



# National Advocacy Service for People with Disabilities

## 2014 Annual Report

### 1. **Introduction**

In 2014 the National Advocacy Service for People with Disabilities (NAS) continued to provide independent representative advocacy while at the same time undergoing significant structural change. Following a review of 46 CIB funded pilot advocacy projects that operated from 2007-2010, NAS was established and launched by Minister Joan Burton TD in March 2011. From 2011 to May 2014, NAS operated under the governance of five Citizens Information Service Boards in Clondalkin, Westmeath, Offaly, Waterford and Leitrim. During this time, 5 Regional Managers, 35 Advocates and 5 Administrators staffed NAS.

In March 2013, Roundtable Solutions presented a report to the CIB Board recommending a restructure of NAS to have one national Board of Management and to create a new National Manager post. In addition, the review recommended the standardisation of caseload management processes and the introduction of Statutory Powers. Following agreement of the CIB Board, CIB proceeded to implement the restructure of NAS and to support NAS in the standardisation of casework processes. The review recommendation for statutory powers related to Advocates access to services, information, files and meetings and only in exceptional circumstances, where collaborative approaches were exhausted. Following discussions with the Department of Social Protection, CIB considered that it was too early in the development of NAS to introduce statutory powers for Advocates.

In November 2013, the new NAS Board was in place and by February 2014, the National Manager appointed. The Chairperson of the new NAS Board met with the Chairpersons of the five Citizens Information Services to prepare for the Transfer of Undertaking and formal proceedings and consultations began with staff in May 2014. Four consultation meetings took place, and all staff transferred on the 1<sup>st</sup> June 2014. Following the restructure NAS operates through four revised regions and a national office, based in Dublin.

The four new regions are:

Region	Including
Greater Dublin	Dublin, Fingal and Wicklow
Northeast & Midlands Region	Cavan, Laois, Longford, Louth, Kildare, Meath, Monaghan, Offaly, Westmeath,
Western Region	Clare, Donegal, Galway, Leitrim, Limerick, Mayo, Roscommon, and Sligo.
Southern Region	Carlow, Cork, Kerry, Kilkenny, Tipperary, Waterford, Wexford

While significant time was spent managing the change process, a key focus remained on the provision of advocacy and ensuring the organisational changes had minimum impact on people supported by the service.

In Dec 2014, the revelations of the RTE Primetime Investigates programme brought to public attention disturbing evidence of unacceptable practices in a service. The RTE programme raised concerns that such practices could exist elsewhere in other services. Independent advocacy has an important role in supporting people with disabilities living in residential settings. The NAS role requires service providers to facilitate residents' access to Advocates and to support meaningful engagement once access is achieved.

## 2. National Advocacy Service Staffing & Budget for 2014

NAS operated with the following staff (WTE) during 2014:

- 1 National Manager
- 4 Regional Managers
- 5 Administrators
- 7 Senior Advocates
- 28 Advocates

There were a number of staff changes due to retirement, resignation and a significant number of maternity leaves. Staff in all regions rowed in to provide cover where there were prolonged staff vacancies and this assisted greatly in keeping services going.

In 2014, the budget allocated to NAS was €3,053,045. Approximately 80% of the budget was allocated to salaries.

## 3. Core National Advocacy Service

NAS provides an independent, confidential and free, representative advocacy service that puts the person at the centre and works to ensure that when life decisions are made, due consideration is given to the will and preference of people with disabilities and their rights are safeguarded.

NAS operates on the principles that people with disabilities:

- make decisions about their lives
- are listened to and consulted by their families and those who provide their services
- access the supports they need to enable them to live their life and enjoy meaningful participation in family, work and leisure
- enjoy the benefits of participation in and contribution to their local communities

NAS offers advocacy to people with disabilities who are isolated from their community and services, have communication differences, residing in inappropriate accommodation, living in residential services, attending day services and with limited informal or natural supports.

#### **4. MAKING CONTACT WITH NAS**

The majority of initial enquiries for advocacy are through contact with the NAS national phone number. Enquires are received directly from people with disabilities, family members, HSE staff, service providers and disability organisations. People are often reliant on family to make contact with NAS and those with limited natural supports request services or community supports to make the links on their behalf to NAS.

Most of the people who accessed NAS in 2014 lived in residential services – traditional institutions, ‘group homes’, mental health wards and supported accommodation. There were also many people living in nursing homes as well as those living with family.

The people who lived with their family often reported receiving inadequate supports from day/support services, particularly people with a diagnosis of autism. Some people experienced cut back to service hours or disputes between the family and the service provider about the suitability of the service provided. Recurring issues experienced by people with disabilities were changes to schedules/plans without appropriate consultation.

The introduction of the HIQA standards in November 2013 has had a positive effect. However, there were some concerns by NAS Advocates that referrals to NAS by some service providers were solely influenced by the requirement to demonstrate to HIQA that advocacy was available to residents

*Example: One service sought NAS promotional leaflets to put in each service users file. NAS became aware that the leaflets were placed in files with no explanation to the individuals concerned. In reply, the NAS Advocate offered to deliver a promotional presentation to all staff teams.*

Enquires received directly from family members, may not always focus on the needs and wishes of the person with disability involved. NAS appraised each enquiry and where necessary explained to the family that the needs and wishes of the person with disability are the primary focus of NAS work.

Occasionally, an enquiry may fall outside the NAS Access and Eligibility criteria and when possible these people are signposted to a service more suited to their needs. Researching options and facilitating access to appropriate services can be time consuming, particularly

when people are distressed, and referred inappropriately to NAS e.g. some people referred solely because they have a disability.

NAS is committed to an equal opportunities policy, which means that no group of people with disabilities are excluded. However, as NAS is charged with supporting the most vulnerable and isolated people, decisions on offering advocacy support are informed by NAS Access and Eligibility criteria. Some of these factors include the availability or absence of natural supports / advocacy services, risk to quality of life and benefits likely to accrue.

## 5. People Supported By the National Advocacy Service in 2014

The 2014 Service activity and caseload statistics are collated from [www.advocacycase.ie](http://www.advocacycase.ie). This is the electronic case management system developed to support casework in the NAS and in CISs. It provides a tool for case management, which supports consistency of approach, case review and safe storage and retention of files.

Provision of NAS services in 2014 was consistent with previous years.

### 5.1 NAS Case Statistics

The number of people in receipt of services since 2011

NAS Statistics	2011	2012	2013	2014
People at Start of Period	206	573	667	671
Total Client numbers	856	1068	1063	1013
New Cases	650	495	397	342
Closed Cases	291	411	399	423
Initial Enquiries	748	872	861	809

In restructuring NAS, the aim was to focus on equity of access by taking into account the population and size of each county, the number of people with a disability and the number of Advocates. NAS expected a more significant increase in the number of people supported during 2014; however, due to the growing complexity of cases, the resistance of services to progress cases to conclusion and significant staff changes, service activity remain consistent with previous years. An ongoing challenge for the service is to ensure increasing numbers of people with disabilities in isolated situations are made aware of NAS.

## 5.2 People Supported By Type of Disability

People with:	Cases
Intellectual disability	30%
Physical disability	24%
Mental Health difficulties	21%
Learning disability	13%
Autistic spectrum	6%
Sensory disability	6%

## 5.3 Number of Issues per Advocacy Case

Of the people supported 36% had one key issue of concern, 56% identified between two to seven issues and 7% had in excess of eight issues, illustrating the complexities in the lives of some people with disability. The most frequent specific issues were housing, health, social welfare, justice and childcare related court cases, family and relationships, money and tax.

Issues :	Cases
Housing	28.30%
Health	19.39%
Social Welfare	12.98%
Justice	11.20%
Childcare related court case	7.24%
Birth, Family and Relationships	5.40%
Money and Tax	4.68%
Education and Training	3.57%
Employment	2.34%
Death and Bereavement	1.50%
Travel and Recreation	1.67%
Consumer Affairs	0.67%
Moving Country	0.61%
Government in Ireland	0.33%
Environment	0.11%

While there was evidence of progression in relation to the will and preference of people with disabilities being taken into account, the frequency with which they were excluded from decisions about their life continued to be significant during 2014.

Housing was the most dominant issue and included housing supports and choosing where and with whom to live. A significant proportion of the people lived in various forms of residential services: traditional and modern institutions, 'group homes', mental health wards, nursing homes and supported accommodation.

While national policy advances the right for people with disabilities to choose where and with whom to live, the Advocates' experiences during 2014 indicate that this was not the reality for many people and a key area for which people sought support.

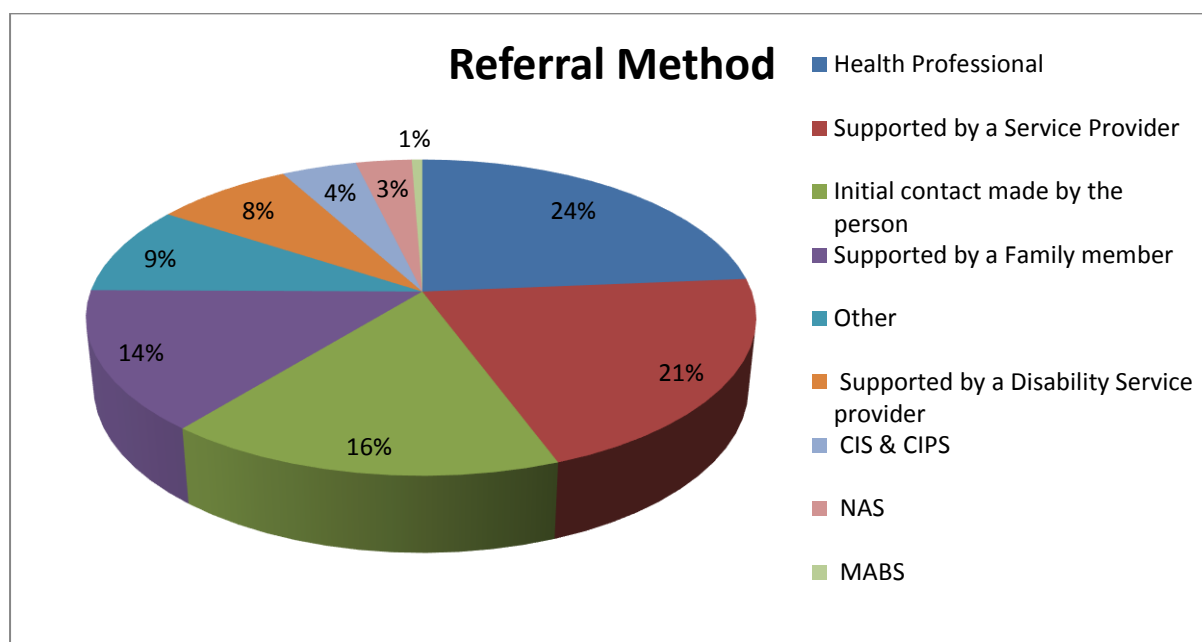
Health matters were the second highest issues presented in 2014 and included medication, information, equipment, physical and mental health. Casework involving health issues included supporting people who had difficulties in accessing health services in community and hospital settings, and supporting people at medical appointments to assist in decision making. Advocates also work with those who wished to complain about health services. Other health related casework involved supporting those who had concerns regarding prescriptions and treatment plans and wished to seek further information.

Social Welfare matters included the full spectrum of benefit issues, appeals and disability issues. Advocates supported access to CIS for such issues where possible.

Justice issues included support in criminal proceedings, childcare proceedings and supporting communication with solicitors. Advocacy casework in this area included supporting people who required legal advice and communicating their instructions to legal professionals.

Advocates supported witnesses in legal proceedings taken by the state, so that they understood the proceedings and asked relevant questions. Advocates also supported those making applications for safety orders and in family law applications including maintenance and access orders. Other areas of justice related casework included inheritance and succession, including accessing solicitors to make wills, or if they were to receive inheritances, or had difficulty in doing so.

## 5.4 How People Accessed NAS in 2014?



Health professionals and service providers referred the majority of people accessing NAS during 2014.

The advocacy requests varied, with key areas repeated -

- Support in accessing important personal information - care plan, transition plan, personal outcome measures (POMS), person centred planning (PCP) documents
- Support in expressing will and preference to ensure input to decisions
- Support in understanding legal / appeal processes to ensure the person's will and preference was heard in these processes
- Support with accessing choice about where and with whom to share accommodation when moving from residential to community living.

## 6. Impact of NAS

Over one thousand people (1013) engaged in an advocacy process with NAS during 2014. At the end of the year, 674 of these people transferred into 2015 casework. People with disabilities were supported in a variety of areas and many had multiple outcomes –

- 18% supported to self-advocate
- 16% explored lifestyle options
- 10% became more independent
- 8% to deal with being excluded from decisions
- 8% family relationships

- 6% lack of access to own money
- 5% inadequate or lack of PA hours
- 5% inappropriate housing
- 5% to develop social connections
- 4% supported to improve communications
- 4% self confidence
- 4% complaints
- 3% poor housing standards
- 2% re-established family connections
- 2% lack of appropriate mental health
- 2% Bullying and harassment

The analysis and available data on outcomes for people need further development with a standard approach across the service.

## **7. National Advocacy Service Awareness Activity**

An important aspect of the work of NAS is to take opportunities to raise awareness of the service and to improve access to advocacy. All regions delivered targeted promotions in key service areas in 2014. There are still some misunderstandings about what advocacy is all about.

In addition, a number of workshops and presentations were made to a variety of bodies and institutes. These included presentations on representative advocacy to students of the MSc in Disability Studies and Clinical Psychology PhD Programme at UCD, Athlone Institute of Technology, UCC, NUIG, GMIT and St Angela's College, Sligo. Most of the students on these courses were placed in services across the country so the impact was national. In delivering the workshops the focus was not only promoting NAS, but also embedding the importance of progressive realisation of a human rights based approach in the mind-set and ethos of young professionals.

NAS forged a partnership with Trinity College following an Advocate's involvement in a complex case. This entailed a person whose living arrangements were precarious who wished to learn independent living skills, which would improve her accommodation options. Given the absence of supports for the individual, the Advocate approached a staff member of the BSc Occupational Therapy Programme. A Life Skills Course was subsequently set up involving three first year Occupational Therapy students and four people interested in learning independent living skills. The course has been running since November 2014 and participants reported that they were putting the skills into practice in their everyday lives.

Whilst HIQA inspections have resulted in greater calls for promotion of NAS, it has not resulted in follow - on enquiries from some services. There were areas where the impact of promotion had little impact, in particular for people with intellectual disability in mental health services. People with a dual diagnosis tended to see-saw between services with no one service provider taking lead responsibility and it is considered likely that people in this category isolated in the community are not yet being reached by NAS.



## **8. WORKING WITH SERVICES**

Service providers are willing to engage with NAS at the initial stages of the advocacy process in terms of promotions, awareness raising and meeting with people who use the services. Factors such as HIQA and HSE Service Level Agreements have had an impact in improving this situation.

There can be challenges and barriers when it comes to the next steps of the advocacy process when Advocates are seeking to obtain information pertinent to the issues arising or as a means of getting to know the person's will and preference. Advocates have experienced delayed responses to emails, letters and phone messages. In some cases, Advocates reported delays of many months with the omission of critical information. There can also be delays or no action taken to implement agreed planned measures, with services citing lack of resources, lack of transport and lack of staff. There is also resistance to working in line with a person's will and preference as opposed to their best interests. People with disabilities and Advocates can be denied access to information and participation in decision-making.

While services have policies that are positive toward advocacy, once Advocates begin to raise issues, resistance and inconsistencies can emerge. Advocacy may be facilitated by services for some people and not for others where the issue is to do with the service itself.

Advocates can experience resistance when trying to progress issues for people who communicate differently and need to spend time observing the person in the service. There appear to be concerns from services that the Advocate will be observing internal practices.

Through case management, team meetings and case review, NAS has developed a number of responses to resistance. These include co-working cases, escalating concerns, using HSE Complaints System/Ombudsman, building relationships with service providers, using National Advisory Group and Regional Advisory Groups discussions.

Advocates continue to forge relationships with service providers and agencies within their regions. This includes the Community Welfare Service, the HSE Disability Service, Child Protection Services, local authorities, and the mental health services. All major service providers and many smaller providers have received a promotional visit. In 2014, a small number of service providers have invited the National Advocacy Service to visit their service. Advocates had difficulty with some mental health services with scheduled visits being cancelled a number of times. Advocates believe that NAS also needs to engage with agencies at a national level to help clarify NAS role.

## **9. Congregated Settings and people with an intellectual disability:**

In some counties, the HSE took a lead on the closure of congregated settings. However, this commitment to closure may have been at the expense of the involvement of the person. For people who had lived in institutions all their lives, moving into smaller group homes can be extremely complex and many placements have broken down.

*One such instance cited involved an attempt by a service provider to move three adults who shared a house for many years in a large town, to a small remote town. An Advocate*

*supported the three people to get their opposition to the move voiced, using the HIQA standards with regard to the right to consultation to support their case, and achieved a successful outcome.*

In other counties, movement was slow and many individuals remained in congregated settings with little indication of planning for transition.

In some instances, there appeared to be unclear plans for de-congregation and yet indications that large residential institutions were aiming to meet deadlines set out by HSE. Concerns were voiced about the speed at which individuals would be moved, with limited meaningful consultation with the person involved about where and with whom they wished to live. Individuals who moved without adequate supports in line with their wishes became isolated living in the community, and struggled to maintain their independent living situation as a result.

There was lack of housing options for people who wanted to share houses with others. With the social housing crisis, some service providers moved people to private rented accommodation. Some people moved without Rent Supplement and were being unfairly disadvantaged financially.

Intensive work for Advocates arose when people indicated a desire to leave a service provider to secure a community living option. People may have been expressing this wish for some time. Advocates often engage with cultures that are resistant to change and hold paternalistic views of the person. There were also examples of good collaboration and meaningful engagement:

<b>Anonymised Case Study 1</b>	
<b>1</b>	<b>Introduction/Context of Referral</b>
	Harry was referred by his service provider with family agreement. He was having serious problems in his community house.
<b>2</b>	<b>Pre Advocacy Circumstances</b>
	At times Harry was in physical and emotional conflict with a housemate and this affected everybody living in the house. Several attempts to improve the situation had been undertaken but the matter had not been resolved from Harry's perspective. The situation escalated.
<b>3</b>	<b>Advocacy Plan</b>
	The service provider wanted Harry to have independent advocacy to ensure his fair treatment and to support his decision-making. Harry agreed with their suggestion to meet the NAS Advocate. The Advocate met with him on several occasions to get to know his will and preferences. Harry liked living in the house but disliked a housemate. He talked about wanting to live with family but was not clear if this was possible.

4	<b>Advocacy Support</b>
	<p>With Harry’s consent, the Advocate also met with staff and family. Family were open to this but shared that they found it difficult to balance Harry’s rights against their own will and preferences. The staff noted challenges with supporting Harry in a home where he did not like everyone, and his actions to express this impacted badly on Harry, on themselves and on others.</p> <p>It was acknowledged that despite complaints and investigations alternatives to his current placement and support package had not been looked at. Access to information was provided with Harry’s consent. All possibilities to resolve the situation were explored with him in the first instance and then with family and staff. Other housing options were explored, including identifying and visiting new properties to rent. Harry did not commit fully to any of these options. Eventually, another community house in the locality was explored where Harry would be more independent but still close to family and preferred community connections. The Advocate and service provider worked with Harry and his family to visit the location, meet others who lived there, and discuss the supports that would be provided. A move was agreed by Harry and the Advocate worked with him and with staff to plan the move in a way that suited him. The service provider was responsive to representations made on Harry’s behalf.</p>
6	<b>Outcomes</b>
	<p>Eventually, Harry moved to a new house. He still has close contact with family and is delighted to be still living in the same area. All parties reported how good the outcome was for Harry and indeed, how positive the process of advocacy had been to ensure Harry was heard.</p>

## 10. NAS Sample Cases

NAS has seen an increase in casework concerning:

- Those who were preparing to leave congregated settings and consider moving to housing or where other residential services were being planned,
- Individuals facing sexual assault charges who had difficulties in understanding legal proceedings – contacts in these cases came from both disability services and legal professionals,
- Individuals living in residential settings who required supports on financial and legal matters and for whom no formal decision-making supports are in place,
- Service providers and families contacting NAS regarding people in residential settings who had difficulties communicating and who were unhappy and/or inappropriately placed.

NAS has a growing number of enquiries from professionals who were not able to provide supports to individuals and sought support for social work or key worker type issues. NAS indicated in most cases that these were not appropriate referrals unless support in decision-making or representation was required.

## Anonymised Case Study 2

1	<b>Introduction/Context of Enquiry</b>
	<u>Choosing where and with whom to live</u> - Hilda had been in hospital for a number of years. Due to her high support needs her hospital discharge assessment recommended nursing home care.
2	<b>Pre Advocacy Circumstances</b>
	Hilda wished to return home and to get an appropriately funded home care package within a reasonable time - frame considering the expected future deterioration of her health. She went on hunger strike because of the delay in receiving an appropriate home care package.
3	<b>Advocacy Plan</b>
	The Advocate engaged with Hilda in relation to her decision to continue on hunger strike and in relation to the health risks attached to her living in the home environment.
4	<b>Advocacy Support</b>
	The Advocate established: <ul style="list-style-type: none"> <li>• The level of support that would be provided by her family members and by her natural support network</li> <li>• the level of paid support necessary for Hilda to live in her own home</li> <li>• Representations were made to the HSE to secure an appropriate home care package</li> </ul> <p>They reflected Hilda's wishes, demonstrated where the liability of risk was apportioned, her awareness of the risk, the minimum paid service support required for a safe discharge to her home, and the training support required for family members including managing their own health.</p>
5	<b>Outcome</b>
	Hilda ceased her hunger strike and received an appropriately funded home care package to live at home.

## Anonymised Case Study 3

1	<b>Introduction/Context of Referral</b>
	<u>Moving away from inappropriate placements</u> - Caroline was referred by a medical social worker. She was living in a hospital setting as a "delayed discharge patient" as their rehabilitation programme was completed.
2	<b>Pre Advocacy Circumstances</b>
	Caroline is in her early forties and requires a living environment that provides her with long-term medical and social supports. The hospital identified a suitable service

	provider to provide a care package, which would meet Caroline's needs; however, the HSE's initial response was that they were not in a position to provide any form of additional funding.
3	<b>Advocacy Plan</b>
	Due to the complexity of the issues, and the extent of the professionals involved, it was necessary to bring the key stakeholders together. The Advocate highlighted that Caroline's needs were not being met in such an inappropriate setting, were inconsistent with national policy, and not in line with best practice, and brought the focus to the creation of a support package in an appropriate setting that would meet Caroline's array of needs.
4	<b>Advocacy Support</b>
	The Advocate progressed Caroline's case by: 1) communicating with the HSE at a high level seeking prioritisation of the case 2) working with all stakeholders to get their detailed short, medium, and long term perspectives 3) working on actual costings as well as on the spectrum of risk factors
5	<b>Outcome</b>
	The advocacy process worked well. The holistic team approach identified her medical and social needs with Caroline. She was supported to find a place of residence that she rates positively where her complex needs are met. This case has now been prioritised for funding by the HSE Disability Services Manager. An alternative funding option was sourced with Fair Deal and this is presently Caroline's preferred option. All parties reported that a strong team approach and contribution from all parties was required, but that they could see the real future benefits of the process. The outcome was positive for Caroline and indeed for all those involved.

#### Anonymised Case Study 4

1	<b>Introduction/Context of Referral</b>
	<u>Increased recognition of will and preference of individuals</u> - David was living in an independent unit on the grounds of a residential service and wanted to live in the community.
2	<b>Pre Advocacy Circumstances</b>
	David used an electric wheelchair and had limited use of one hand. He received a high level of support, including personal care, cooking and cleaning from service staff and felt that the constant presence of staff was intrusive. His links with his extended family were limited. He was looking for more independence and control over his life.
3	<b>Advocacy Plan</b>
	<ul style="list-style-type: none"> <li>The Advocate worked to identify a service that would support David to live independently in the community.</li> <li>His existing service provider was in a position to offer this support.</li> </ul>
4	<b>Advocacy Support</b>
	<ul style="list-style-type: none"> <li>When David decided to go with his existing service provider, recurrence of over</li> </ul>

	<p>protective/safeguarding practice was his main concern.</p> <ul style="list-style-type: none"> <li>• The service appointed a Transition Co-ordinator who carried out a significant amount of the work required.</li> <li>• This allowed the Advocate and David to focus on ensuring his full participation so that he could set out exactly what he wished from his service</li> </ul>
5	<p><b>Outcome</b></p> <p>David now lives in his own home in the community, with support. He is able to decide what he would like to do on a daily basis, and has been supported to access services in his new community. He is very happy with his new independence.</p>

### Anonymised Case Study 5

1	<p><b>Introduction/Context of Referral</b></p> <p><u>Control over Financial Decisions</u> - An enquiry was made with Frank's consent for advocacy. Frank had mixed feelings regarding family influence and service control in relation to of his financial decisions.</p>
2	<p><b>Pre Advocacy Circumstances</b></p> <p>Frank had recently received a large inheritance, which had brought his situation to the fore. Previously, Frank had already expressing concern that the policies and procedures in his day service were controlling and that he was not being afforded the opportunity to make fully informed financial decisions. There were no individualised arrangements in place to meet his wishes and requirements.</p>
3	<p><b>Advocacy Support</b></p> <p>The Advocate worked with Frank to identify what he wanted from his support persons and a plan was devised on future decision-making processes and how conflicts could be dealt with.</p>
4	<p><b>Outcome</b></p> <p>Frank's financial plan was well received. He is more confident in decision-making and commented that he feels a sense of empowerment. In addition, the service has adopted this approach with the other residents who now have individualised financial plans in progress.</p>

### Anonymised Case Study 6

1	<p><b>Introduction/Context of Referral</b></p> <p>Service providers question the advocacy approach, particularly with people who communicate differently - The Advocate was excluded from access to professional assessments that were used to limit a person's movements where there was no history of immediate or serious risk of harm to the person.</p>
2	<p><b>Pre Advocacy Circumstances</b></p> <p>In this, case the person had been travelling to the family home to stay overnight at weekends for seven years without incident. Following an unsubstantiated concern</p>

	being raised by a relative, the service provider brought this arrangement to a halt citing health and safety risks. The cessation of the long-standing home visit arrangement resulted in distress, loss of appetite and insomnia for the person.
3	<b>Advocacy Support</b>
	Despite professional approaches by the Advocate to raise concerns and seek more information on the person's behalf, they were excluded from meetings related to this decision for a significant period. The organisation prepared clinical and social work reports. The organisation denied the person's wish to reinstate their home visit arrangement despite the person's and his parent's preference to spend time together as before.
4	<b>Outcome</b>
	The service did not respond to formal correspondence outlining the areas of concern. The service engaged with extended family members whose relationship with the person was unclear. The person and the Advocate were unable to change this situation.

## 11. Conclusion

During 2014, NAS was established as a national service, with one national Board. The NAS Board committed their time to the strategic development and delivery of NAS for people with disabilities.

NAS staff strove persistently to ensure that when life decisions were made, due consideration was given to the will and preference of people with disabilities and that their rights were safeguarded.