



National Advocacy Service for People with Disabilities Casebook



2023



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

Spotlight on Finances

1. Finances and Access to Identification	5
2. Finance and Decision Making	7
3. Digital Exclusion in The Banking Sector	9
4. Third Party Control of Finances	10
5. Property Rights	11

NAS Case Studies

6. Accommodation and Capacity Building	12
7. Capacity Building and Complaints	14
8. Home Support Hours	16
9. Health - Under 65 in a Nursing Home	18
10. Family and Relationships	20
11. Parenting with a Disability	22
12. Safeguarding and Housing	24
13. Residential and Healthcare Settings	26
14. Social Care	28
15. Residential Choices	30
16. Capacity Building	32
17. Access to Justice	34
18. Healthcare Settings	36

Foreword



Welcome to our second annual Casebook. This publication contains a selection of the many advocacy interventions worked on over the past year by the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service.

When we released our first Casebook in 2022, we wanted to share the important work carried out by NAS and The Patient Advocacy Service. Influenced by its success and the positive feedback we have received, the Casebook has now become an annual publication.

The Casebook provides a snapshot into the work of both services and provides 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 independent advocacy services in Ireland and the many issues supported by both NAS and The Patient Advocacy Service.

The 2023 Casebook also includes a collection of 'Access to Finance' cases from NAS, which highlight the growth in advocacy issues relating to financial autonomy. These cases are part of a larger body of work carried out by NAS in 2023, including a social policy paper entitled: 'Examining the Barriers to Equal Access to Finances for People with Disabilities in line with their Human Rights', which will be published at a later date.

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 about their care in a Public Acute Hospital or a Nursing Home. The service also offers support to people in the aftermath of a Patient Safety Incident.

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 relating to parenting with a disability, housing, healthcare, and much more.

In April 2023, The Assisted Decision-Making (Capacity) Act 2015 (ADMCA) commenced. The Act aims to achieve key reforms including the abolition of the wards of court system for adults. A core principle of the Act is the presumption that everyone has capacity until proven otherwise. Equally, a person should be fully supported to make their own decisions as far as is possible, emphasising that a person's will and preferences must be considered at all times. Such principles underpin the work of Independent Advocates and while we only touch on the Act in this year's Casebook, it is an area that will develop further in the coming years.

I hope that these case examples provide rich insight into what our Services do, highlighting the importance of independent advocacy, showcasing the positive impact we have had 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 either NAS or the Patient Advocacy Service in 2023. I wish to extend my thanks to 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.

Spotlight on Access to Finances:

NAS has seen a significant growth in advocacy issues relating to financial autonomy in its overall work. This section places a specific emphasis on the widespread social policy issue of 'Access to Finances' for people with disabilities. This focus incorporates various strands of work, including the production of a Social Policy Research paper entitled: 'Examining the Barriers to Equal Access to Finances for People with Disabilities in line with their Human Rights', the production of an Easy-to-Read booklet that supports people to understand their rights when it comes to their money and participation in a Banking Roundtable event to generate potential solutions to overcome barriers.

This year's Casebook spotlights a collection of 'Access to Finance' case examples to demonstrate the types of issues those we support face in trying to access and manage their money. In some cases, people had been completely excluded from accessing their own finances. In other situations, people were provided with an allowance, limiting their autonomy and life choices. People can face challenges with banking and digital exclusion, may experience control of their finances by others and may even experience financial abuse. The trend of issues emerging are consistent across Ireland and NAS has been contacted by numerous people, their families and services calling for major change and progress on this issue. In addition, the ADMCA now places an onus on all of society to treat people with disabilities equally.

The following collection of financial case studies reveals the extent of this issue and showcase the positive impact that Independent Advocacy has had and can have for those experiencing such challenges.



1. Finances and Access to Identification



Context:

Janet rang the NAS National Phone Line to say that she had poor mobility for a variety of reasons and significant mental health difficulties so was unable to leave the family home. Janet was struggling to change her bank account to another bank as she did not have a driving licence and had never had a passport.

Janet's existing bank account had been queued for closure in January 2023. She understood that any direct debits, standing orders and payments, including Social Welfare and Disability Allowance, would not be paid into her account and would be returned after that date. She was finding the switch to a new bank very stressful, and it was impacting her mental health as she also had no natural supports. Janet also wanted to obtain a Public Services Card which would help her access services online. She had previously contacted the Department of Social Protection to request a Public Services Card meeting online on grounds of reasonable accommodation, but this request was declined.



Actions by the Advocate:

Janet and her Advocate agreed on a plan to address the issues and the Advocate contacted the Department of Social Protection to inform them of Janet's access needs and inability to leave her home. The Advocate discussed the rights of a disabled person to have reasonable accommodation when requesting official documentation from a Public Body and asked that the Department support Janet accordingly.

The Department responded that the Standard Authentication Framework Environment (SAFE) registration process, which they use to authenticate and then issue customers with a Public Services Card, is usually carried out in the Department's public offices. However, local offices can facilitate appointments where customers find it difficult to attend the office as each Intreo office is equipped with a mobile unit. Decisions on the mobile service are made by local management on a case-by-case basis.

The Advocate supported Janet to contact her local Intreo office to request a home appointment. Janet was supported by her Advocate to write out her request prior to making the phone call and to anticipate the Intreo Local Manager's questions in advance. Intreo visited Janet in her home, and she was issued with a Public Services Card in thirty minutes.

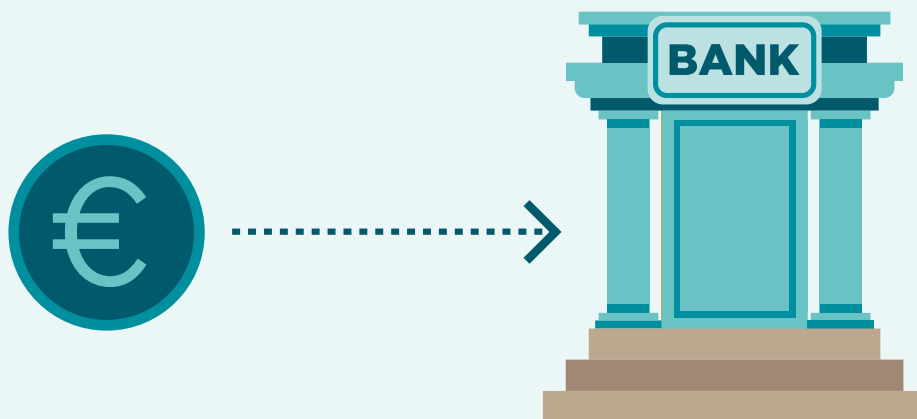
The Advocate discussed the steps to obtain an Irish Passport with Janet who stated that she would be unable to attend the Garda station in person for the formal identification process. The Advocate contacted the Garda station on Janet's behalf and discussed the context of her request. Gardaí visited Janet's home to confirm her identity on her Identity Verification Form and on her passport photos. Janet processed her passport application online and was delighted to receive her Passport some weeks later.

The Advocate advised Janet on the role of the 'Vulnerable Customer's Unit' in Financial Institutions as she had been unaware of enhanced supports to customers in certain circumstances. Her local bank branch was inaccessible and did not respond to requests to help her open an account. The Advocate sent Janet the contact details for 'Vulnerable Customer's Units' in several banks. With the support of her Advocate, Janet contacted a bank of her choosing and discussed her requirement to switch her current bank account. At this point, Janet had the necessary identification to open her new current account. All of this was completed online without Janet having to attend a branch in person and the bank staff understood that Janet was nervous in dealing with them and provided her with support.



Outcome:

Janet was able to open a bank account, transfer all her direct debits and receive her social welfare payments into her new account. Janet also received her passport. She was grateful to NAS for their support and knows that she can ask for help at any point in the future should new issues arise.



2. Finance and Decision Making



Context:

Joe is in his mid-fifties and has an intellectual disability. Joe had been living with his parents until recently and his family had always managed his finances. They continued to do so when he moved into his new home in the community, which meant Joe had limited access to his own money. This was impacting on his choices and quality of life. Joe was supported by staff in his new home to make a referral to NAS.



Actions by the Advocate:

The Advocate met Joe in his home and spent time with him. The Advocate learned that Joe enjoyed sports and speaking about the teams he supported. Joe told his Advocate he was saving for a hat and scarf from his favourite club team.

Joe said he had noticed all the choices other people had when he moved to his new home and that he did not have the same choices because he had very little spending money. This meant he could not afford to go out with friends for a social evening. Joe also told the Advocate that staff in his service bought him tickets for local matches because he could not afford to.

The Advocate listened to Joe in detail and understood that Joe's will and preference was to have the same access to his money as the other people he lived with. The Advocate and Joe agreed an advocacy plan to support him to achieve this outcome.

Joe was supported by his Advocate in meetings with his family, during which, the Advocate established that Joe was in receipt of Disability Allowance and a second monthly income from a Trust Fund. Joe's family were appointed as his agent with the Department of Social Protection and collected his Disability Allowance. His family confirmed there was a joint bank account in his name, into which they deposited the balance of his Disability Allowance after his Long Stay charges and pocket money are paid. Joe's family said they bought birthday and Christmas presents for family members on his behalf.

Joe had been unaware of any of this information and had not given his consent to the arrangements his family had put in place. Joe's family explained they did not trust anyone else to look after his money and suggested increasing his pocket money by €5 a week.

During the meeting, the Advocate learned that when Joe was awarded Disability Allowance, his family had not declared the Trust Fund income to the Department of Social Protection. The Advocate explained to his family that because of this Joe was at potential risk of an overpayment charge from the Department of Social Protection. The Advocate sign-posted Joe's family to Citizens Information Services and the Operational Guidelines for Means Tested Payments.

Joe's family were unhappy after the meeting and postponed several meetings arranged with Joe and the Advocate. Joe began to demonstrate a good understanding of money management skills and the Advocate suggested that he could be supported by his service provider's Financial Policy to manage his own money. The service provider reviewed their Financial Policy with Joe and his family. Despite this, Joe's family refused to recognise him as an adult with the autonomy, ability and supports available to manage his own finances.



Outcome:

The Advocate supported Joe to contact the Department of Social Protection and make his own preferred arrangement plan for his Disability Allowance payment. After a weekend visit at home, Joe returned with his bank card, pin number, and bank account statement. He was supported by his Service Provider to change the pin number and address on his account. Joe was also supported to seek legal advice on the additional payment. Since then, Joe has continued to develop his money management skills and now pays his own Long Stay charges, as well as purchasing tickets for local matches.



3. Digital Exclusion in The Banking Sector



Context:

Ciara has Cerebral Palsy and requires additional time to manage and use technological devices. Ciara sought the support of a NAS Advocate as she was unable to access her online banking due to the introduction of increased online security measures. These increased security measures timed out before Ciara was able to enter the required codes. Up to the introduction of these new security measures, Ciara independently accessed her own account and was distressed at losing autonomy in this important area of her life. She now needed to ask staff to support her when accessing her banking and did not want to have to rely on this option long term. Ciara informed the advocate that she felt her financial autonomy was gone as she had to rely on staff for the first time in her life around money matters.



Actions by the Advocate:

The Advocate and Ciara agreed on a plan to make Ciara's online banking accessible. The advocate wrote to Ciara's local Branch Manager and at Ciara's request called in to the branch in person to discuss Ciara's issue. The Bank Manager agreed to investigate the issue but neither Ciara nor her advocate heard back.

With Ciara's consent, the Advocate escalated the issue to the bank's internal complaints department. At the same time, the Advocate wrote to the Banking & Payments Federation of Ireland who put them in contact with a security specialist within the bank. After liaising with the security specialist, it was agreed that an SCA (Strong Customer Authentication) Exemption was required. This SCA exemption was explained to Ciara, who in turn, wished to apply for it.



Outcome:

Since this exemption, Ciara has now returned to independently accessing her online banking and is once again in control of managing her financial affairs.

4. Third Party Control of Finances



Context:

Joan lived with her family and attended a day service. She received €20 allowance each week for attending the day service and valued this money as it allowed her to have lunch in a local restaurant once a week. Staff in her day service discussed with Joan that she could eat out more often by using her Disability Allowance, however Joan was not sure where this money went or how much she was even receiving.



Actions by the Advocate:

The Advocate worked with Joan to agree a plan to meet with her family to learn more about her money. In preparation for this meeting the Advocate supported Joan to learn more about what she was entitled to.

As Joan loved music, the Advocate and Joan called a meeting to initially discuss Joan's goal of saving money from her Disability Allowance to enable her to attend a concert. The Advocate was aware that initially it would be easier for Joan to have something to work towards. Joan asked the Advocate not to address the issue of financial control with her family in order to maintain her relationship with her family as these were important to her.

While the meeting started off with Joan and the Advocate working towards Joan's wish to save for a concert ticket, as the meeting progressed, family expressed dissatisfaction at exploring this issue citing the cost of supporting Joan at home, saying there were unseen costs.

Joan informed the Advocate that she did not want to upset her family and no longer wanted to pursue this option.



Outcome:

The Advocate discussed Joan's rights with her and made her aware of the role of the Safeguarding and Protection Team and supports available. The Advocate respected Joan's wish not to progress the issue and assured her she could come back to NAS at any point in the future if she needed support. This example demonstrates the level of resistance and pressure that people often face in trying to exercise their financial autonomy.

5. Property Rights



Context:

Susan is in her mid-fifties and has a mild intellectual disability. She has been in a registered service for decades, but is unaware of her financial position or her property rights. The service suspects that she may have some entitlement to the family home, and an amount of money, but have not sought this information from Susan.



Actions by the Advocate:

The Advocate raised this issue when the service asked the Advocate to support Susan to make a will. The service told the Advocate that although they were communicating with the family, they had not relayed any information to Susan about these conversations. At her request, the Advocate engaged with the service provider, to initiate Susan's inclusion in these discussions.

Following this, the Advocate queried why nothing had been undertaken by the service to support Susan in understanding the wider responsibilities of owning property, her rights and entitlements, and why this was only being implemented through the intervention of an Advocate.



Outcome:

The service agreed to include Susan in the discussions they were having with her parents and provided some capacity building work so that Susan had as much information as possible to make informed decisions.



6. Accommodation and Capacity Building



Context:

Georgie is in his thirties and was hospitalised in a mental health unit in his local hospital. Although Georgie was discharged, he was unable to return home. Georgie, alongside his services and support workers, agreed that his home situation was inappropriate, and funding was sought for a residential placement. Georgie required the support of an Advocate to articulate himself and explain the impact the situation was having on him.



Actions by the Advocate:

Georgie wanted a residential placement with appropriate supports in the community. The Advocate spent significant amounts of time with Georgie to build a trusting relationship and develop an understanding of his preferred communication style. This enabled Georgie to express his wishes and concerns to the Advocate.

The Advocate listened to and observed Georgie's communication using internationally recognised approaches to non-instructed advocacy, including human rights and ordinary life principals, witness-observer and a person-centred approach. The Advocate spent time with Georgie and his supporters in a setting that was familiar to Georgie, which enabled a better understanding of Georgie's situation.

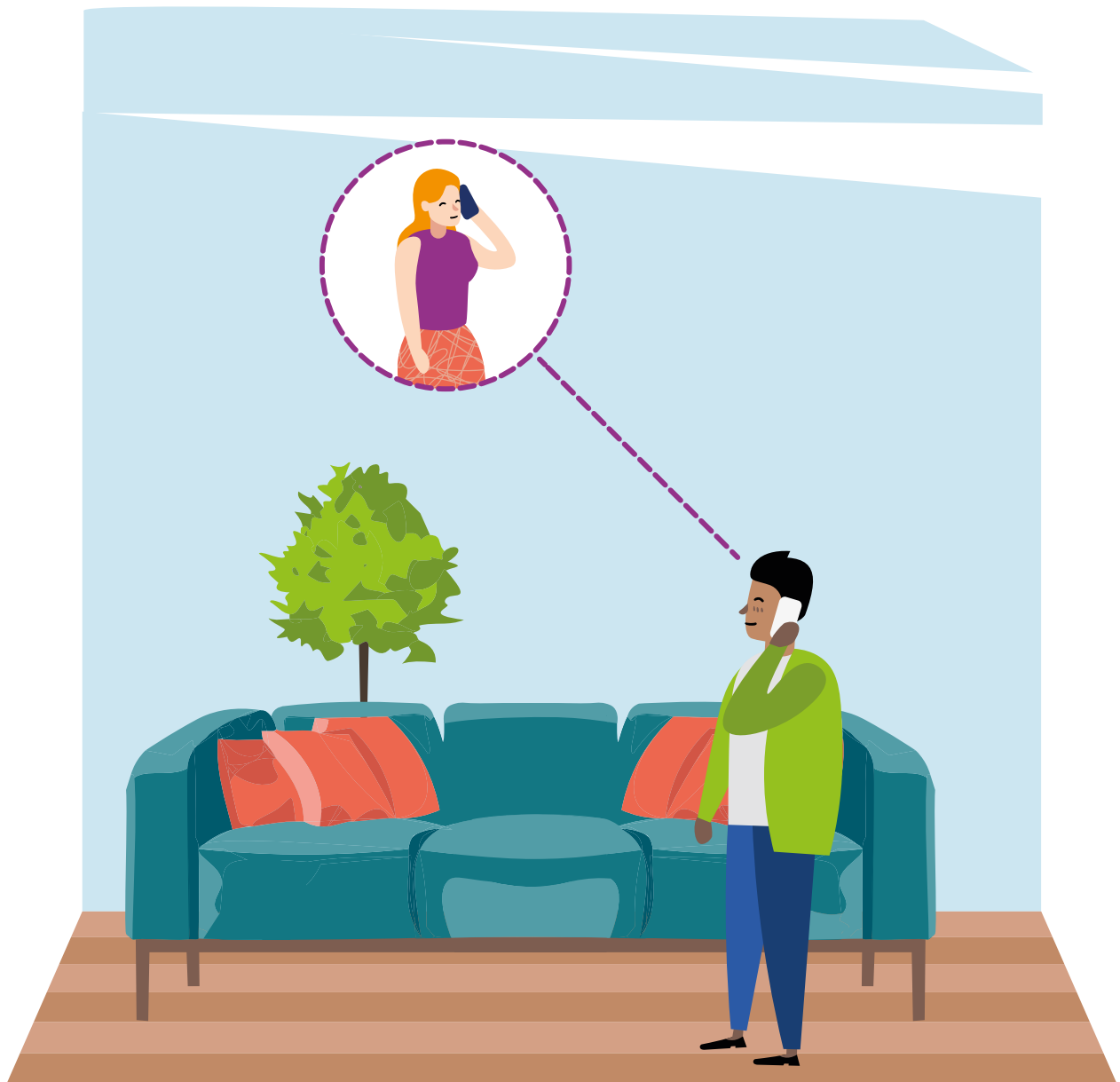
The Advocate supported Georgie to write to Senior Management at the HSE Disability Service in his own words describing how he felt about where he lived. Georgie described feeling isolated from supporters and usual community activities. He wanted answers and expressed his wishes in relation to his future home.

With Georgie's consent, the Advocate made a complaint to the HSE and raised a complaint with the Mental Health Commission. The Advocate liaised with HSE Disability Service, the mental health team and the community service provider team to ensure Georgie's wishes were known.



Outcome:

Georgie moved into his own home and is supported on an on-going basis by a multi-disciplinary team and is an active member in his local community. Georgie told the Advocate he was really pleased in his new home.



7. Capacity Building and Complaints



Context:

Michael has a physical disability and lives alone in a rural location. He has limited natural supports and is isolated from his local community. Michael requires support to live independently. He also needs help co-ordinating his care needs and to engage in meaningful activities locally. As a result, he contacted NAS requesting support from an Advocate.



Actions by the Advocate:

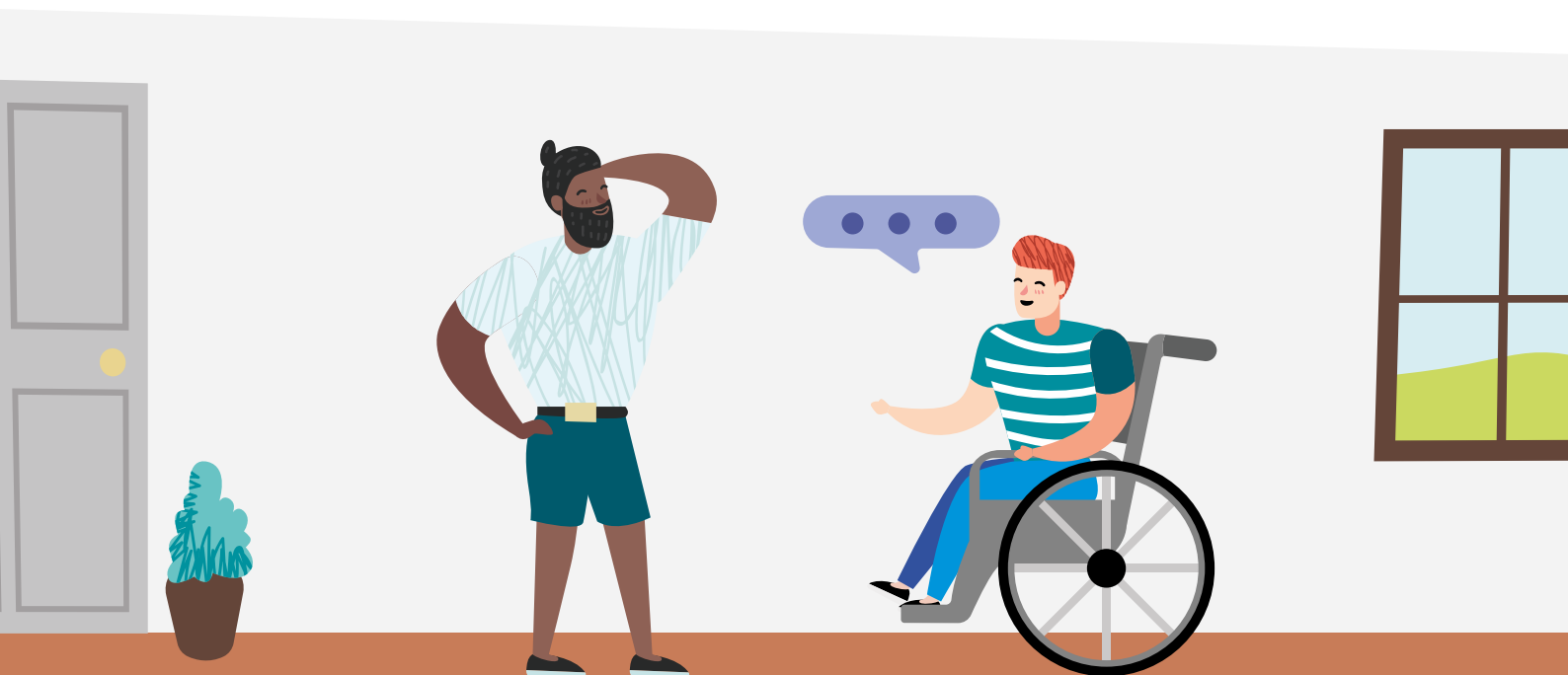
The Advocate explained to Michael that the community-based HSE Disability Service might be able to provide support to help him live independently. Over a period of months, the Advocate helped Michael to apply for support from his local HSE service provider and to gather relevant medical documentation for his application. The service provider subsequently advised Michael that his application was unsuccessful, outlining that he did not meet the HSE's eligibility criteria. Michael was unhappy with the outcome and wanted to appeal the decision. With support from his Advocate, Michael submitted updated medical information to appeal the decision, but his appeal was not upheld by the HSE.

The outcome was extremely disappointing for Michael as he strongly believed that he met the eligibility criteria as outlined by HSE Disability Service. Michael's Advocate explained to him that he could make a complaint to the Office of the Ombudsman. The Advocate outlined the complaints process and provided information on what to include with the complaint. Following this, Michael decided he wanted to go ahead with the complaint. He told the Advocate that their support and guidance in making the initial application and appeal to the HSE made him feel empowered to complete the Ombudsman complaint form. With light support from the Advocate, Michael wrote to the Ombudsman outlining his complaint.



Outcome:

Michael's complaint was upheld by the Ombudsman, after which he was contacted by the HSE. They advised him that he would receive support from his local HSE Disability Service. Michael was delighted with the support he received from his Advocate. Michael is hopeful that the new supports will ensure his ongoing care needs are met, and that he can continue to live independently, as well as play an active role in his local community.



8. Home Support Hours



Context:

Jim is in his mid-forties and has an Acquired Brain Injury (ABI) and limb amputations following an accident. Jim spent time in hospital and when he was discharged, he was admitted to a nursing home as his home was inaccessible. He was supported by his family to apply for social housing and while waiting for accessible housing, Jim was supported to return to his family home. Jim was subsequently offered an accessible apartment by his local authority. However, due to a delay from HSE Community Services in the package of care that Jim required to live independently, he could not take up the tenancy.



Actions by the Advocate:

The Advocate met with Jim to discuss his concerns. The Advocate took time to explain the advocacy process to Jim and reassured him that they would work at his pace and only with his consent. Jim expressed his appreciation for the respect he was shown. An advocacy plan was agreed to support Jim to access supports to regain independent living skills and access social protection entitlements.

Jim was assisted by his Advocate to gather information, including his hospital discharge plan and needs assessment, which identified his need for 40 hours Personal Assistance support to live independently in the community. The Advocate also supported Jim in meetings with the HSE Disability Service. The HSE Disability Service had assessed Jim's support needs at an insufficient number of hours stating he would have developed functional skills in the years following his accident. The Advocate supported Jim to explain that as his family had provided all of his care needs apart from personal care since his accident, he would have to relearn and regain the skills necessary for independent living.

Jim was supported by the Advocate to link in with a local ABI service for support with independent living and to help manage his short-term memory loss. The ABI team carried out a needs assessment and made several proposals to support Jim to regain his independence. The ABI service agreed to provide weekly support to help Jim rebuild his independent living skills.

The Advocate assisted in dialogue between the HSE Disability Service and the ABI service. The HSE Disability Service re-evaluated their earlier decision on Jim's needs with the additional information they received through the advocacy process and increased their support provision. Jim now had sufficient and appropriate support to be able to live independently.

The Advocate supported Jim to evaluate his financial status, ensuring he was informed of all entitlements and additional supports that he could apply for through the Department of Social Protection. These included the Additional Needs Payment, Living Alone Increase, Household Benefits Package, Fuel Allowance and Telephone Support Allowance.

A Neuropsychologist in the ABI service assessed Jim and suggested a specific communication tool to aid Jim's short-term memory. This helped Jim, for example, to manage his rent and other household bills. It also ensured Jim was supported to attend appointments and meetings with friends, which improved his social connections.



Outcome:

The Advocate's work with Jim increased awareness across the stakeholders of the value of NAS' Independent Advocacy model and enhanced the willingness of services to work co-operatively. Jim's experience of working with the Advocate supported an improved person-centred approach with services in relation to problem resolution and the development of stronger working relationships in the interests of the person.

From a Social Policy perspective, NAS identified that access to Personal Assistant support can be inconsistent and inadequate because of a lack of implementation of the 2021 National Service Plan, which includes provision for an additional 40,000 Personal Assistant hours, with a total target of 1.74 million hours to support people with a disability to live self-directed lives.



9. Health - Under 65 in a Nursing Home



Context:

Gerard is in his twenties and communicates differently. He is living with his parents while studying to become a teacher. A few years back, Gerard contracted a rare condition that affected him physically and cognitively. As a result, his medical team advised that he would need support with all daily activities for the rest of his life.

Gerard spent some time in his local regional hospital while he waited for rehabilitation support. His Medical Social Worker made an enquiry to NAS as Gerard had many life decisions to make following his illness. The Social Worker suggested an Independent Advocate to ensure Gerard's will and preference would be central to all decisions around his future.



Actions by the Advocate:

The Advocate spent time getting to know Gerard and met him several times in his local hospital and rehabilitation services. The Advocate gathered information about Gerard from people who knew him best, to build a picture of his values, beliefs and will and preferences. Regular contact with family and friends was important to Gerard and he wanted to live close to his family after his discharge from hospital.

Gerard was supported by the Advocate at multi-disciplinary team meetings with his medical team where it was recommended that he would benefit from specialist neuro rehabilitation. The Advocate ensured Gerard had appropriate information to decide where he would receive neuro rehabilitation. The Advocate provided information in ways he would understand and gave him adequate time to consider his options before reaching a final decision. Gerard chose to move on a temporary basis to a nursing home with a specialist brain injury unit.

The Advocate met with key decision-makers regularly and supported them to secure funding for extra physiotherapy and occupational therapy services for Gerard while he resided in the nursing home. The Advocate also helped Gerard to request funding for a Personal Assistant who would take him on social outings from the nursing home.



Outcome:

The Office of the Ombudsman “Wasted Lives Report” highlighted experiences of persons under 65 years old living in nursing homes. One of the recommendations of the report was that funding be allocated in a pilot project to support people to move from nursing homes to a more appropriate residence of their choosing.

To support Gerard to avail of this pilot project, the Advocate wrote to the HSE and attended many meetings, highlighting Gerard’s will and preference, which were brought to the attention of key decision-makers. This resulted in a very positive outcome for Gerard as he was allocated funding under the pilot project. He now lives in a house near his family home, which is staffed to support him to live independently, and he can access his community whenever he wants. Gerard is proud of his new home and hosts his family and friends who visit him regularly.



10. Family and Relationships



Context:

Jane has an intellectual disability and mental health diagnosis. She was living in unsuitable accommodation and was worried she might be made homeless. Jane had recently experienced the death of a parent and there was a breakdown in the relationship with her family. She was unaware of her welfare entitlements and was not linked in with any support services. There were outstanding bills associated with the family home, which had been transferred to Jane leaving her in debt. Jane also believed that her family were excluding her from her rights and entitlements regarding the family's Estate.



Actions by the Advocate:

Jane told her Advocate that her family had attempted to exclude her from obtaining her full share of her parent's Estate. Jane required support with accessing social welfare, as well as housing, legal, disability and social supports. Jane's will and preference was to stay in the family home, but it was unsuitable to her needs so was deemed unsafe. Jane found accommodation in another area but wanted to return to her local community.

The Advocate worked with Jane to agree an advocacy plan centred around Jane's accommodation needs. The Advocate supported Jane with where she wanted to live and provided information on her financial and inheritance rights, including clarification on who was responsible for the family debts.

The Advocate helped Jane gather information on all the outstanding accounts and supported her to communicate with service providers. Jane discovered that most of the debt was already outstanding prior to her agreeing to transfer accounts into her name. The Advocate supported Jane to obtain records that showed she had already moved out of the home when some of the debt had accumulated.

The Advocate worked with Jane to explore applying for a transfer to new accommodation and to have the outstanding debts cancelled. Jane was also refunded money she had already paid towards the debts. The Advocate supported Jane to obtain Free Legal Aid and helped her to draft a letter to her parent's solicitor asking for information about her inheritance.

These actions resulted in Jane obtaining her rights to the equal share of her parent's Estate.

The Advocate helped Jane apply for and receive Disability Allowance, social welfare supports and a medical card, as well as enabling her to link in with a social worker and day service, who now support her with independent living skills.



Outcome:

After some reflection, Jane decided not to move house choosing instead to stay in her current home. Jane is enjoying living in her home, decorated to her taste, she has money to spend as she wishes and has no outstanding debt. Jane attends her day service and has made new friends and links in the community.



11. Parenting with a Disability



Context:

Elena, a young mother with an intellectual disability, was referred to NAS through her solicitor. Interim Care Order proceedings had been put in place as it was argued Elena was not meeting her child's needs. The solicitor knew Elena had an intellectual disability and was finding the legal process difficult to navigate. Her solicitor suggested NAS could help as she had already had a previous positive experience with the service.



Actions by the Advocate:

Elena told the Advocate she had been hiding her disability when dealing with Tusla- Child and Family Agency as she worried it would negatively impact her perceived ability to parent. Elena felt very left out of what was happening, and as a result, the service presumed she wasn't interested in being involved in conversations around her child. It turned out Elena had been finding it very difficult to keep up with the communications and was hesitant to ask questions or ask for additional information. Although Elena was aware of some of the issues that had been raised, she was still unclear about the details in the court application and of the concerns that had been identified. Elena told the Advocate that everything felt disconnected, and she was finding it hard to see a clear picture.

The Advocate helped Elena to build up an understanding of her rights, including her right to parent, her right to seek supports and her right to receive information in an accessible manner. The Advocate supported Elena to communicate her concerns to Tusla- Child and Family Agency who agreed to work with her and provide relevant supports.

Elena was also supported by the Advocate to break down the information in the court reports and associated documents. Once she had a better understanding of the issues, she then began planning how to address the mounting issues. The Advocate identified relevant services available to Elena and supported her to engage with a family support worker assigned to her through Tusla- Child and Family Agency.



Outcome:

As Elena's advocacy support with NAS progressed, her confidence grew. She told the Advocate she no longer felt the need to hide her disability, but instead felt empowered to ask for help. Elena worked hard to address the key areas of concern identified by the court and Tusla- Child and Family Agency. Once she resolved her financial issues and improved her housing conditions, the legal case against her was withdrawn and Elena's child remained with her. Elena thanked the Advocate for their support throughout the process and for helping her to understand her rights as a parent with a disability. She said she felt a sense of empowerment, and in the future, she would not be afraid to ask for help as she knew it was her right to do so.



12. Safeguarding and Housing



Context:

Mary has an intellectual disability and was referred to NAS with the support of her service provider. She had been living in the family home where she was the alleged victim of physical and emotional abuse. Supports available to her in the community were limited and applications made by Mary's service keyworker to increase her supports had stalled. Although Mary had been on the housing list for several years, she was told there was a substantial wait for single-person housing despite the noted safeguarding concerns.

During the pandemic, Mary became even more isolated in an environment where she felt vulnerable and afraid. Mary's place of work had closed and opportunities for her to leave her home became extremely limited. Covid-19 meant she was unable to access emergency accommodation as services were unavailable. As a result, Mary chose to remain in the family home with safeguards in place until appropriate housing and support could be sourced. By the time the NAS Advocate began work with her, Mary's situation had reached crisis point.



Actions by the Advocate:

The Advocate worked with Mary to identify the most urgent issues affecting her. They agreed to tackle her safeguarding situation, housing needs and find relevant supports. The Advocate supported Mary to raise her concerns in the safeguarding process, ensuring her views were taken into consideration, and her rights were upheld. The Advocate then worked with Mary to raise her concerns to all key stakeholders and supported Mary to complete applications as well as draft and submit letters or reports which outlined her will and preference. Additionally, the Advocate helped Mary draft and submit a letter to the Local Authority outlining her living arrangements and the impact it was having on her, as well as the risks and stressors she was experiencing. The letter enabled the Local Authority to understand how having a new home would make Mary feel safer and happier. She was supported by her Advocate in meetings with the Local Authority to self-advocate and represent her needs.

After months of engagement with the Local Authority by the Advocate, Mary received an offer of a home in a location she was very happy with, and additional support was approved by the service provider.



Outcome:

Mary is now happily living in her new home and has appropriate supports in place. She has discovered a love of cooking, and her quality of life has improved significantly, bringing with it lots of new opportunities. Mary no longer needs safeguarding supports as she is living a life free from abuse.

Mary has shown that with the right support in the right environment, anything is possible. Mary told her Advocate that she finally feels happy and safe.



13. Residential and Healthcare Settings



Context:

Anne communicates differently and lives in a residential disability service. She was referred to NAS by a concerned relative because she was spending most of her day strapped into her wheelchair. Anne had previously enjoyed the freedom to self-mobilise in her home. Her relative was concerned about restrictions being placed upon Anne's movement and her inability to engage in activities she previously enjoyed. Professionals advised that Anne wasn't physically able to self-mobilise anymore due to a decline in her physical health in recent years.



Actions by the Advocate:

The Advocate spent time with Anne to get to know her. The Advocate read through Anne's care plan and linked in with her circle of support for further information. It turned out Anne spent very little time outside of her home engaging with the local community or socially. Staff gave the reason that the bus could only carry one resident at a time, and this was in constant use by other residents. Anne's circle of support spoke about how she enjoyed being out of her wheelchair. The care plan detailed very few outings from home for Anne.

The Advocate attended several multi-disciplinary team meetings to ensure Anne's wish to be able to spend time out of the wheelchair was heard. After this, several trials were done to assess Anne's movement after which it was unfortunately determined that it was not medically safe for Anne to spend time out of her wheelchair.

The Advocate made a referral on behalf of Anne to the Human Rights Committee in relation to the lack of transport available for Anne to leave her home. The Advocate outlined how current transport arrangements were impacting Anne's quality of life as she rarely spent time engaging in meaningful activities outside of her home.



Outcome:

Anne's wishes were a central part of the decision-making process around her health. Ultimately, due to her complex medical needs, it was not possible for Anne to spend time out of her wheelchair. However, Anne now has greater access to the community and improved quality of life as her residential service received new transport that enables Anne to go out on a regular basis to enjoy local, everyday activities.



14. Social Care



Context:

Jamie is in his thirties and has lived at home with his parents all his life. Jamie communicates by using a small number of words. As his parents are getting older, Jamie was referred to NAS by his Social Worker as professionals working with him thought that Jamie should move into a residential service to best support his future needs.



Actions by the Advocate:

The Advocate spent several months getting to know Jamie and spent time with him both at home and in his day service. Using different person-centred approaches, the Advocate was able to gain an understanding of Jamie's likes and dislikes and how he spends his days. The Advocate spent time communicating with Jamie's family and support staff to gather more information and learn as much about Jamie as possible. Throughout the process, the Advocate encouraged all involved to keep Jamie at the centre of the process.

After some time, Jamie began a two-month trial at a house in the community to enable him to sample the option. The Advocate continued to meet with Jamie regularly at the new house. The Advocate observed through Jamie's verbal communication, his body language and his actions, both in the house and the day service, that he missed his family and wanted to return home.

After the two-month trial, a meeting was held to discuss a possible move for Jamie. The Advocate highlighted at the meeting that from their time getting to know Jamie, they believed that it was his will and preference to continue living in his family home. It was agreed by most of those present at the meeting that Jamie did not seem to want to leave his family home. The Advocate requested that alternative options be explored to best support Jamie. Eventually, it was agreed that monthly respite and a Personal Assistant working with Jamie for a few hours each week would be a good support to both Jamie and his family and more in keeping with Jamie's own will and preference.



Outcome:

With the support of the Advocate, Jamie returned to his family home and continues to live there with additional supports in place, such as respite and Personal Assistant hours. He is living a happy and fulfilled life, in the home of his choosing.



15. Residential Choices



Context:

Paddy is an older man who has lived in a residential service for over twenty years. Paddy contacted NAS as he was having difficulty accessing his upstairs bedroom due to declining physical health.



Actions by the Advocate:

The Advocate met with Paddy to discuss the issue and explore his wishes. As his physical health was deteriorating, Paddy explained that he felt he needed a bedroom on the ground floor as using the stairs to get to his bedroom was becoming a challenge. Despite this, he felt the service was not listening to him on this issue.

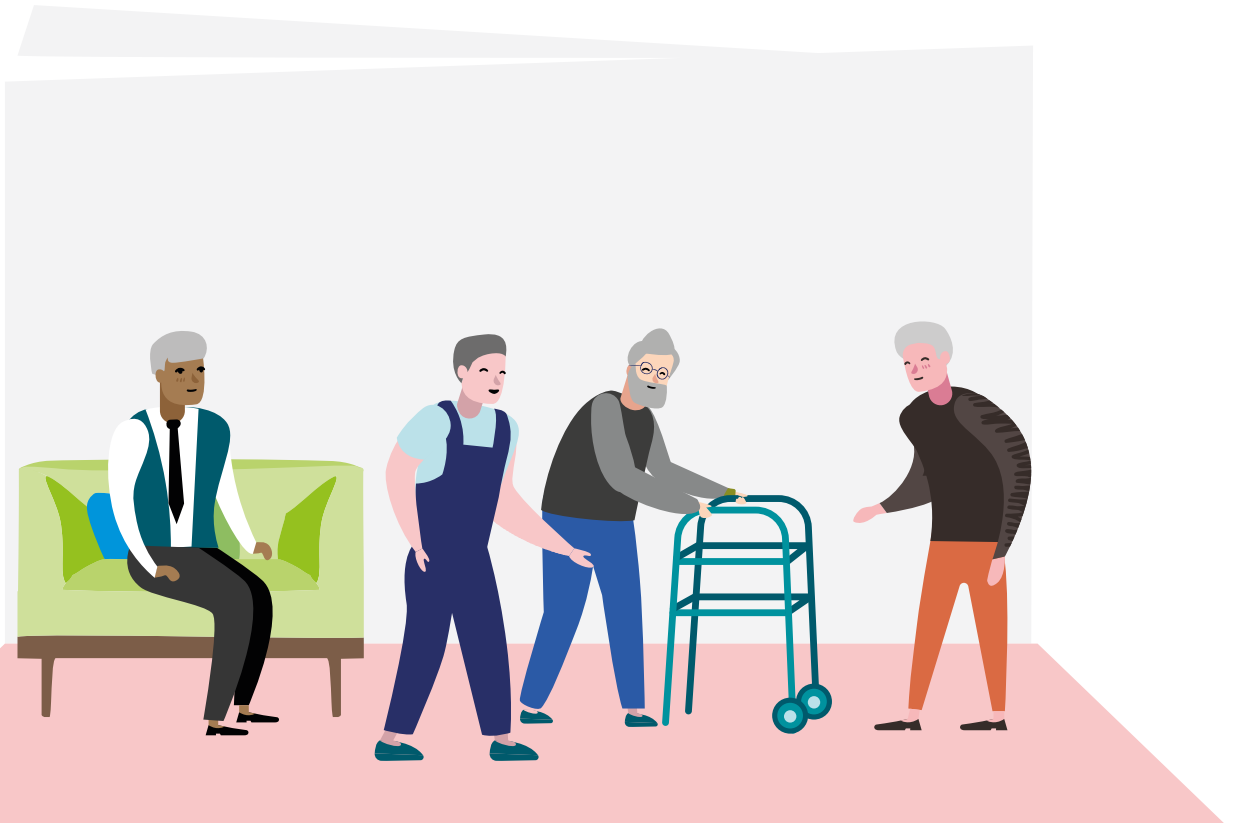
The Advocate supported Paddy to communicate his wishes to the Service Manager but was told that the two bedrooms on the ground floor were taken by two residents with mobility issues so it was not possible for him to move. The Advocate then asked for Paddy to be referred to an Occupational Therapist (O.T.) for an assessment. The O.T. concluded that with the right supports Paddy could still use the stairs. It was later confirmed that Paddy had arthritis in one of his knees which was causing him pain.

Despite a second O.T. assessment requested by the Advocate, the O.T. stated that Paddy should be able to access the stairs, with the right supports. As a follow-up, Paddy and his Advocate drafted a letter of complaint to the service detailing that Paddy felt he was not being listened to and his needs were not being met. Upon receiving the complaint, the service arranged to meet Paddy and his Advocate to let Paddy know there was a bedroom available in a house in a nearby town. The house was a bungalow with three other gentlemen living there, all of similar age. Paddy agreed to visit and complete a trial to see if he liked the house. The Advocate supported Paddy throughout the trial, ensuring that all his questions and queries were answered.



Outcome:

After a two-month trial period in the new house, Paddy agreed to move into the house on a permanent basis. Paddy has been living in the house for the last six months and is much happier there as his bedroom and bathroom are fully accessible and he is now also closer to his family. With the Advocate's support, Paddy was listened to by the service and together they were able to identify a way to meet his changing residential support needs.



16. Capacity Building



Context:

Sheila is in her fifties and was awaiting discharge from hospital following an accident. Based on her assessed needs, the only option offered to Sheila by the hospital was a nursing home. As Sheila was extremely independent prior to her accident, she strongly believed that with appropriate supports and further rehabilitation, she could make further progress and regain her mobility and strength. Sheila was aware that if she went to a nursing home, the supports and therapies she would need may not be available to her. Her family supported Sheila to contact NAS.



Actions by the Advocate:

Sheila told the Advocate she was unhappy about the decision-making process and expressed her fear of ending up in a nursing home. She was worried about the impact this would have on her emotionally, financially and on her quality of life. Sheila wanted to return home and felt her condition could improve with greater access to physiotherapy.

The Advocate supported Sheila to request a review of the decision to place her in a nursing home to Senior Management. While the decision of the multi-disciplinary team was not overturned, the Advocate supported Sheila to lodge a complaint on the decision-making process as Sheila felt it had not reflected the progress she had made to date.

The Advocate helped Sheila to self-advocate for appropriate home supports and additional community interventions, such as physiotherapy, which would facilitate Sheila's will and preference to live at home and further her rehabilitation and work towards regaining her mobility.

Throughout the process, the Advocate supported Sheila to have her views heard. The Advocate also supported her to navigate a formal complaints process and explore all appropriate options, including helping Sheila to identify options such as legal advice, request files and seek meetings with appropriate professionals.



Outcome:

With the support of the Advocate, Sheila moved home and in the following months, continued to avail of appropriate home supports and physiotherapy to continue her rehabilitation journey.



17. Access to Justice



Context:

Kathy is autistic and has an intellectual disability. She attended a disability day service who contacted NAS on her behalf for support as she was being charged with money laundering offences. Kathy had been approached by criminal parties online. She shared her private financial details and was deceived into also sharing her banking information. Kathy reported that the criminal elements, who she thought were her friends, used that information to launder a large amount of money. Before contacting NAS, Kathy had been interviewed by Gardaí and charged. She had accessed legal advice and was due to appear in court. No information had been presented about her disability and the background of the case to her solicitor.



Actions by the Advocate:

The Advocate met with Kathy and her keyworker to gather more details about the background of the case and provide Kathy with the supports she needed. With her consent, the Advocate contacted Kathy's solicitor to ask about the case and what was going to happen in court. The Advocate then relayed all the information to Kathy. The Advocate supported Kathy to meet her solicitor and barrister when the case was heard in court. Kathy was also prepped by her Advocate for court hearings to ensure she understood what would happen during the hearings. Kathy was very nervous and was finding it difficult to understand what was happening during the hearing.

Together with Kathy, her keyworker and parent, the Advocate outlined Kathy's background, her support needs, her need for access to information and how she understood approaches from strangers to Kathy's lawyers who subsequently shared it with the court. During the court hearings and meetings with her legal representatives, the Advocate supported Kathy to understand what was happening and helped her ask questions.

After each hearing, individual meetings with Kathy, her parent, the Advocate and Kathy's legal representatives were also held to prepare her for the next step. Kathy's case was eventually dismissed as it was recognised that Kathy had not used any of the money received for her own benefit and that she did not understand that she was being taken advantage of by others. She was cautioned by the judge.



Outcome:

Kathy's disability support service put together a programme of supports to help Kathy understand issues about internet use, social media and what to do if contacted by strangers. She also received information about managing her money. Kathy was very relieved that the court case ended and that she did not have to face a trial.



18. Healthcare Settings



Context:

Eileen is autistic and has an intellectual disability. Eileen was referred to an Advocate by her day service. She was living with a parent at the time and her family were in conflict with the day service over the type of support she was receiving; they wanted more support in the family home and ultimately a full-time residential placement. Eileen's wishes were not sought or listened to by her family and the day service was concerned about this.



Actions by the Advocate:

The Advocate began to work with Eileen to ascertain her will and preference and to represent her at meetings held between her family, the day service provider and HSE managers who funded the service. Suggestions that Eileen apply for housing with the local authority were initially refused by her family. Meetings were very strained and family members rejected offers of support for Eileen's rights to be upheld. Solutions for respite or full-time accommodation were dismissed. No offer of full-time social care was provided.

The service provided transport for Eileen to and from her day service, but the service was unable to provide supports outside of service hours. Eileen was often home alone for long periods. Safeguarding concerns were raised about Eileen being alone without support and also being restricted from attending the day service. Respite was offered but Eileen did not attend regularly as family members said they did not think it suitable.

During the time NAS supported Eileen, her parent sadly died, and she went to live with a family member. There was very little information provided to Eileen or her Advocate about her parent's Estate. The Advocate's efforts to have contact with Eileen were limited by her family and contact with her peers and day service supports became very restricted. This situation was further affected by Covid-19 restrictions and the limitations of the day service provision at this time.

Eileen was then brought to A&E as family said they could no longer care for her. Although Eileen did not have a medical need, she was admitted to hospital for assessment. The hospital Social Worker and Intellectual Disability Liaison Nurse contacted NAS for advice and support for Eileen. Advocates visited Eileen and approached the HSE to seek funding for appropriate supports. Her day service also visited and provided support, but this ceased eight months into her admission as they were no longer funded to support her. Eileen had limited access to her finances and became increasingly isolated, she was distressed and spoke less and less to those working with her.

The Advocate explored Eileen's will and preference with her and used different means of appropriate communication, including social stories to see what Eileen wanted. Initially, the HSE suggested Eileen be referred to homeless services, but the Medical Social Worker and Advocate pointed to Eileen's increased support needs, which would not be met in emergency accommodation.

Several different services were approached to assess Eileen, with one eventually appointed to build a relationship with her. They sought a placement for her in a home in the community, but funding approval was withdrawn, and Eileen remained in an acute hospital setting for twenty months with limited contact with her family and no enduring relationship with an organisation that knew her other than NAS. During this time, NAS supported Eileen to submit complaints and sought legal advice on her behalf regarding issues which arose on several occasions.



Outcome:

With the support of her Advocate, Eileen has now moved to a home in the community and is living with several others who she relates well to. Eileen now has her own bank account. Access to her rights and entitlements was progressed with support by the Advocate and the Disability Service Provider who will seek decision-making supports via the ADMCA as required.





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

**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