with a recommendation from the National Advocacy Service Regional Manager, wrote to the Banking & Payments Federation of Ireland, who in turn put the Advocate in contact with a security specialist within the bank's national team.

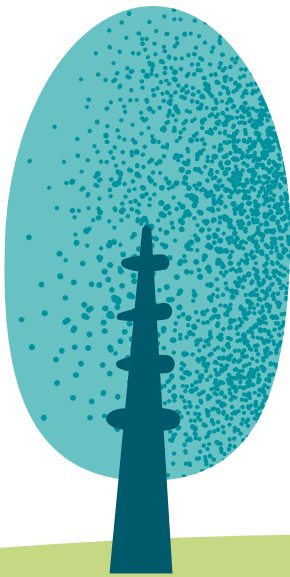


On liaising with the security specialist, he explained that a SCA (Strong Customer Authentication) Exemption was required. This SCA exemption was explained to Clara, who wished to apply for it and was supported by the Advocate to do so.



Outcome:

Since the SCA exemption has been agreed and actioned by her bank, Clara has returned to independently accessing her online banking and is once again in control of managing her financial affairs.



3. Choice and Autonomy on Where To Live



Context:

Mark is an adult with a degenerative physical disability and mild intellectual disability. He lived within institutional settings until moving to a small community apartment. A few years ago, Mark began using a wheelchair and his home was no longer accessible. His home was assessed by a number of professionals to be inappropriate for his physical needs and to pose a risk to his safety. The professionals advised that Mark would also benefit from additional staff support to promote his quality of life. Mark wanted a more appropriate home as he was unable to freely access his community and engage in it meaningfully. Mark felt his life was being controlled. Mark began working with an Advocate from the National Advocacy Service on this issue.



Actions by the Advocate:

With support from the Advocate, key stakeholders were made aware of Mark's wishes, the impact on his quality of life and the risks the current accommodation posed to him. Representations made in the past had successfully secured some additional support for Mark, such as an electric wheelchair, but had not progressed the matter relating to an appropriate home. The service that supported Mark at this time felt they could not provide this placement to him and they escalated this to key stakeholders.

Unfortunately, Mark had an accident in his home and was hospitalised. The service informed Mark that he could no longer return to his home due to the risks it posed to his safety. The Advocate supported Mark to express his frustration about this decision, seek clarity on how this decision was made and inform the service he wanted to return to his home until something more suitable was available. Despite this, the service advised they were not in a position to support Mark back to this home. Mark was very upset about this. Mark was limited in his options to escalate this due to the service owning his home.

The Advocate supported Mark to write to all key stakeholders, advising them of what was happening to him, his will and preference, the risks of being in hospital, the impact to his quality of life and how the decision by the service breached his human rights.

This initiated a conversation between the key stakeholders and Mark to understand his long-term home preference and the staffing support required. Key stakeholders suggested options to Mark which did not correspond with his will and preference, such as a nursing home. The Advocate supported Mark to make an informed decision around this offer and helped Mark put in writing his decision that under no circumstance did he consent to being discharged to a nursing home.

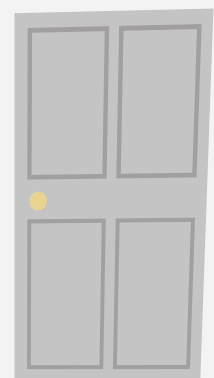
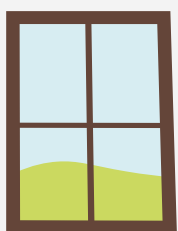
With the Advocate's support, pressure was placed on key stakeholders to resolve the issue and come back to Mark with an offer which was more appropriate to his age, needs and wishes.



Outcome:

After many months and a lot of resilience and tenacity from Mark, key stakeholders identified accommodation which was more appropriate. Mark, his Advocate, his social worker and a friend visited this new accommodation to see if it suited him. Mark was supported to make an informed decision and accepted this accommodation.

Mark has since moved into his new home and has begun to live the life of his choosing in a home that meets his needs, and aligns to his will and preference. Mark has made friends with peers who have similar interests, hosted his family for a visit, and made plans to recommence day services and get back out to his community activities.



4. Support with Decision-Making



Context:

Sarah is a woman in her mid-forties who has an intellectual disability. She lived at home with her father until he required urgent, full-time nursing home care. A decision was made to move Sarah to the same nursing home so she would have continued daily contact with her father. Sarah has a brother who lives outside of Ireland. He keeps in regular contact with her by phone and video calls but has been unable to return to Ireland due to Covid-19 travel restrictions. Sarah attends her day service 2 days a week and has personal assistant (PA) hours on 3 week days in the nursing home.

The HSE Disability Service in Sarah's Community Healthcare Organisation (CHO) identified Sarah as a candidate for inclusion in a pilot project to move people under 65 years old inappropriately placed in nursing homes, to more appropriate accommodation. This pilot project emerged from the Ombudsman's 'Wasted Lives' report, with funding allocated to explore alternative options for 18 people nationally. Sarah was referred to the National Advocacy Service by HSE Disability Services as a placement in a Residential Service had been identified as an option for Sarah within the CHO.

On receipt of the referral, the Advocate established that Sarah was unaware of any proposed move, she had been excluded from the decision making process and that consent from her brother was being sought for the move. There were time constraints around the decision to move Sarah and a real danger the funding and/or offer of the placement would be withdrawn.



Actions by the Advocate:

The initial actions undertaken by the Advocate were to express Sarah's wishes to the 3rd parties. Sarah had the right to be included in the decision making process. The Advocate also clarified Sarah's consent was required for the move. The Advocate supported Sarah to shift decisions being made by others in her 'best interest', to Sarah being included in making decisions based on her will and preferences.

The Advocate worked collaboratively with Sarah, her day service keyworker and her PA. The Advocate spent time with Sarah to establish if she would like to move to a new home and to understand what was important to her in her daily life (relationships, friendships, activities etc.).

The Advocate helped Sarah arrange an initial visit to the placement on offer and to trial a number of overnight visits to experience on a practical level what it would be like to live in this new accommodation.

The Advocate documented all the visits and overnights with photographs and designed an easy to read document which Sarah could use when the time came to reflect on a decision whether to move. The Advocate also developed a visual decision making tool which ensured that Sarah fully understood that if she moved to the placement on offer her father would be remaining in the nursing home.



Outcome:

At the end of the process, Sarah communicated verbally and by referencing the interactive decision making tool created by the Advocate, her decision to move to the new placement. She also wished to remain connected to her day service and to have regular visits with her father in the nursing home. With Sarah's consent, her Advocate communicated the process undertaken and Sarah's decision to her family and the HSE. Sarah has recently moved to her new home.



5. Consensual Adoption



Context:

The Child and Family Agency, Tusla, made a referral to the National Advocacy Service on behalf of Maria regarding the adoption of her child by foster carers in whose care she had been in since birth. Maria's child, who is a young adult, wanted to be adopted by the foster carers. Maria has a mild intellectual disability and lives on her own in the community. Maria has access and sees her child once a month.



Actions by the Advocate:

Maria met with the Advocate and they agreed that the advocacy issues were to support Maria to understand the processes around adoption, to ensure that she understood the outcome of her decisions and to support her with meetings. As the case was a consensual adoption, Maria's consent to the adoption should be a full, free and informed decision. The legal process is different in a contested court case.

The Advocate noticed that Tusla did not have adoption information in an easy to read or plain language format and wrote to Tusla to explain that this resource was important to support Maria's understanding of the process. The Advocate also wrote to the adoption authority to identify this gap and they confirmed the issue would be raised at their next review in the summer of 2021.

The Advocate accompanied Maria to meetings with the Adoption Social Worker, whose role was to outline to Maria in a way that she could understand, all the steps and processes involved in the adoption. The Social Worker worked through the steps and processes systematically over four meetings. Notes were created for Maria detailing clearly all that had been discussed and answering her questions about the process. The Advocate followed up with additional meetings and phone calls to Maria to check her understanding and consent along the way. This part of the process supported establishing Maria's consent to the adoption.

The Advocate accompanied Maria to a capacity assessment, which was requested by Tusla and also accompanied Maria to a meeting with the 'authorised person', which is part two of the process – consent to the making of the adoption order. This involved the filling out of a questionnaire and

the signing of an affidavit by Maria. The Advocate obtained a copy of the questionnaire prior to the meeting to support Maria's understanding of it. The role of the authorised person is to explain the adoption order and its consequences and be satisfied that Maria's consent is full, free and informed. At this meeting, the Advocate asked the authorised person to speak slowly and to repeat information on a number of occasions to ensure Maria fully understood the information.

The Advocate, her Social Worker and her solicitor reviewed the questionnaire with Maria to check her understanding of it and to establish her will and preference as to attending at or being informed about the date of the adoption hearing. The final step was to lodge the adoption order and await the official hearing. Maria said she did not want to attend this hearing, but did want to know when it was happening.



Outcome:

With the support of the Advocate through the consent process, Maria was able to demonstrate her understanding of how her rights as a parent were going to change. She would no longer have an automatic right to access her child, access would be dependent on the child's wishes and the goodwill of the adoptive parents. In this case all were willing for access to continue.

The adoption went through successfully and Maria continues to meet up regularly with her child.



6. Capacity Building



Context:

Anna, who is in her mid-fifties with an intellectual disability, received support from staff in her day service to make a referral to the National Advocacy Service. Anna's parents were working on a plan to ensure future security for Anna after they passed away. Anna had lived with her parents all her life and had never experienced living anywhere else. Anna was very unsure of the plan and voiced that she would like advocacy representation for her wishes to be heard.



Actions by the Advocate:

The Advocate met with Anna and explained the role of the National Advocacy Service. Anna requested that the Advocate meet with her parents and discuss the importance of Anna being at the centre of the decision-making process regarding her future. Anna was empowered to voice her will and preference in meetings with people included in her circle of support. The Advocate helped Anna to explore and express her will and preference regarding the options available to her, such as social housing and options of respite to use as a trial for living away from the family home.



Outcome:

Anna explored what location she wished to live in and chose to apply for social housing through her Local Authority. The Advocate supported Anna to apply for a social worker to assist in the process of future planning and to seek the supports Anna felt she needed for the future. Anna was also supported to apply for a trial of respite services in her chosen location.



7. Health



Context:

Matt has an intellectual disability. He lives in a community residential home and communicates differently, using body language and gestures. Last year, Matt was diagnosed with dementia and began having seizures. Matt's health declined and a palliative care plan was put in place by services for him.

When Matt's health deteriorated, it was decided that should Matt have another seizure and become unwell, his disability service would support him to remain at home due to the high levels of Covid-19 in his local hospital at the time. A 'Do Not Attempt Resuscitation' (DNAR) order was put in place.

Following an inspection by the Health Information and Quality Authority (HIQA), a need for independent advocacy support for Matt regarding his DNAR was identified. The disability service provider sent in a third-party referral to the National Advocacy Service on Matt's behalf.

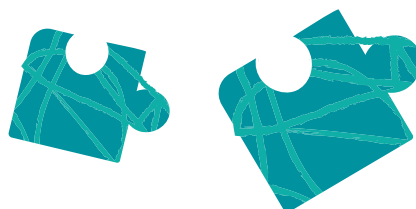


Actions by the Advocate:

The Advocate spent time with Matt and spoke to his family and staff members who knew him well.

The Advocate reviewed Matt's file and the DNAR. The Advocate then documented their findings and presented them to the service.

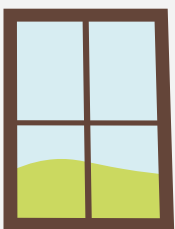
The advocacy report identified the need to review Matt's DNAR in line with International Human Rights and HSE Guidelines. The report referred to the HSE Consent Policy and HSE Guidance Regarding Cardiopulmonary Resuscitation and DNAR Decision Making during the Covid-19 pandemic.





Outcome:

The disability service provider supported Matt to meet with his General Practitioner (GP) and provided a copy of the report to the GP before the meeting. Matt's DNAR was then reviewed in line with International Human Rights and HSE Guidelines. The outcome of this review was that the DNAR was deactivated.



8. Residential and Healthcare Settings



Context:

Tom, who is in his twenties, has a dual diagnosis of autism and an intellectual disability and communicates differently. At the time of the referral to the National Advocacy Service, Tom's day service support had broken down and his family were struggling to manage Tom's care at home. Covid-19 restrictions were also in place.



Actions by the Advocate:

An advocacy plan was developed to support Tom with three key issues: finding a suitable home in the community where his needs would be best met, for Tom to live a high quality of life in the community, and for Tom to be supported to continue to have a loving relationship with his family.

The Advocate wrote to the disability manager in Tom's Community Healthcare Organisation (CHO) area, providing a summary of the current situation for Tom at home, and highlighting the fact that Tom had no professional supports in place. The Advocate stressed the urgent need for supported accommodation for Tom.

Following this letter, the HSE suggested a solution of a new day service to meet Tom's needs. The Advocate outlined that there was plenty of evidence of failed day services in Tom's past and a residential service would be a better support for him now.

Due to Tom's high support needs, he was in receipt of monthly weekend respite breaks. At the end of one of these break's, Tom's family did not collect him and stated that they were no longer in a position to care for him at home.

Following this event, an urgent tele-conference was held, in which the respite service stated that their service was not a long-term solution for Tom. The Advocate escalated the matter and wrote to the HSE Head of Disability Services, requesting a meeting with all key stakeholders to discuss Tom's case.

After several requests, a meeting was held with the Head of Disability Services. During this meeting, Tom's family and the Advocate were informed that a bespoke service had been found for Tom. The house was in the community, with 24-hour staffing and its own transport. Two other persons with a similar profile and needs to Tom reside in the house. Tom, his Advocate, and his family were invited to visit the house and meet with the Person in Charge and staff members.



Outcome:

After a transition process, Tom moved to his new home. The Advocate met with Tom and he appeared content in his new home. The Advocate was informed of Tom's weekly schedule, community visits, his links with professional supports and his regular visits to his family home, supported by the service.



9. Family and Relationships



Context:

Susan is a young woman with an intellectual disability. Susan has lived with her family all her life. Susan has a mental health diagnosis, which means she sometimes shouts. She was prescribed medication for her mental health, however her family felt that it was not right for her, so Susan did not take it. Susan's family brought her to hospital as they felt that Susan might have a different condition, that she might be in pain, and they felt this needed exploration and treatment. The family contacted an Advocate as they were worried that Susan was not getting the right treatment. Susan's family said they would not take her home from hospital until she had all the necessary tests.



Actions by the Advocate:

The Advocate met with Susan. Susan said she found it hard to understand why she was in hospital. Due to Covid-19 restrictions, Susan could not leave the hospital while she was an inpatient and therefore could not go to her day service. Susan said she was missing her friends and her family.

Susan had many different tests and was diagnosed with a neurological disorder, which could be managed with medication. Susan's family did not accept this diagnosis and said they would not take Susan home until they were confident everything else was ruled out. The clinical team advised that all the appropriate tests had been completed and Susan should be discharged, having been in hospital for more than six months. However, Susan's family said she could not come home as they felt she was still unwell. The family said they could not manage her symptoms.

Susan met with her Advocate and said she wanted to get out of hospital and to go back to her day service. Susan spoke of being bored and lonely, she did not like to use technology so found it hard to maintain links with the outside world.

The Advocate told Susan's family about what Susan wanted, and attended meetings with key services to plan for Susan's care and discharge, emphasising Susan's wish to return to her usual life and routine.

As Susan could not return to her home, the Advocate contended that Susan should not be moved to a step-down unit, but she should be found a suitable longer-term disability appropriate placement.



Outcome:

The Advocate helped get information about residential services that might suit Susan. The hospital social worker made several referrals and her day service provider offered Susan a home. The Advocate talked to Susan about the placement and Susan was happy to visit and to then trial it. Susan moved into a shared house with some people that she already knew. Susan is now happy living in her new home with her support staff. Susan has returned to her day service and can visit her family when she wishes.



10. Health



Context:

Billy is a middle-aged man with an intellectual disability. He was admitted to an acute hospital for a number of months during Covid-19. Billy was referred to the National Advocacy Service by a family member, as they were worried that he was not receiving appropriate care.



Actions by the Advocate:

Billy had not received the Covid-19 vaccine when he was admitted to hospital. Initially, his family member said he had not received it because he was ill, but further discussions with his family member revealed that they did not want him to be vaccinated. Billy's family member said they felt the vaccine was unnecessary and it would put him at additional risk.

The Advocate attended a meeting with Billy's family member and the Multi-Disciplinary Team (MDT) in the hospital. The clinicians advised why they felt it was in Billy's best interest to have the vaccine, and how they wanted to work in partnership with his family. The Advocate explained the HSE consent policy and noted that no adult can consent or refuse on behalf of another person, outside of specific legal situations. The Advocate also gave details of various information resources that were available to Billy and his family about the vaccine.

Billy's family member did not agree that Billy should be vaccinated and had a solicitor write to the hospital threatening legal action if Billy was given the vaccine without their permission.

The Advocate linked with the clinical and social work team to give Billy information about Covid-19 and the vaccine. The Advocate accessed easy to read and video information that was produced for people with intellectual disabilities which helped to explain about Covid-19 and the vaccine. The Advocate and a nurse met with Billy to look through some of the information about Covid-19. Billy understood that Covid-19 was an illness and that it made some people very sick. Doctors met with Billy's family member again to discuss the vaccine, and again Billy's family member stated they did not agree with Billy having the Covid vaccine.



The Advocate wrote to the senior social worker, noting the risk in delaying Billy's access to the vaccine and voicing concern that Billy remained unvaccinated based on the refusal of a person with no authority to deny his access to this intervention.

Billy's medical team decided they would proceed with the vaccination if Billy did not directly refuse as it was in his interests due to the risk of infection while he was in hospital. The hospital had another meeting with Billy's family member and explained that Billy needed to have the vaccine as there was a major outbreak and he was at substantial risk as he was on an acute ward.

The family member threatened legal action or to remove Billy from hospital if his access to the vaccine was to proceed. The Advocate referred Billy's family member to the HSE guidelines for consent and the specific legislation relating to the Covid-19 vaccine. The social worker also offered to meet with the family member separately to review the information with them.



Outcome:

The hospital arranged for Billy to have access to the vaccine. The consultant explained what was happening to Billy before he was offered the vaccine. Billy was happy to have the injection and afterwards informed his Advocate that he had had the vaccination.



11. Decision-Making and Capacity Building



Context:

Valerie was supported to contact the National Advocacy Service by her service provider. Valerie had been living in temporary respite accommodation due to a family member's health deteriorating. Due to a lack of alternative suitable accommodation, Valerie remained in the emergency placement for longer than planned. Valerie was moved to other settings at weekends and holidays to free up the bed in the emergency respite for others. Valerie had no room to call her own or to personalise as she wished and there was a lot of uncertainty in Valerie's life which she was unhappy about.



Actions by the Advocate:

The Advocate identified the main advocacy issue which was to establish where Valerie would like to live long-term. As Valerie was initially nervous about expressing her views, the Advocate spent time with her, building Valerie's confidence and trust and supporting her to speak up to staff about her experience of living in respite. It was challenging to meet regularly with Valerie, due to Covid-19 public health restrictions, but the Advocate utilised Zoom to maintain contact and build up a good working relationship.

The Advocate supported Valerie to meet with her staff support team, once she felt confident to do so, to tell them how difficult she found living in respite, especially with the moves to other locations at weekends etc. The Advocate contacted the HSE Disability Services to highlight Valerie's predicament, and supported Valerie at meetings with the HSE Case Manager.

As a result of these interventions, Valerie was given the opportunity to try house sharing to see if she liked it. The Advocate supported her through this process, making sure that Valerie was listened to and was central to the decision making process. Valerie decided she did not enjoy house sharing, and instead requested a residential placement in a location close to her family home.

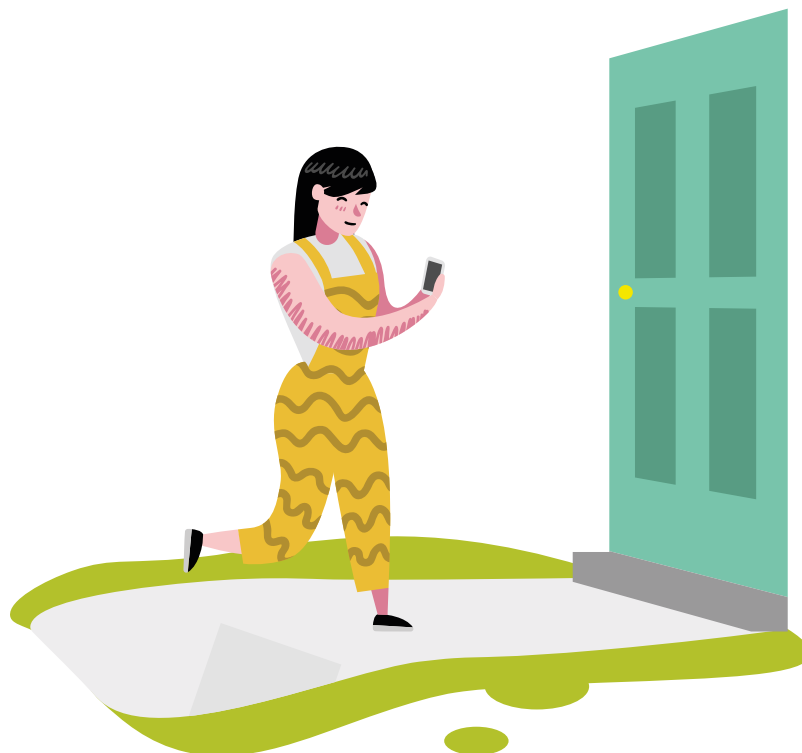


Once a suitable placement was identified for Valerie, the Advocate supported her through a transition process, ensuring that the move was managed well and that Valerie was involved in all planning and comfortable with the pace of change. This involved attending planning meetings with Valerie, ensuring that all steps of the process were presented to Valerie in easy to read/social story format, visiting the placement along with Valerie to get her views on the new service and checking in with Valerie after an initial trial period to ensure she was still happy with her new home.



Outcome:

Valerie is now happily living in her new home and attending a new day service. Valerie lives in a permanent residential setting. She is very excited to have her own room which she has decorated to her own taste. The service staff have remarked that the involvement of the National Advocacy service in this case “as a separate entity has been really positive for Valerie”. Valerie said that she feels more confident to raise issues should they arise in the future. Throughout the process, there was excellent co-working between the Advocate and staff in the service. This led to further enquiries from the service to the National Advocacy Service.



12. Housing



Context:

Ali contacted the National Advocacy Service as he was at risk of homelessness. He sought support from the Service to explore options and to navigate the Local Authority system. Ali had been living in a family member's home but was asked to leave as the house was being sold. Ali had no previous experience of homelessness and was very concerned about his future. Ali had experienced mental health and addiction difficulties in the past and was afraid he would be placed in emergency accommodation which could negatively impact on his recovery.



Actions by the Advocate:

The Advocate linked with Ali on his issue and listened to his concerns. The Advocate took guidance from Ali who requested support on gathering information on the supports available to persons at immediate risk of homelessness. After the initial meeting between Ali and the Advocate, Ali said he was being really listening to and was very grateful that his concerns, wishes and questions were being heard.

The Advocate helped Ali to gather information, supporting Ali to identify other supports that could help progress his case. Ali expressed frustration over conflicting information provided by the Local Authority on the Rental Accommodation Scheme (RAS), the Housing Assistance Payments (HAP) Scheme and options for emergency accommodation. The Advocate provided clear and accurate information to Ali and broke down the steps Ali needed to take in a clear and manageable way.

The Advocate recommended that Ali re-engage with the Mental Health Services to seek their support around the risks of going into unsuitable emergency accommodation. Ali linked in with the services and self-advocated for the help he needed.





Outcome:

Ali was accepted into emergency accommodation for a two-week period. After that time, Ali was offered a tenancy in an area of his choice. Ali is relieved to be in a safe and secure home and commended the Advocate on the support they gave him when he was very unsure about his future accommodation options.

Ali's need for advocacy and other supports to resolve his housing crisis was exacerbated by a lack of appropriate emergency accommodation options in rural areas. The progress of Ali's case was delayed due to a lack of affordable private rented housing. Ali was unable to source his own accommodation without significant support.



13. Housing



Context:

Sheila, who is in her early forties, is a resident of a nursing home. She contacted the National Advocacy Service regarding her wish to return to live in the community. Sheila was admitted to the nursing home 3 years earlier as she had no rental property when being discharged from hospital. She was informed at that time that a nursing home was her only option.



Actions by the Advocate:

The Advocate met with Sheila to gather information and clarify how Sheila came to reside in the nursing home. The Advocate spent time with Sheila to explore and understand what her life was like prior to moving into the nursing home. Sheila wanted to know if she could return to live in the community and explained that a nursing home environment was not suitable for her.

Together, Sheila and her Advocate worked on an advocacy plan to achieve Sheila's desired outcome. The Advocate provided information to Sheila about her rights, the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and the Ombudsman's Report on Wasted Lives. The Advocate provided Sheila with information on mainstream services and highlighted the issue of young people being inappropriately placed in nursing homes.

The Advocate liaised and negotiated at inter agency meetings on Sheila's behalf, outlining her rights, the UNCPRD, the Ombudsman's Report on Wasted Lives and Sheila's will and preference to return to live in the community. The Advocate supported Sheila to self-advocate throughout this process and Sheila wrote to the local authority describing the impact of living in a nursing home at a young age was having on her mental health.





Outcome:

As a result of the Advocate's support, Sheila was offered a local authority tenancy, personal assistant hours and a community support worker from homeless services. Sheila's rights were upheld throughout the advocacy process.

Sheila has engaged with mainstream services in her new community and now has more available to her. This has given Sheila a sense of control and choice over her own life. The Advocate encouraged and supported Sheila to self-advocate and build her capacity in speaking out. Sheila said this has resulted in her increased confidence and a sense of belonging in the community.

The Advocate was informed by the nursing home that they have amended their admissions policy in an effort to ensure that should a young person be admitted in the future, appropriate supports and services, including access to the National Advocacy Service, are in place prior to admission.



14. Quality of Life



Context:

The National Advocacy Service received a third party referral to provide advocacy support to Anne, a young lady living in a large residential service. Quality of life concerns were raised for Anne who had had little opportunity to engage with her local community or participate in any social activities. Attempts by staff supporting Anne to secure social supports or services had been unsuccessful.



Actions by the Advocate:

At the outset, the Advocate met with Anne to try to ascertain her own wishes. Anne has an intellectual disability and communicates differently. She primarily uses gestures and behaviours to communicate and has limited verbal communication. As Anne could not verbalise her wishes, the Advocate used a combination of four internationally recognised approaches to independent advocacy i.e. (i) person centred approach, (ii) witness observer, (iii) ordinary life principals and (iv) rights based approach.

By adopting a combination of these four approaches, the Advocate could represent Anne's perspective and raise issues on her behalf. The Advocate highlighted to the service provider that Anne's right under the UN Convention on the Rights of Persons with Disabilities (UNCPRD) had not been upheld to be supported to have full inclusion and participation in her local community. The Advocate also showed that Anne had very little stimulation or social interaction in her daily routine and her quality of life was impacted negatively as a result.





Outcome:

Following the representations from the Advocate, the service provider approved funding for Anne for ten personal assistance hours each week, for social purposes. A personal assistant (PA) was appointed to Anne and they initially built up a rapport with her through the use of table top activities, such as arts and crafts in Anne's home. Over time, in line with Anne's wishes, the PA began supporting her to access services and activities in her local community.

The appointment of a PA has been a really positive step for Anne as it has enabled her to build relationships and a social network locally. The support has ensured that Anne's right to participate fully in her local community has been respected and her wishes taken into account. Anne now enjoys regular social outings and activities and is an active member of her local community.



15. Parenting with a Disability



Context:

The National Advocacy Service received a third party enquiry to provide advocacy support to Emma whose child was living in the care of foster parents. Emma lived independently in the community and had a mild intellectual disability. She told the Advocate that since her child had been taken into care many different professionals had become involved in her life. Emma said she found formal meetings in relation to her child very stressful and said this sometimes prevented her from attending, even though she knew the meetings were important.

Emma told the Advocate that when her child was taken into care a schedule had been agreed whereby Emma would enjoy regular access visits with her child. Emma conceded that while she had initially attended the access as arranged, over time her attendance had become sporadic. When the Advocate first met with Emma, she said she hadn't attended access with her child in over a year.

Emma told the Advocate that she wanted to have a relationship with her child and wanted to try and re-establish access visits. Emma said she was worried that this would not be possible as it had been so long since she had seen her child. Emma did not have any natural supports to advocate on her behalf.



Actions by the Advocate:

The Advocate supported Emma to liaise with the Child and Family Agency, Tusla, and outlined Emma's wish to re-establish access with her child. Over the course of a number of meetings, a new access plan was developed to support Emma and her child re-establish contact.



This plan clearly set out the time and date of each access visit and also clearly outlined Emma's duties and responsibilities in advance of each access meeting. As part of the plan, a Social Worker agreed to link in with Emma before and after each access visit for support.



Outcome:

The access plan has since been put in place. Emma has told the Advocate that this access plan has given her the opportunity to reconnect with her child and build upon their relationship. She said that having the support of an Advocate gave her the confidence to speak up and assert her right to have a meaningful relationship with her child.



16. Housing



Context:

Sebastian was referred to the National Advocacy Service by a service provider. Sebastian had a neurological injury following an accident. His will and preference was to live as independently as possible in his family home and have access with his child.



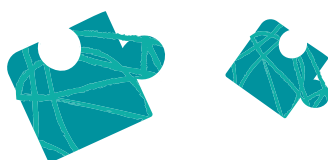
Actions by the Advocate:

The Advocate met with Sebastian and his supporters to gather information and agree an advocacy plan. Several issues had to be addressed simultaneously. Sebastian stated he wished to remain in the family home, if possible, as he was experiencing such upheaval in so many other aspects of his life at this time. Sebastian's financial situation needed to be improved so he could retain his independence and dignity. Sebastian also sought regular, planned contact with his child and a divorce from his spouse.

Sebastian had experienced a significant reduction in income following the separation from his spouse and was at risk of becoming homeless. The Advocate provided information and advocacy support to improve Sebastian's financial situation and identified that Sebastian was eligible to apply for Invalidity Pension.

The Advocate helped Sebastian apply for Legal Aid in order to secure legal services to support access to his child and legal advice regarding divorce proceedings. Legal aid was awarded and the Advocate supported Sebastian in meetings with his solicitor. The Advocate linked Sebastian to appropriate disability services which worked with Sebastian to develop a personalised communication toolkit. This toolkit was vital to assist Sebastian with information management throughout the legal process.

The Advocate supported Sebastian to meet with a money advisor from MABS, the Money Advice and Budgeting Service, who provided advice and practical assistance to review the debt accrued on Sebastian's home. The MABS advisor worked with Sebastian and the Advocate to agree and communicate a financial plan with creditors.



With the support of the Advocate and MABS, Sebastian availed of a defined process known as The Mortgage Arrears Resolution Process (MARP). This code of conduct establishes how the lender must communicate with the borrower and assess their situation with the aim of coming to a resolution. In addition, the Advocate supported Sebastian to have his application for social housing completed and accepted by the Local Authority.



Outcome:

Sebastian was supported to apply for and access an Invalidity Pension payment. Once this payment was awarded, Sebastian was eligible for other Social Welfare payments such as the Living Alone Allowance, HB1, Fuel allowance, and a free travel pass. Securing these resources led to an immediate improvement in Sebastian's quality of life and future choices. Also achieved through advocacy support were outcomes such as capacity building and access to information to support decision-making and choice. Sebastian has made significant gains in terms of capacity and skill building and is managing the activities of daily living very well.



17. Complaint re Care in a Public Acute Hospital



Context:

Susan contacted the Patient Advocacy Service to make a formal complaint about the care given to her father, who had passed away in hospital. Susan's father had been a patient in the hospital and was discharged home, only to be readmitted with a serious illness a few days later.

Susan spoke to an Advocate from the Service, expressing her concerns and outlining the issues she wanted to raise in her complaint to the HSE. The issues were poor communication from hospital staff, being unable to visit her father, lack of personal care, lack of discharge planning and end of life management.



Actions by the Advocate:

The Advocate from the Patient Advocacy Service gave Susan information and advice about how to request her father's records through Freedom of Information. The Advocate then supported Susan to review the records.

The Advocate empowered Susan to draft a formal complaint to the hospital, which included all the issues she had concerns with, including the lack of discharge planning and the Do Not Attempt Resuscitation (DNAR) form. Susan requested a family meeting with the hospital as part of the complaint.

The hospital responded to the complaint, however, it did not fully deal with the issues Susan had raised. Her request for a family meeting had also not been granted. The Advocate supported Susan to request an internal review of the complaint and this was sent to the hospital group.

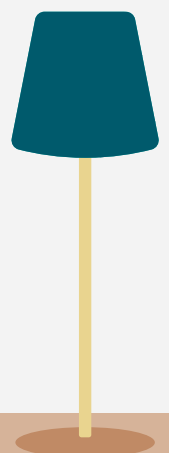
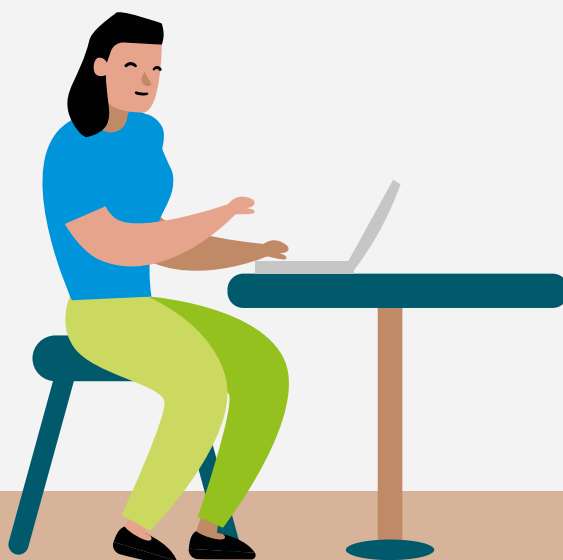
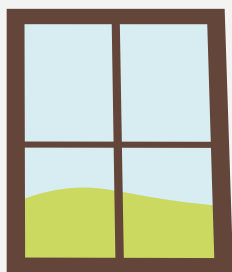
The internal review of Susan's complaint resulted in the family being offered a meeting by the hospital. The Advocate attended the meeting in a supportive role. The complaint was discussed in detail, with the family having an opportunity to voice concerns that had not been addressed in the written response to their complaint.

A series of recommendations came from the meeting which resulted in policy changes within the hospital and new training to be put in place for staff in the hospital. The family were also given an apology.



Outcome:

Susan was satisfied with how the complaint was dealt with. She felt that her concerns were addressed and that they had been listened to as a family. Susan was invited to share her story as part of induction training with new staff in the hospital.



18. Complaint re Care in a Public Acute Hospital



Context:

Paul contacted the Patient Advocacy Service regarding a complaint about the care his mother had received in a public acute hospital. Paul has a disability and prefers to communicate verbally rather than in writing.

Paul's mother passed away during the Covid-19 pandemic, following an illness. She had been admitted to hospital feeling unwell, after which she tested negative for Covid-19.

Due to Covid restrictions, Paul and his family were unable to visit their mother, but they phoned the ward on several occasions to speak with her. However, a lot of their calls went unanswered and there was very poor communication between the hospital team and family. The following evening Paul's mother's health deteriorated and she passed away. Paul and his family were unhappy with her treatment and had questions they wanted answered.



Actions by the Advocate:

The Advocate empowered Paul to draft and send his written complaint to the HSE. Paul requested a meeting with the hospital and although the Advocate could not attend, they helped Paul prepare for it. The meeting did not answer all his questions and Paul was advised he could request a further meeting if he needed.

The Advocate supported Paul to request a further meeting, which was refused. Paul then requested an internal HSE review of his complaint and to ask why a further meeting had not been given. The HSE upheld their decision to refuse another meeting.

The Advocate suggested that Paul should escalate his complaint to the Ombudsman. Initially, the Office of the Ombudsman said they could not investigate the complaint, as it involved Clinical Judgement which was outside their remit.

However, the Advocate empowered Paul to contact the Office of the Ombudsman again, referring to the processes that were not handled correctly within the HSE complaints process and to the HSE policy regarding Paul's preferred method of communication.

As a result, the complaint has been referred to the Office of the Ombudsman's Investigation Team who will discuss and investigate with the hospital why they refused the second meeting.



Outcome:

Paul is awaiting the findings of the Office of the Ombudsman's investigation, but is hopeful that a second meeting with the hospital will be provided to clarify some of the answers provided and discuss issues that were not answered in his complaint.



19. Complaint re Access to Care



Context:

Pat contacted the Patient Advocacy Service to request support to make a complaint because he had been unable to access specialist care in a public acute hospital for the treatment of his illness.

Pat was being treated privately for his illness, but an issue meant he had to request that his care be transferred to the public hospital. He had been trying for years to transfer his treatment and he had no access to specialist care, treatment plans or prescriptions. Pat felt he was being dismissed.



Actions by the Advocate:

The Advocate empowered Pat to organise his care history chronologically, specify his questions and desired outcomes and structure his complaint letter to the HSE.

The Advocate explained the HSE's 'Your Service Your Say' complaints management process to Pat, what he could expect to happen and the timeframes. The Advocate also empowered Pat to structure his complaint around the HSE's Health Charter by highlighting what treatment he should expect as a patient in terms of access to specialist care, communication with staff and participation in his own care.

The Advocate researched the HSE policies that were relevant to Pat's situation and supported him to reference them in his complaint letter, further illustrating the importance of access to specialist care.



Outcome:

The complaint was submitted to the hospital and they thanked Pat for his well-structured letter which provided them with information and context that hospital staff had not previously understood. Pat received a call from the specialist consultant who apologised for the misunderstanding and an appointment was arranged. He is currently receiving the specialist treatment he requires.



20. Complaint re a HSE-Operated Nursing Home



Context:

Aoife, a resident of a HSE-operated nursing home, contacted the Patient Advocacy Service with issues around the care and support the nursing home had provided when she had suffered an injury. Aoife had fallen in her bedroom after slipping on a loose cable, but she was not taken to hospital for two days. She went on to spend a week in hospital. Aoife wanted to know why she had not been taken to hospital sooner.



Actions by the Advocate:

The Advocate spoke to Aoife to ascertain the details of what had happened, explore any issues or other information she wanted to discuss and identify the outcomes she wanted to achieve.

The Advocate explained to Aoife that she had the option of making a formal complaint through the HSE's Your Service Your Say complaints process, or she could proceed with the informal route of speaking directly to the nursing home.

With Aoife's permission, the Advocate spoke to the Person in Charge in the nursing home on her behalf. The Person in Charge stated that an investigation would take place.

Following this investigation, the Person in Charge contacted the Advocate to advise that on the day of the fall, Aoife was assessed by a GP who made a clinical decision not to transfer her to hospital. This decision was revaluated two days later, and Aoife was transferred to hospital.

The Person in Charge advised that staff were keeping an eye on Aoife and advised that should she have another fall, she would be transferred to hospital. Aoife's Care Plan was updated to reflect this direction.



Outcome:

The Advocate had a follow-up call with Aoife, providing her with the outcome of the investigation and the information from the Person in Charge. Aoife said she was happy with the information provided. She decided not to make the formal complaint as she was satisfied that her issue had been dealt with.



21. Complaint re Care in an Acute Hospital



Context:

Fiona contacted the Patient Advocacy Service following a traumatic experience in relation to her maternity care in hospital. She wanted answers about what had happened and had decided to make a complaint about her care to the HSE.

Fiona was informed by the hospital that a Coroner's post-mortem had been called. She also received a letter from the hospital informing her that an Internal Review was taking place under the HSE Incident Management Framework policy.

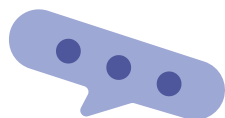
Fiona asked her Advocate for support around this review process. She also wanted to seek an external review, independent of the hospital, to understand what had happened during her maternity care.



Actions by the Advocate:

The Advocate from the Patient Advocacy Service empowered Fiona to request copies of her clinical and non-clinical healthcare records from the hospital, via a Freedom of Information (FOI) request, and helped Fiona to review the files once received.

The Advocate discussed the options available to Fiona around making a complaint, including contacting the Nursing & Midwifery Board, the Medical Council and the Office of the Ombudsman. Fiona was also provided with information about the HSE's Open Disclosure policy following an incident within a hospital.



The Advocate explained the Review to Fiona and provided her with ongoing support throughout the process. The Advocate helped Fiona prepare for her meeting with the Review team, including drafting questions she wanted to be considered, supporting her at the Review meeting, and reviewing Review reports.



Outcome:

An inquest was held, with recommendations issued by the coroner to the hospital. The Final Review Report was issued a year and a half later. Fiona was not satisfied with the Final Report. With the support of her Advocate, she lodged a complaint with the Office of the Ombudsman about the lengthy delays with the review process and the final report being issued.

Fiona was also supported to submit a complaint to the Hospital Group regarding the lack of external review to examine what happened. Fiona continues to be supported by her Advocate to determine what happened.





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



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



National Advocacy Service (NAS) for People with Disabilities & Patient Advocacy Service

Level 3 Rear Unit
Marshalsea Court
Merchants Quay,
Dublin D08 N8VC

NAS National Line: 0818 07 3000
advocacy.ie
info@advocacy.ie

Patient Advocacy Service
National Line: 0818 29 3003
patientadvocacyservice.ie
info@patientadvocacyservice.ie

design by thewonderworks.ie