National Advocacy Service
For people with disabilities

National Advocacy Service for People with Disabilities

Casebook 2024

Contents

Foreword by Chairperson

Welcome to our third annual Casebook. This publication contains a selection of the varied advocacy work of the National Advocacy Service for People with Disabilities and the Patient Advocacy Service over the past year.

The National Advocacy Service for People with Disabilities, which is funded by the Citizens Information Board (CIB), focuses on ensuring the rights of people with disabilities are upheld. It provides people with disabilities across Ireland with an independent, professional and free advocacy service that helps people to have their voices heard, make their own decisions and live their lives independently.

The Patient Advocacy Service is commissioned by the Department of Health (DoH) and provided by the National Advocacy Service for People with Disabilities. It is an independent, confidential and free service which provides empowerment advocacy to people who wish to make a complaint about their care in a Public Acute Hospital or a Nursing Home. The service also offers advocacy to people in the aftermath of a Patient Safety Incident.

This year’s casebook contains an increased number of case studies providing insight into and detailing the complex case work carried out by Advocates in both services. The Casebook highlights the important role independent, professional advocacy can play in supporting people to have their human rights protected and promoted.

The Casebook shares the lived experience of a diverse range of people who access our independent advocacy services across Ireland.

As you read the case examples in this publication, you will notice that advocacy is generally offered when people need specific and tailored information or support. You will read about the different forms of advocacy, including empowerment and representative advocacy, and you will see that these situations are often very emotive for both the people receiving advocacy and our Advocates. Our Services provide advocacy in relation to issues, for example, issues relating to housing, healthcare, social care and much more, including complex difficulties experienced by parents with a disability.

I hope that these case examples provide you with rich insight into what our Services do, highlighting the importance of independent advocacy, showcasing the positive impact we have had on people and 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 accessed our Services in 2024. I wish to extend my thanks to CIB for their continued endorsement of the National Advocacy Service for People with Disabilities 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 all the staff of both Services for their work ethic and dedication in providing high quality professional advocacy services.

Rosemary Smyth

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. Capacity Building

Context

Amy is in her mid-twenties and has an intellectual disability. Amy lived with her parents and was often coming home upset from her day service. Concerns regarding abuse arose for Amy and she was supported to make a referral to NAS to seek support. Amy's parents were worried about Amy's safety and wellbeing while in the day service and were concerned about her being visibly upset. Her family had already started to make plans without Amy's involvement for a transition to another service. Amy was very unsure about what she wanted to do.

Actions by the Advocate

The Advocate spent time getting to know Amy, learning how she communicates and learned that Amy preferred to use short two-to-three-word sentences along with pictures, social stories and Lámh (a type of sign language) to communicate. Together, Amy and her Advocate created an advocacy plan to help Amy follow up with the service in relation to the safeguarding plan and also supported Amy to explore her options for day services. The Advocate supported Amy to make her wishes known to all those in her life.

The Advocate and Amy met with the Day Opportunities Manager to discuss Amy's options. The Advocate and Amy spent some time exploring Amy's wishes, the things she liked and wanted from her day service and the things that made her unhappy. Amy did not enjoy using the services transport and wanted to learn to travel independently. The Advocate explored Amy's wishes to visit and learn about other Day Services. Amy eventually decided that she did not want to move service, instead with the support of NAS she told her service she wanted a plan to learn how to travel independently. Amy's Advocate supported her at meetings to ensure Amy was kept at the centre of the decision-making process regarding day service. Amy was empowered to voice her will and preference with the people included in her circle of support. Amy's Advocate supported her to seek assurances in relation to the safeguarding plan and to ensure Amy had access to a social worker.

Outcome

Through NAS Advocacy, Amy learned about her options in relation to day services in her area. She was supported to make her own decisions and to voice her wishes to her circle of support. Amy started to receive a person-centred service from her day service in line with her goals for the future. The service ensured Amy's safety and addressed the safeguarding concerns. Amy thanked the Advocate for supporting her to make her own decisions and to express her wishes.

2. Assisted Decision-Making

Context

John, a 45-year-old man with an intellectual disability, has lived in a community group home for most of his adult life. In early 2023, John's residential service announced a restructuring that would require him to move to a new home. John was very upset by this and felt that the decision was made without properly considering his preferences and feared the change would disrupt his routine and well-being. John began to feel that his voice was not being heard in decisions that directly affected his life, such as changes to his living arrangements and future planning.

John was referred to NAS, and he was assigned an Advocate who met with him to discuss his concerns. The Advocate worked to build a trusting relationship with John, explaining the Advocate's role in supporting him, empowering him to voice his own opinions, and helping him understand the choices he faced.

Actions by the Advocate

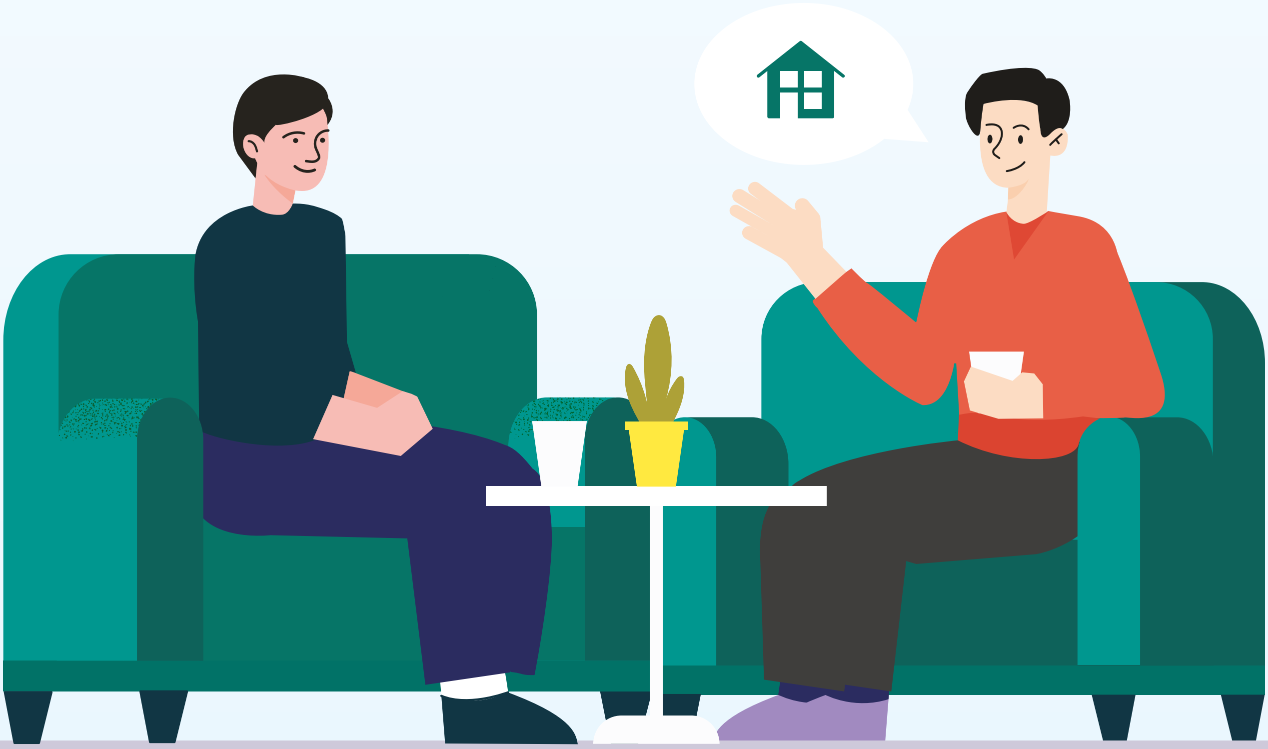
The Advocate began by helping John understand the changes to his living situation. This included explaining what his options were for alternative accommodation. The Advocate used accessible language, visual aids, and had multiple conversations and meetings with John.

Once John understood his options, the Advocate supported him in articulating his preference to remain at the current home or, if that was not possible, to choose another option that met his needs and comfort. The Advocate arranged meetings with service management, and John attended these meetings with the Advocate by his side, feeling empowered to voice his concerns and preferences.

Outcome

Through the support of NAS, John's situation was significantly improved. His Advocate ensured that John's voice was considered in the decision-making process around his future home. John was offered a place in a new home that closely resembled his current living arrangement, and this decision was made with his full participation and input.

This case highlights the crucial role of the National Advocacy Service in ensuring that individuals with disabilities are not left out of key decisions that affect their lives. Through advocacy, John was able to exercise his right to have a say in his living arrangements thus improving both his quality of life and his sense of autonomy.



3. Housing

Context

Ade is a young woman with a mild intellectual disability who also experienced periods of poor mental health. She has been in foster care since she was a child. Due to the trauma Ade experienced in her early life she had additional support needs, and her former foster care family were struggling to best support her. Ade felt her wishes on how she wanted to spend her time and live her life were not being respected. She was attending a day service with a disability service provider. There was a concern that Ade was at risk of homelessness. She had been refused medical/disability priority for housing with the Local Authority and wanted support to appeal this decision. Ade was aging out of aftercare with Tusla who supported a referral to NAS to support Ade to make her own decisions and express her will and preference regarding her future support and living arrangements.

Actions by the Advocate

Ade's Advocate met with her to discuss her concerns and explained the advocacy process to her. Together they agreed an advocacy plan supporting Ade to apply for priority housing based on exceptional social grounds. The Advocate helped Ade to seek a referral to the primary care mental health team who worked on a report to support Ade's housing application. The team also offered support strategies to Ade to help with independent living. The Advocate, Ade, her Social Worker and the Tusla Aftercare team created an emergency plan in case her current living and care arrangements broke down.

After some time, the carer relationship broke down and Ade found herself homeless. The Advocate supported engagement with Tusla in relation to Ade's situation and Ade was offered a single room in a homeless service until suitable accommodation and care supports could be arranged. Ade's Advocate ensured her case was escalated to a steering committee between the HSE, Tusla and the Local Authority, where young care leavers experiencing homelessness were considered for suitable housing schemes. Ade remained in the homeless accommodation for a long time which negatively impacted her mental health. Eventually, with ongoing NAS advocacy support, an offer for long term housing through a housing scheme was made. Ade accepted this offer and was linked with a SLI worker (Support to Live Independently).

Ade was offered a place on an independent living programme and received outreach support as she adjusted to living independently in the community. Throughout all these engagements with multiple people, services and stakeholders, Ade's NAS Advocate was a constant support ensuring her voice was heard and her wishes respected.

Outcome

Ade was granted housing through the social housing scheme and now lives independently. Her accommodation is close to her day service, and she is supported to travel independently to visit her relatives. The disability service provider was able to offer increased support provision to Ade now that she had her own home. Ade's relationship with her former carer improved as Ade's wishes in terms of how she wanted to live her life were respected.

4. Parenting with a Disability

Context

James is in his thirties and has an intellectual disability. James made a self-enquiry after hearing about NAS during a visit to the Citizens Information Service. James has a child in primary school. However, following the breakdown of the relationship with the mother of his child, James faced several family law court hearings on access orders, guardianship, and the child's passport and travel arrangements. James felt that, as a parent with a disability, with the child in the care of their other parent, there was an uneven distribution of power when it came to decisions about the child. James felt that his voice was not being heard.

Actions by the Advocate

James told his Advocate he found it difficult communicating with his solicitor. James's Advocate supported him to set up both in-person and remote meetings with his solicitor in advance of Court hearings which ensured that James was accommodated to fully understand the court process and his Solicitor's advice. His Advocate supported James to prepare for meetings with his Solicitor, identify questions he wanted clarity on, and supported him to underline his will and preference in relation to parenting his child and access arrangements to his Solicitor.

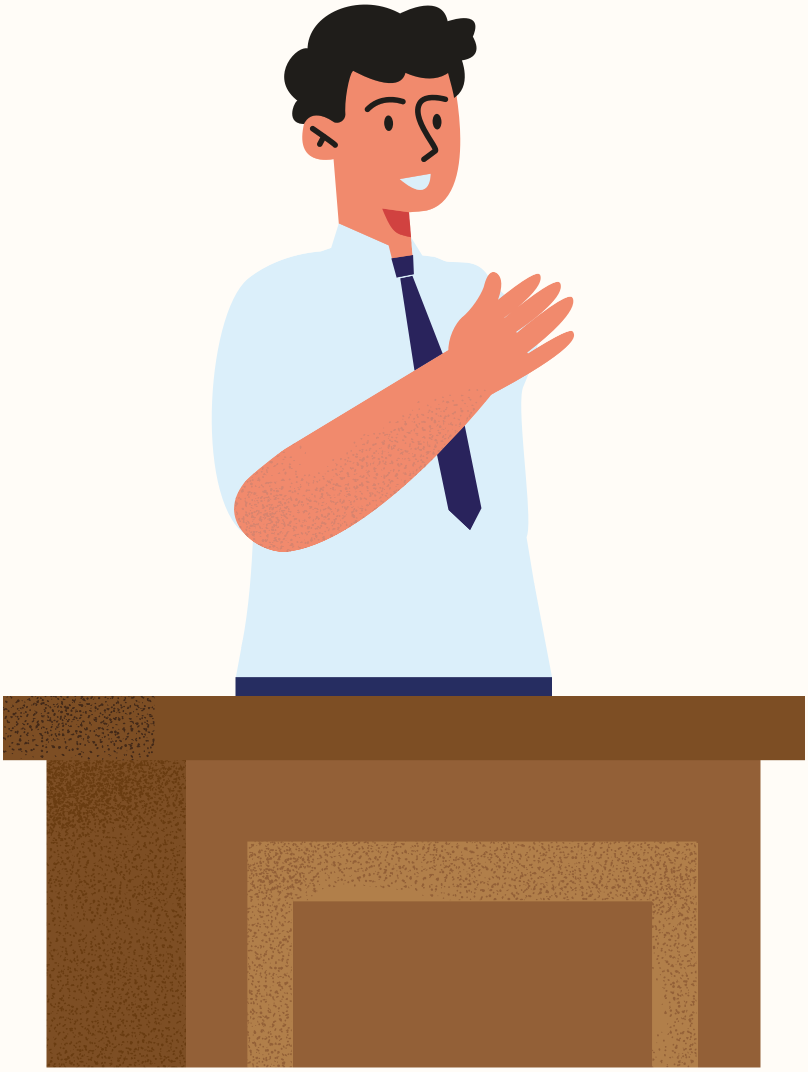
James felt very pressurised by his parents who attempted to influence his decision making around the arrangements that were being considered. The Advocate supported and empowered James to explore all the options for himself, understand his right to make his own decisions, even if his decisions might appear to be unwise by his parents or other third parties. At James's request, the Advocate supported James to update his parents on the decisions he had made, and the instruction that he had given his solicitor.

James was required by the Court to prepare for access, identify supports for access and engage with parenting classes. His Advocate supported James to research supports, and to link with a resource centre in his community who could support him with access plans and provide a suitable setting for access. The Advocate supported James to self-advocate and signposted him to engage with local community services and to review and access parenting classes. The Advocate helped James to collate adequate information for the Court, to demonstrate that he was proactively engaging with parenting supports in his community.

Outcome

James said he felt empowered to attend the family law hearings with the support and preparation of his Advocate. He added that in working with NAS he was given the space to be able to consider the options available and to weigh up the potential consequences of making different decisions. This helped him to make independent decisions free from the influence of his family, and to instruct his solicitor on the decisions he had made, who in turn represented his will and preference to the Court.

Working with his NAS Advocate and solicitor, James was supported to make a District Court order appeal and understand the process and timelines, and to attend the Circuit Court hearing. James was able to take the stand and be cross examined in Court following the preparation and support of the Advocate prior to, and on the day of the Court hearing. James was empowered to link with parenting services and supports in his community, who will continue to support him with access arrangements and the changing needs of his child.



5. Social Care

Context

Earl is in his mid-forties and is a gifted artist. He has a rare, inherited disorder that causes progressive damage to his nervous system. The condition impacts his mobility, muscle strength, speech, hearing and energy. Earl self-referred through the NAS National Line. At the time of contacting NAS, he used a wheelchair, had limited use of his hands, and his speech was slurred. Earl lives alone, in a spacious, fully accessible two-bed local authority tenancy, with two different companies providing support to him.

His quality of life was severely impacted by his deteriorating health, Earl's great fear was that he would be forced to move to live into a nursing home as an appropriate level of Personal Assistant (PA) support hours would not be made available to him.

Actions by the Advocate

Working with his Advocate, Earl outlined that his support package was not delivered in a way that matched his needs. Earl had previously requested that one service deliver all the support hours, this was turned down on several occasions. Earl had a very limited social life as neither service could guarantee available support staff past 7.30pm. Earl talked to his Advocate about having to leave his best friend's wedding early as he did not have staff to support him later in the evening. On numerous evenings Earl was supported to bed as early at 7.30pm, remaining in bed until the first PA arrived in his home at 9am the following day.

Earl was adamant that the funder and support providers did not fully acknowledge the extent of the deterioration in his health, and he wanted a comprehensive support needs assessment. He wanted his NAS Advocate to support him to rearrange the timetable of support, and where necessary, to increase his care package. Most of all, he wanted to be treated as a citizen with rights. While he had made numerous attempts to have his concerns addressed, he felt he was 'fobbed off' by those providing and funding his supports.

The Advocate worked with Earl to address these issues, collating documentation from his medical team as well recording his wishes and views from his own lived experience, outlining how the current support arrangements were impacting on his right to engage in his community and remain in his community, his right to bodily integrity, his right to make decisions about his life and to have such decisions respected and addressed. All material was submitted to the funder and the support providers, and Earl's Advocate supported him at meetings with all key stakeholders.

Outcome

As a result of NAS advocacy support to Earl, a comprehensive support needs assessment was carried out, resulting in one support provider of Earl's choice delivering all support to him. Additionally, Earl's support hours were increased to include some overnight PA hours. With the support of his Advocate, Earl was supported to ensure his concerns were heard and his supports provided in a manner which gave him back his independence.

6. Residential and Healthcare Settings, Decision-Making and Access to Justice.

Context

David is in his late forties and has a learning disability. David was living in an apartment in a low-level support residential service. He was experiencing mental health issues and had been admitted to hospital. David was informed by the service provider that they were not able to support him in the current service due to his changing support needs and the limited services that they offered. David's family got in touch with NAS as they wanted to ensure he was adequately supported to understand his options.

Actions by the Advocate

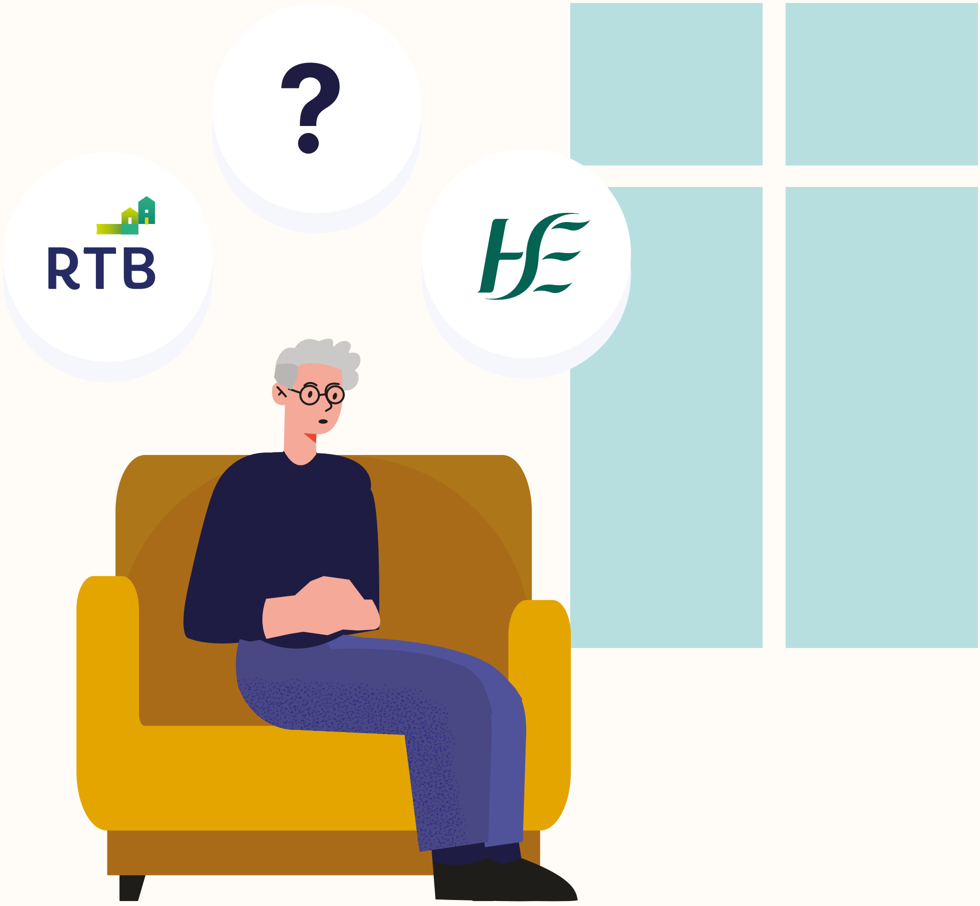
David met with his Advocate who explained the advocacy process and discussed his situation. David's wishes were to find a new residential placement and to remain independent with some support, which was set out in the agreed Advocacy Plan they developed together.

With David's agreement, the Advocate attended multi-disciplinary team meetings and supported him to have his voice heard and asked questions about his transitional plan from hospital and about his future support services. The Advocate ensured that David was at the centre of decision-making at all times during these meetings. David was supported by the Advocate to understand his service options, but he chose not to inform his family as he felt they would not respect his right to explore these. David and his Advocate explored the importance of support during transitional periods and David said that he would consider discussing his plans with his family at a later stage.

David took part in a trial period within a new residential service, but following an incident, the new service confirmed they were not able to support David due to his changing support needs, essentially evicting him with minimal notice. David's Advocate supported him to attend meetings with the Service Provider and the HSE to understand his options and highlight his rights as a tenant of the service. David was also supported by the Advocate to meet with his family to discuss the current issues with the service provider and to voice that he wanted people to understand his support needs. With his Advocate's support, David was able to consider his tenancy rights, options, and access to justice paths, such as linking in with the Residential Tenancy Board and accessing legal supports.

Outcome

David engaged with the Residential Tenancy Board and was awarded financial compensation because of the eviction. David was helped by the HSE to source a new placement that better met his support needs and aligned with his expressed wish to remain independent with support from services. David was happy to have the support of his family during the transitional period to a new service. He thanked the Advocate for their support throughout the process and said he really appreciated it.



7. Under 65 in a Nursing Home.

Context

Jo is 55 years old and has lived in a nursing home for the last four years. She moved there because of medical needs after losing her natural carer. Her self-referral to NAS included a request for assistance to ensure she had more meaning and choice in her day. Jo said she felt so lost in the nursing home as people who resided there were mostly elderly and unwell, and the staff were always busy helping the older people who needed care more than she did. She added she felt like she was bothering them when looking to chat to people or interact with them. Jo did not want to highlight this as she felt she did not want to be causing trouble or bother people when they were always so busy. Choices to leave the nursing home for excursions were limited as the transport was shared between other centres.

Actions by the Advocate

When the Advocate met with Jo, she explained she used to attend a Day Service and would like to return there. Leaving the nursing home would give her opportunities to explore her community, socialise with peers, learn new skills and have variety in her day. The Advocate engaged with The HSE Disability Services to identify funding and explore day care opportunities. Jo was funded for a Day Service but it was identified that Jo required additional equipment to support her safely in her day service.

A significant challenge was identified in accessing funding under the Public Health system to support with equipment for Jo as she was a long-term nursing home resident. The Advocate needed to regularly engage with various therapy professionals and public health decision-makers to get Jo the equipment she needed and seek options for funding. This proved to be a very slow process. Jo was increasingly dismayed, and it was affecting her quality of life daily. The Advocate explained various options to Jo to highlight her disappointment at the delay and Jo decided to follow the complaints process to escalate the urgency of her case.

Outcome

Following on from the complaints process, which successfully demonstrated the need for Jo to receive personal supports, Jo received visits and support from the Day Service team in her Nursing Home while she waited to attend the service in person. This package ensured Jo had personal support and a choice of activities tailored to her psychosocial needs. Funding was soon confirmed, and Jo is now attending a regular Day Service of her choice. Jo expressed how she felt empowered by NAS Advocacy while being involved and informed in all stages of the decision-making process.

8. Housing and Living arrangements, Capacity Building

Context

Jim is in his mid-thirties and has a mild intellectual disability and poor mental health. Jim was living in a very unsuitable home while experiencing significant health issues in his life. Despite the house being unsafe and sub-standard, Jim was not being listened to by his landlord when he raised these issues. Jim's medical consultant said his living arrangement was impacting on his declining health. Jim subsequently contacted NAS as he required support in relation to exploring alternative living arrangements, increased living supports from numerous services and understanding options around possible legal redress.

Actions by the Advocate

Jim required communication support to ensure that key information was provided to his healthcare professionals, and that Jim's situation was also communicated to relevant parties to highlight the need for urgent action to source suitable housing.

Jim's declining health and the link to his unsuitable housing situation and impact on the health was at the centre of the Advocacy Plan agreed by Jim and his Advocate. Jim's Advocate supported him to obtain medical letters highlighting concerns for the long-term impact of his current housing on his health and Jim's urgent need for an alternative home. The Advocate also helped Jim to secure supports from Threshold, a charity that helps renters facing housing difficulties and homelessness and supported him to obtain legal advice. Jim's legal support made representations on his behalf to the current landlord regarding the issues of concern with the state of his home.

Additionally, Jim had progressing health concerns and felt that his quality of life was impacted due to the dreadful state of the house. He was also living in isolation and at times he felt that he was not appropriately supported by medical services. Jim's Advocate provided information to him on local Mental Health Supports, support groups and possible community engagements. The Advocate worked with Jim to explore options available to apply for financial supports for additional costs of living through the Community Welfare Officer.

Outcome

Jim stated that he did not feel listened to before the involvement of his NAS Advocate. The Advocate provided key self-advocacy and communication support to Jim that enabled him to make representations to the Housing Authority when previous attempts at communication had broken down.

Jim now lives in much more suitable accommodation that is not impacting his health while he awaits an alternative long term council home. Jim is now in a better financial position due to additional supports that he was able to obtain from the Community Welfare Officer with the support of his NAS Advocate. Most importantly, Jim says he is now equipped with information on all the relevant supports available in the community to support him in the long run. Jim said he feels safe now as he knows NAS will be available to him if he needs them again in the future.

9. Inappropriate Accommodation, Social Care

Context

Tom is in his forties and has an intellectual disability and a mental health diagnosis. Tom had been living in a homeless hostel and was extremely unhappy in this environment. Tom engaged with Mental Health services and occasionally attended a Mental Health Day Service. He has no family support so staff at the Mental Health Day Service supported him to contact NAS.

Actions by the Advocate

The Advocate met with Tom to explore his concerns and explain the advocacy process. Tom told the Advocate that he was lonely in the hostel and just wanted a home to call his own. The Advocate worked with Tom and his keyworker in the homeless service to explore how Tom could best be supported to establish his disability and support needs. The Advocate supported Tom to attend Multi-Disciplinary Team meetings to discuss the requirements for Tom to be able to live safely in his own home. A supported residential living model was identified as the most appropriate option and a business case for funding was drafted. Funding approval took a long time to secure as clarity was sought on whether funding would be provided through Disability services or via Mental Health services. All this time Tom remained living in the homeless hostel.

Throughout this period, the Advocate and Tom met regularly. They continued to highlight the detrimental impact remaining in the homeless service was having on Tom's mental health, and the affect on his dignity and quality of life. With the support of his Advocate, Tom escalated these concerns to the head of the HSE area to seek clarity and a decision on which service would fund and implement the proposed business case.

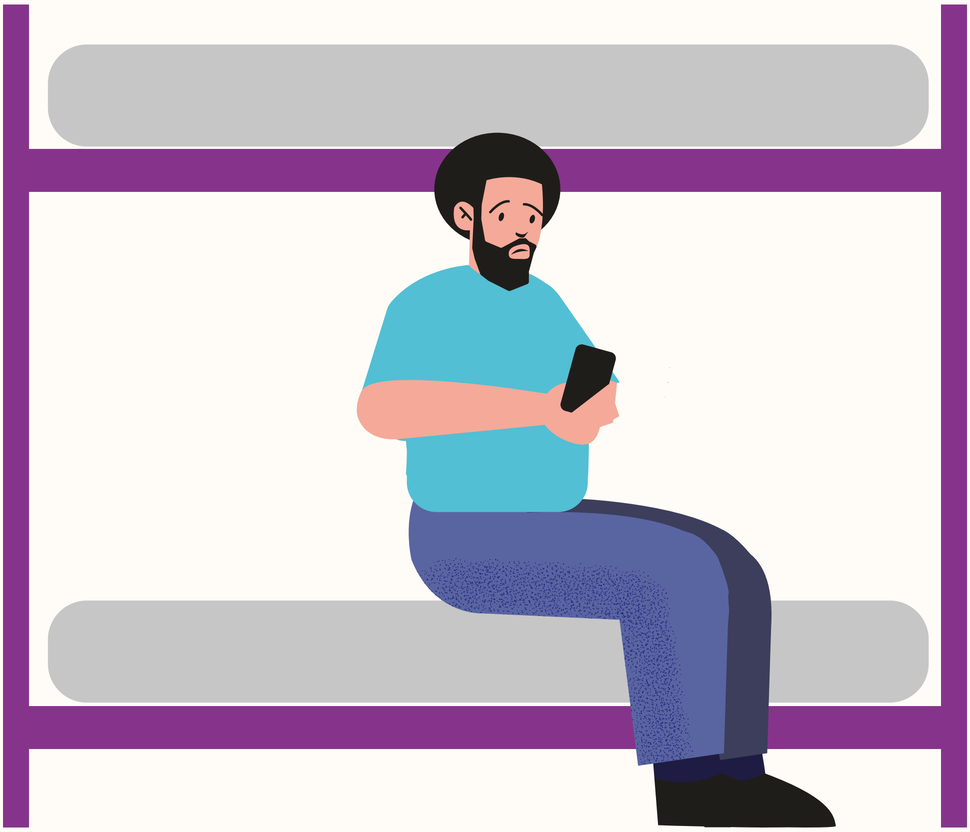
The Advocate actively engaged with key stakeholders to ensure that Tom's needs remained the focus and priority for funding.

While Tom remained with the homeless service the Advocate also supported Tom to meet with a keyworker to explore how he could develop his independent living skills. This included a referral to a community Occupational Therapist for individual sessions, exploring care plans and learning finance management skills.

Funding was eventually granted after a lengthy waiting period and a residential service provider was identified. The Advocate worked with the Social Worker to develop a transition plan centred on Tom's specific support needs.

Outcome

Tom was supported by NAS to have his voice and will and preference heard at each stage of the process to find a home. Tom is now happily living in his new home with supports from staff who have the appropriate training to assist him.



10. Quality of Life and Equal Rights

Context

Kevin is in his mid-fifties and lives with other people in his community-based home, he has an intellectual disability and uses a wheelchair. Kevin is an intentional communicator and uses social stories to understand key events/changes in his life. Due to several safeguarding concerns arising in his home, the service planned to reduce the number of people living in the house. As Kevin is quiet and easy-going, it was decided he could be moved as he could easily adapt to living in a different home. Kevin was referred to NAS because decisions were being made in the "best interests" of the entire household group by professionals and his will and preference was not being heard or considered.

Actions by the Advocate

The Advocate worked closely with Kevin and his circle of support guided by his Speech and Language Therapist (SLT). Throughout the exploratory and information gathering phase, it became apparent that Kevin spent a lot of time alone and separate to the other house members. Staff stated this was his preference. Kevin also attended a Day Service, and the information gathered there by his Advocate indicated that Kevin had a variety of interests. He loved music, enjoyed attending concerts and had established friendships with others who attended his Day Service. He socialised regularly with his friends with support from Day Service staff.

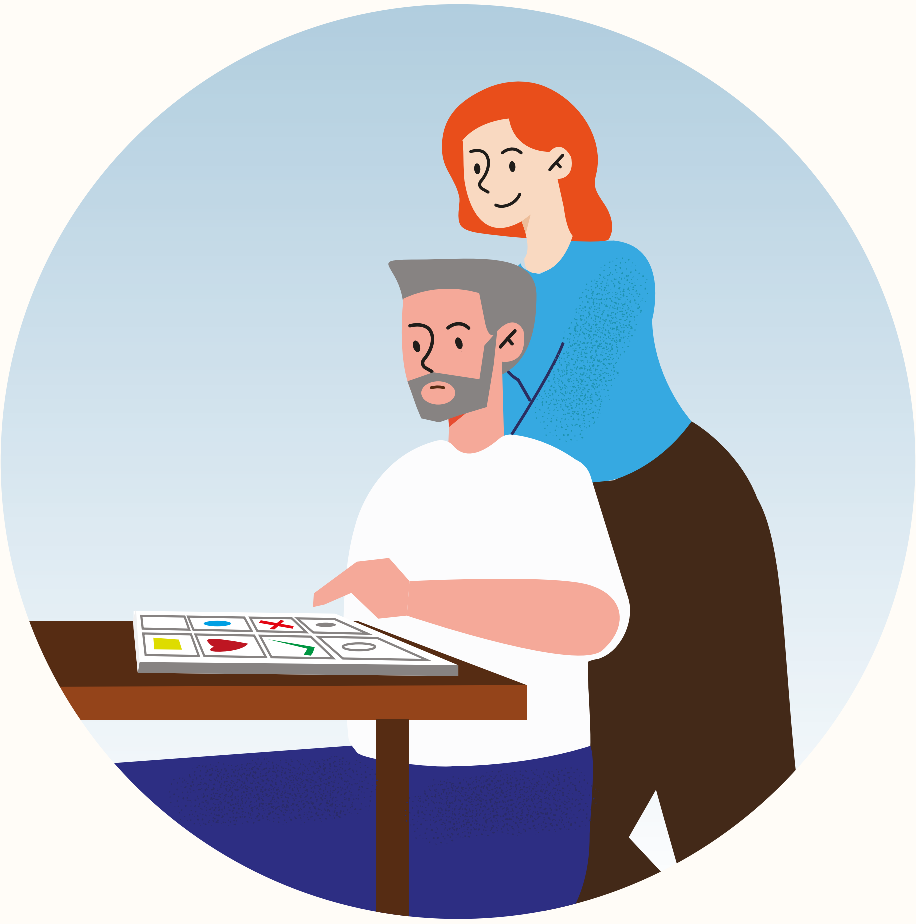
Staff regularly removed Kevin from volatile situations in the home which were upsetting to him, which meant he was isolated a great deal of the time. This led to a pattern of behaviour where Kevin was considered at risk, which impacted contact with his housemates. Kevin got along very well with two other people living in the house and the Advocate learned the incompatibility issues lay between two of his other peers.

Kevin's staff and wider circle of support in his home were very familiar with his communication style so it would significantly disadvantage Kevin were he to move to different accommodation. Kevin indicated he was happy to remain in his home if the behaviours/moods within the house improved. The Advocate supported Kevin to write a letter of complaint to local and senior management using key learnings gained through time spent with Kevin.

A meeting with all key stakeholders was arranged in Kevin's home. This ensured that everyone could see Kevin's home and see the impact their decisions would have on him. Kevin had the opportunity to participate as fully as possible in the meeting.

Outcome

Decisions, taken by others to ensure Kevin's safety, were now seen as limiting his quality of life. Kevin's SLT designed a communication book to improve communication with Kevin among services supporting Kevin. The Service Social Worker is now supporting residents to build their capacity to manage their own safety. The service is looking at alternative residential options for the three people, which will future proof Kevin's circle of peer support.



11. Supporting Adherence to the Assisted Decision-Making (Capacity) Act 2015

Background:

Tom is a 68-year-old man with early-stage dementia who lives independently in his home with assistance from home care services. Tom had always been clear that he wanted to maintain his independence for as long as possible. Tom's family were concerned about his ability to manage his finances and medical care. A family member wanted a Decision-Making Representative (DMR) to act on Tom's behalf for all decisions concerning his personal welfare and finances under the Assisted Decision-Making (Capacity) Act 2015 (ADM Act).

Tom's home care provider supported Tom to contact the National Advocacy Service (NAS) to ensure that his rights were upheld and to help Tom to understand his full range of options to enable him to maintain his autonomy and make his own decisions.

Actions by the Advocate

The NAS Advocate met with Tom to understand his wishes and needs. Tom was clear that he wanted to continue living as independently as possible and to retain decision-making control over his life, even if he needed some support. The Advocate explained the various options available to Tom under the ADM (Capacity) Act and helped him to understand the guiding principles of the Act, such as choosing the least restrictive option to respect his rights.

The Advocate provided information to Tom and explained that a Decision-Making Representative (DMR), would effectively remove Tom's decision-making rights and transfer them to another person. The Advocate encouraged Tom and his family to learn about less restrictive alternatives that would allow Tom to continue making decisions with support.

Adhering to the ADM Act's guiding principles, the Advocate encouraged Tom and his family to explore alternatives to a DMR. A Decision-Making Assistance Agreement would allow Tom to retain control over his decisions while also receiving the support he needed from a trusted individual, who could help him understand the information required to make decisions. In situations where Tom might need more intensive support, a Co-Decision-Making Agreement would be a better alternative to a DMR. A Co-Decision-Making Agreement would enable Tom to share decision-making responsibility with a trusted family member, whilst still retaining control and involvement over his decisions.

Over several meetings the Advocate worked with Tom and his family to ensure they understood the different options and how each might allow Tom to maintain as much independence as possible while receiving the support he needed.

Outcome:

Tom and his family recognised that a Decision-Making Representative was not necessary. Instead, Tom chose to set up a Decision-Making Assistance Agreement, where his brother would provide him with support for his financial and medical decisions. Tom told his Advocate that he felt this arrangement would allow him to stay in control of his life and ask for help to make informed choices when he needed it.

NAS ensured that Tom's rights were upheld in accordance with the ADM (Capacity) Act and that the least restrictive option was chosen, allowing him to maintain his independence and dignity. Tom's experience highlights the critical role the National Advocacy Service (NAS) plays in supporting individuals with disabilities to make decisions in line with the guiding principles of the Act. By advising on less restrictive options and ensuring adherence to the Act's guiding principles, NAS advocates empower individuals like Tom to retain autonomy and control over their own lives while receiving appropriate decision-making support.

12. Under 65 in Nursing Home

Context

Jacob is in his thirties and has an intellectual disability. A short stint in hospital after a breakdown in his semi-independent living arrangement has meant Jacob has been living in a nursing home for the past eight years. Jacob's move to the nursing home was supposed to be a temporary arrangement to allow him to recover from an illness but no further action had been completed by the relevant stakeholders to source more appropriate accommodation for Jacob since. Jacob has no family support in his locality. The nursing home supported Jacob to contact NAS as he expressed on many occasions his unhappiness at living in a nursing home.

Actions by the Advocate

The Advocate spent time getting to know Jacob to build a trusting relationship with him. With Jacob's consent, the Advocate gathered information from the nursing home staff, staff at Jacob's Day Service and from written reports to build a picture of Jacob's life and needs to date. Jacob and the Advocate developed an Advocacy plan; Jacob wanted to leave the nursing home and live independently in his local community with support.

Jacob was supported by his Advocate to write to key decision-makers in the HSE outlining his situation. A meeting was subsequently arranged with the HSE and his Disability Service provider where agreements were made to advance Jacob's wishes, but these did not materialise. With his Advocates help, Jacob submitted a complaint to the HSE under Your Service, Your Say complaints process but did not receive a response by the defined deadline.

Jacob's Advocate followed up on the complaint on Jacob's behalf and escalated the matter within the HSE. After much correspondence it transpired the complaint had been lost when it was assigned to the Complaints Department in another area. Jacob and his Advocate also completed the HSE Under 65 in Nursing Home survey together. Jacob was visited by the relevant HSE team to discuss his wishes to live elsewhere but again because Jacob wishes to live in a different area to where his nursing home is located the matter was transferred to another team and was not acted upon.

Jacob's Advocate supported Jacob to write to the HSE and detail the unsatisfactory ways in which he has been dealt with by the HSE and the impact it had on him.

Outcome

Since escalating the issues, Jacob has received an apology from the HSE and there is now a staff member in the HSE assigned to support Jacob's move to his chosen community. Jacob is currently reviewing a number of options available to him and says he is much happier since NAS became involved.

13. Access to Finances

Context

NAS received an enquiry on behalf of Michelle who was unable to access her bank account. Michelle is a young person who resides in a nursing home following an accident and has no family available to support or assist her with her issue. Michelle had no access to her bank account and was unaware of her savings totals. Michelle did have access to her money which was held in her Patients Private Property Account (PPP) account through her service.

Actions by the Advocate

A NAS Advocate met with Michelle to explain the Advocacy process and discussed Michelle's wishes regarding her finances. The Advocate also gave Michelle a copy of the NAS My Money My Rights publication to help her to understand her rights. Together they agreed an Advocacy Plan.

Michelle's Advocate supported her to write to the bank requesting a statement on her account. The bank wrote back to Michelle and advised that her account was dormant. Michelle's Advocate supported her to liaise with the bank to reactivate her account which involved sending on a copy

of her birth certificate and passport for identification purposes. Michelle's account was reactivated, and she was able to see how much money she had in her account. The Advocate discussed with Michelle ways she would be able to access the account going forward. Unfortunately, Michelle had no one to take her to the bank and due to dexterity issues, Michelle was unable to use an ATM card or an ATM machine. Her Advocate helped Michelle to understand her options of keeping the account open or having all her finances moved to her PPP account.

During their time together Michelle and her Advocate spoke about her life before the nursing home. Michelle had enjoyed an active lifestyle in her community doing various things she enjoyed prior to moving there. Michelle now understood she had money to employ her own Personal Assistant (PA) who could help her re-engage with her community and hobbies. The Advocate helped Michelle understand her right to spend her money on herself or as she chooses. Michelle discussed ideas like changing the décor of her bedroom and was eager to go out again for walks, lunches and concerts. Her Advocate contacted a PA service to get information for Michelle.

Michelle employed a private PA for a time, and as a result could access activities and events in her local community. However, Michelle has been without a PA recently due to PA staff shortages. Her Advocate continues to work with Michelle and the relevant service provider on this issue.

Outcome

As a result of NAS Advocacy, Michelle's voice was heard and listened to by the relevant services. Michelle now has a better understanding of her money rights. Through the advocacy process, Michelle's bank account was reactivated. Although Michelle now has access to her bank account, Michelle is unable to use an ATM card, an ATM machine or online banking due to dexterity issues and Michelle is unable to travel to the bank to access her money as she has no PA at present. NAS support is ongoing.

14. Decision Making

Context

Jack is in his mid-fifties and has an intellectual disability. He lives with family and attends a Day Service. Jack has a keyworker in his Day Service who supported him to contact NAS for support with decision-making and an issues arising in relation to an upcoming outpatient surgery procedure in hospital.

Actions by Advocate

During the initial meeting with his Advocate, Jack shared a letter sent from his consultant to a member of his family. The letter confirmed that Jack's family member was happy for the surgery to go ahead and asked the family member to sign the consent form, "as Jack's next-of-kin", advising the family member to attend hospital with Jack on the day of the surgery. Jack told his Advocate he did not understand why his family member had to sign the consent form for him and attend hospital with him. All the information on the surgery procedure was sent directly to Jack's family member, and not to Jack completely excluding him from the decision-making process. The approach was not in keeping with the guiding principles of the Assisted Decision-Making Act to presume that every person has the capacity to make decisions about their life.

Jack and his Advocate agreed an advocacy plan to work on resolving the issue. The Advocate explained Jack's rights around consent, specifically in relation to consent to medical procedures and together they reviewed the HSE National Consent Policy. Jack said he wanted to sign his own consent form and did not want his family member to support him on the day of surgery. Jack agreed for the Advocate to follow up with his consultant directly to discuss consent and Jack's rights.

With the support of his Advocate, Jack contacted his consultant's office and left messages requesting a callback. When there was no response, Jack was supported by his Advocate to write to the consultant outlining the issue with the consent process, and Jack's rights in relation to consent. Jack stated his family member has no legal authority to consent to his surgery, and that he did not want his family member to attend on the day of surgery.

The Advocate encouraged Jack's keyworker to support him to follow up with the Consultant's office when no response was provided. The keyworker received a call back from a nurse confirming that Jack would sign his own consent form on the day of the surgery. The Advocate provided Jack and his keyworker with easy-to-read resources on the procedure, and videos explaining the procedure and recovery. Jack watched the videos on his iPad.

Outcome

Jack attended hospital on the day of his surgery and a nurse went through the consent form with him. Jack was fully informed of the procedure and what to expect and was able to ask questions to the admission nurse. This enabled Jack to give his informed consent to the surgery and he was then able to sign his own consent forms.

15. Coercive Control and Safeguarding

Context

Patricia is in her late fifties and has an intellectual disability. Patricia had always lived independently. However, when she became ill, a relative started controlling her life against her will and preference. Patricia was renting a house from the relative and the relative managed the heating, television channels, and Patricia's medical appointments. Family members were prohibited by the relative from visiting Patricia in the hospital and subsequently, in her home. Patricia was paying the bills but did not have access to the statements and could not regulate the temperature in the house. The relative would come into the house uninvited, often when Patricia was at her Day Service to open and read her mail or move her possessions. The relative started corresponding with Patricia's GP and her Day Service on behalf of Patricia. They would not inform Patricia when she had a medical appointment or would inform her at the last minute, to try to prove that she was incapable of managing her life without them. The relative threatened to lock Patricia out of the house or put her into care if she did not comply with their demands. The relative never had any legal authority over Patricia as an adult, but self-identified as her carer.

Actions by the Advocate

The Advocate met with Patricia and got to know her and what was important in her life. Patricia said she would like to be able to live her own life without fear or interference. She detailed emotional and psychological abuse, which included deprivation of contact, humiliation, blame, control, coercion, isolation, and being blocked from services or supportive networks by her relative over a long period.

The Advocate supported Patricia in alerting the HSE Safeguarding and Protection team and the Gardaí to the psychological and physical abuse and was with her throughout the investigation process. The Advocate helped Patricia to contact her GP and her Day Service to assert her rights as an adult. Patricia requested that all services corresponded with her and not her relative. With the help of her Advocate, Patricia wrote to the Residential Tenancy Board to detail the deficits within the house, including the landlord accessing the house without her consent. Patricia and her Advocate researched and applied for alternative housing supports. Patricia was also helped by NAS to write to services to seek recompense for bills she had overpaid and was subsequently reimbursed for all outstanding payments.

Outcome:

Patricia was offered and accepted an apartment in a new complex. Patricia now has full control over her life and understands her rights. She attends a Day Service and is involved in her new community. Patricia does not have a relationship with her relative. She can invite friends and family to her apartment without fear or judgement. Patricia knows that if she requires support in the future NAS will be there for her.

16. Family and Relationships

Context

Mick is in his forties and has an Acquired Brain Injury (ABI). He was referred to NAS by his outreach service worker. Mick had divorced from his partner a few years previously but said he did not feel he had appropriate support from his legal team throughout the process. During the initial divorce settlement, he was provided with no support and told the Advocate that as a result he had signed a settlement that he did not understand. Mick is currently engaged in a review of his divorce agreement to adjust the terms in relation to assets and the care of their children.

Actions by Advocate

Mick told his Advocate he felt overwhelmed and revealed that he did not understand the legal process. Mick was worried about being without support in talks and alone in court due to his previous experience of the divorce agreement. Mick's main support was a neighbour who would be unable to help him due to the in-camera rule in family court.

Mick had engaged a legal team and a barrister. Mick's Advocate supported him to understand his right to parent, his right to request information from the court and informed his legal team that all information should be communicated in a format that he could best understand
Mick was afraid that his disability could be used against him in relation to access rights to his children.

With the help of his Advocate, Mick communicated his concerns to his legal team. His Advocate also worked with Mick to help him understand the proposals being explored and how they may impact him going forward. Mick felt empowered to instruct his legal team in line with his wishes with the help of his Advocate.

Working together with his Advocate, Mick built his confidence and understanding of the process. He felt able to ask questions throughout the process and to clearly state what he wanted his legal team to request.

Outcome

The Advocate empowered Mick to fully understand his rights and he was supported to direct his own legal team throughout the process. With the help of his Advocate, Mick was supported to meaningfully engage in mediation at an equal level to his ex-partner which, he said, was not the case during his initial separation. With the support of the Advocate, Mick built his confidence, he successfully engaged in the mediation and settlement process and both parties reached an agreement. Mick was thankful to his Advocate for their work with him and said he will come back to NAS if issues arise for him in the future.

17. Assisted Decision-Making

Context

Jessica is in her early forties and had an acquired brain injury following a road traffic accident. After initial treatment in Hospital, she moved to a nursing home awaiting rehabilitation. Jessica had no family in Ireland to provide care and support to her as she was originally from overseas. On her admittance to a rehabilitation facility, discussions were had with Jessica and her family about her future. Jessica wanted to stay in Ireland. The clinical staff working with her believed she needed support in making decisions about her finances and personal care and made an application for a Decision-Making Representative (DMR) to the Circuit Court. Her service supported her to submit an enquiry to NAS to support Jessica outlining her will and preference in the Court process.

Actions By Advocate

Jessica had limited English, so her NAS Advocate secured an interpreter for all meetings. Jessica also communicated through signs, a communication board and facial expressions. Her NAS Advocate ensured the same interpreter supported Jessica in all their meetings so that trust could be built between Jessica and her Advocate.

Jessica asked her Advocate to help her to communicate to her family and others who she would like to support her with decision making and to assist her explore her future living options.

Jessica did not wish to return to the Nursing Home, however the Nursing Home had control of Jessica's money from the time she transferred there from hospital. The Nursing Home was appointed as her Agent to receive her Department of Social Protection payments. Jessica's Advocate supported her to outline that she wished to have control of her own finances and to set out her wishes for future living plans to the hospital and to the Court.

Jessica asked her Advocate to speak with her family about NAS Representative Advocacy. When her family visited Jessica in Ireland, NAS set up meetings and translation services to explain the Assisted Decision-Making Act, the role of the Advocate and Jessica's wishes to her family.

Jessica's Advocate supported her at transition planning meetings, with disability support providers, with her Legal Aid Board Solicitor and to attend the Court hearing in person with appropriate interpreters and personal assistance. The NAS Advocate ensured Jessica was supported to understand what was happening in the Court process and to have her voice heard in Court.

Outcome

An order was made by the Court appointing a DMR from the Panel of Representatives. A disability support service was commissioned to help Jessica to move to suitable housing based in the community. Jessica's Advocate attended all subsequent planning meetings and informed the disability service and the Decision-Making Representative about the work previously completed. Jessica's right to access her own money held by the Nursing Home was also addressed The NAS Advocate supported Jessica to voice her will and preference to her appointed decision supporter as outlined in the Decision Support Service Code of Practice for Independent Advocates.

National Advocacy Service
For people with disabilities

Patient Advocacy Service
INFORMATION | SUPPORT | EMPOWERMENT

NAS is funded & supported by the
Citizens Information Board

The Patient Advocacy Service is funded and
supported by the Department ol Health

Citizens **Information** Board
information · advice · advocacy

An Roinn Sláinte
Department of Health

National Advocacy Service (NAS) for People with Disabilities
& Patient Advocacy Service
Level 3 Rear Unit
Marshalsea Court
Merchants Quay,
Dublin DO8 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