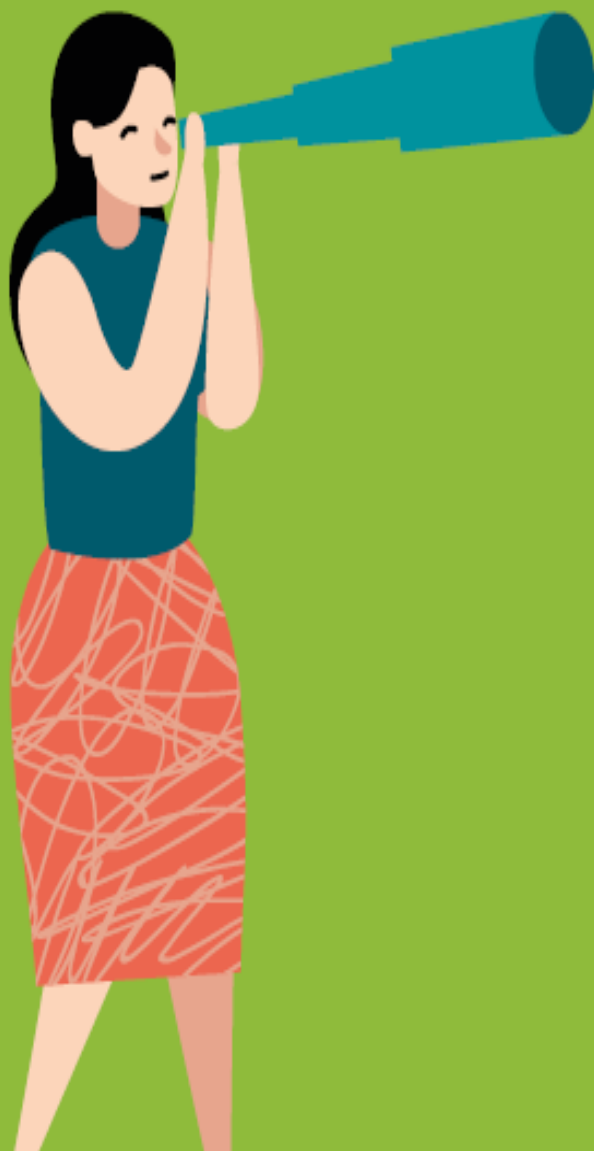




Presentation to National Open Disclosure Office HSE

David O'Duffy
Senior Advocate (Southern Region)



Vision statement

Our vision for society is one where people with disabilities can exercise their rights – with dignity, autonomy, equality and independence at the core. We recognise the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

About the National Advocacy Service

- Established 2005 as pilot projects, national company since 2014
- Funded and supported by the Citizens Information Board
- Partially meets CIB statutory obligation to provide an advocacy service for people with disabilities
- Fully professional, independent, free and confidential service
- Independent of the HSE- no HSE funding
- 50 paid, professional staff across Ireland – Code of Practice and Management and Supervision structure
- NAS staff work in line with a full suite of NAS Advocacy policies

Our Family Tree....



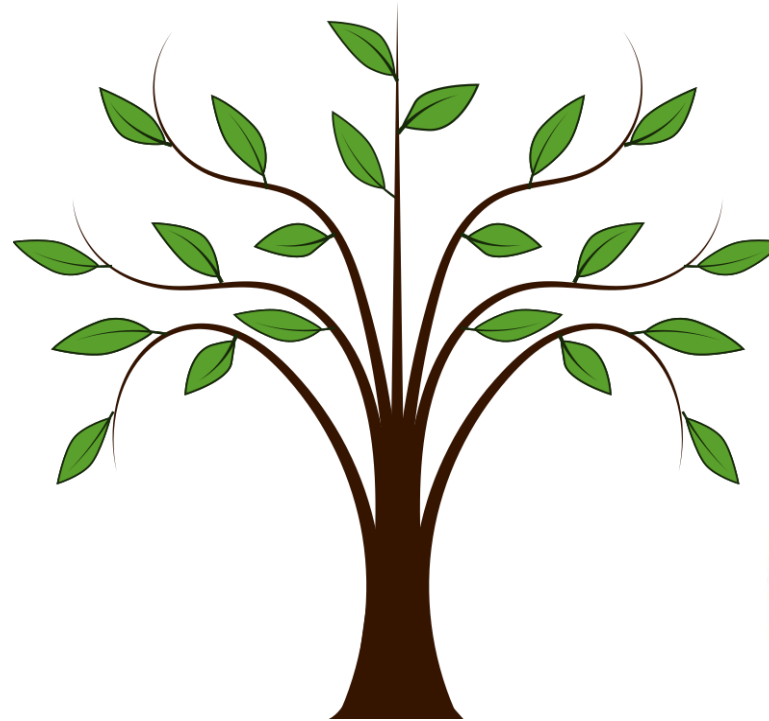
Patient
Advocacy
Service



MABS Helpline

0761 07 2000

Monday to Friday: 9am - 8pm



Citizens
Information

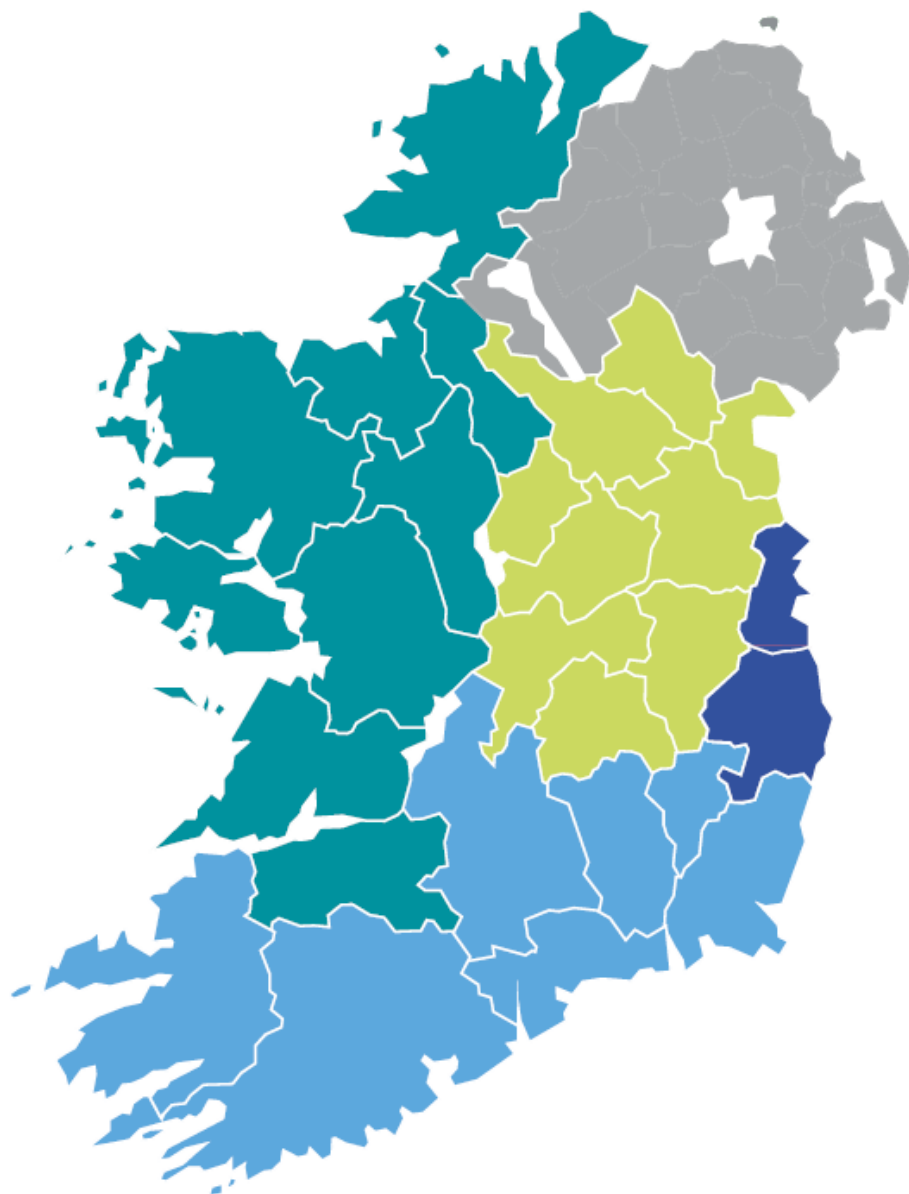





**NATIONAL ADVOCACY
SERVICE**

FOR PEOPLE WITH
DISABILITIES

SIGN LANGUAGE
INTERPRETING SERVICE

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



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

About the National Advocacy Service



NAS has a particular remit for adults (aged 18+) with disabilities who:

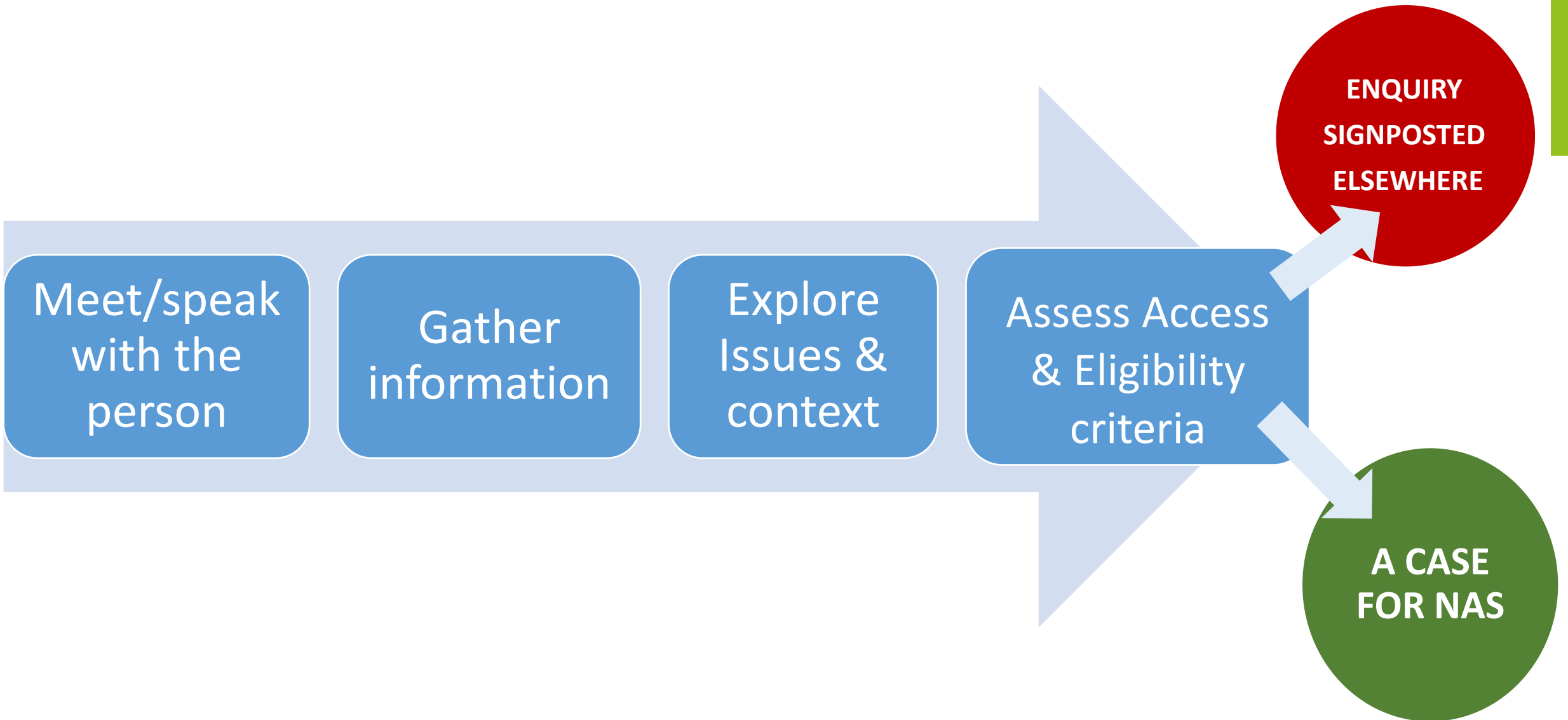
- Live in the community & are isolated from their community and services.
- Have communication differences.
- Are inappropriately accommodated.
- Live in residential services.
- Attend day services.
- Have limited informal or natural supports.

Enquiry Process



- ❑ A person can apply for the service by calling national line
- ❑ 0761 07 3000 or online at www.advocacy.ie
- ❑ Anyone can make an enquiry on behalf of a person via the national line or online enquiry form
- ❑ We receive enquiries from;
 - People with disabilities
 - Family and friends
 - Disability services
 - HSE services
 - HSE Safeguarding Teams
 - Health and social care professionals
 - Advocacy groups
 - Solicitors and legal professionals

Enquiry Process



Enquiry Examples

- Self –Referral: 34 YO Woman Terminal Huntington’s Disease and applying for Disability Allowance. Which was pre-approved by the dept. Issue was that she was facing challenges in accessing SWA as a result of covid19 and was being expected to attend in person to the Welfare Office so as to fill in the form in person. She found it difficult to hold a pen. She filled it in online and sent it in. This wasn’t accepted. Supported person in accessing the Complaints Officer with the Local Service and referred to Free Legal Aid for further advice.
- Third Party Referral from Social Work from an Acute Hospital setting. 42 YO Man ABI awaiting a referral to a specialised treatment facility. He was also homeless. Discharge plan in place although the receiving service were wanting additional guarantees from the acute hospital regarding their own discharge from their service. Contacted treatment hospital social work and discussed issue and requested that the person get seen from a rights perspective as he was being denied treatment which was necessary for a positive rehabilitative prognosis. Hospital expedited referral.
- Social Work Disability Services Referral. 28 YO Woman requiring and wanting a gynecological procedure. Moderate ID. Consultant queried capacity. Advocate working with person, and Mom plus social work. Addressed issue by working with person in order to ascertain capacity and consent. Communicating over a period of time with person. Brought back to Consultant and further re-iterated HSE National Consent Policy which assumes capacity and it is up to the service provider to address this.

NAS provided
information,
advice, one-off
interventions
and short-term
advocacy in
3,456 initial
enquiries in 2019



14%
increase
on 2018

This included writing a letter,
information provision by phone,
short-term support and referrals
to other services

Representative advocacy issues included:



housing and
accommodation
50%



health
23%



justice issues
12%



parenting with
a disability
8%

Issue Categories 2019



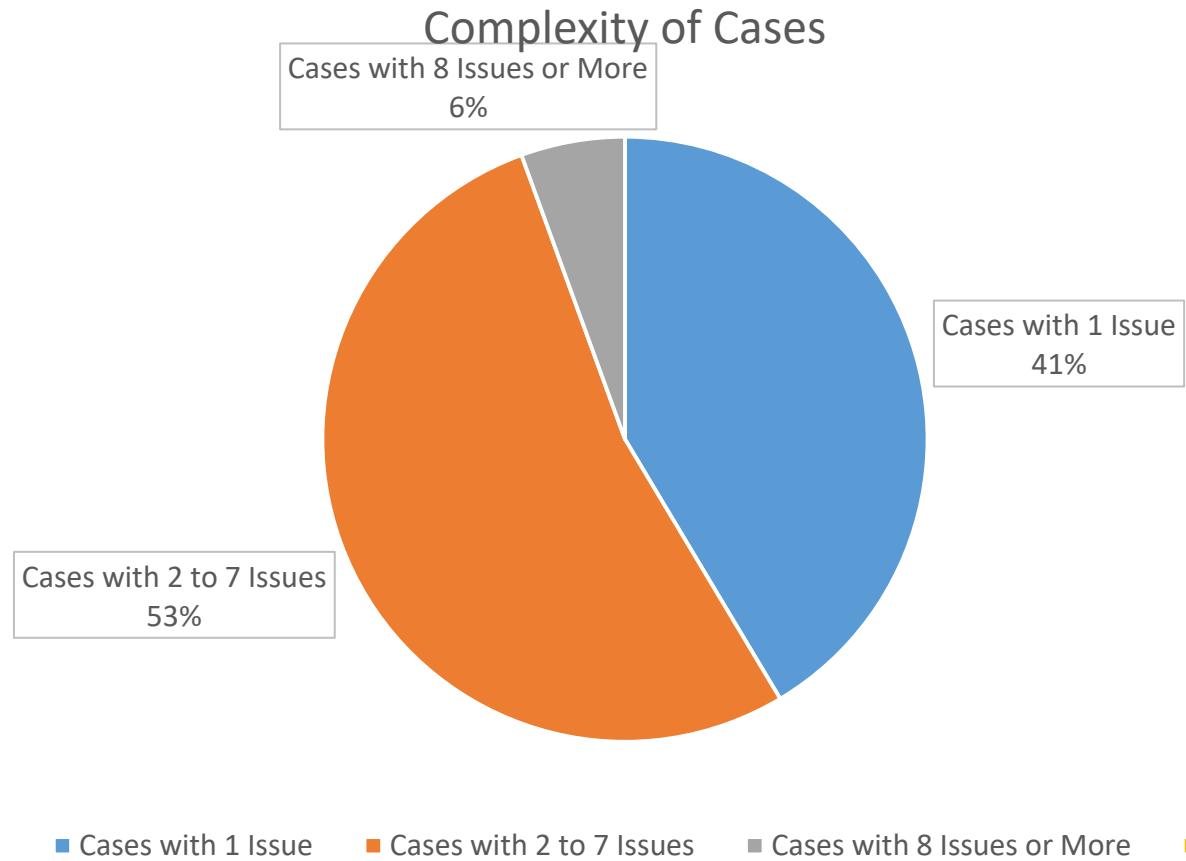
Housing: includes homelessness, inappropriate residential placements such as young people in nursing homes, lack of choice in terms of residential placements, de-congregation, rent and arrears and social housing list issues.

Health issues: include access to healthcare services, treatment choice and meaningful engagement in defining treatment plans.

Justice issues: include Ward of Court cases, wills and probate, personal injuries claims, rights of residence and criminal cases.

Parenting with a Disability: typically refers to cases where a parent with an intellectual disability is subject to an intervention by social services in relation to their child/children.

Complexity of Cases



Types of Disabilities met in NAS

| People with... | 2018 | 2019 |
|-------------------------|------|------|
| Intellectual Disability | 45% | 49% |
| Physical Disability | 31% | 32% |
| Mental Health | 24% | 24% |
| Learning Disability | 17% | 14% |
| Autistic Spectrum | 12% | 11% |
| Sensory Disability | 8% | 8% |
| Acquired Brain Injury | 8% | 12% |

Types of Issues in Casework



- ☐ Health (physical, neurological, mental health)
- ☐ Abuse, Neglect, Mistreatment and Exploitation (Safeguarding)
- ☐ Perceptions of Risk/upholding of rights (e.g. issues linked to consent/capacity)
- ☐ Community Services (or lack thereof)
- ☐ Legal Issues (Ward of court/Parents with a disability involved with child protection issues)
- ☐ Inappropriate Placements (e.g those living in acute hospital settings with no medical needs)
- ☐ Individualised Funding
- ☐ Access to money
- ☐ Rights restrictions [e.g. Chemical, Physical, Environmental & Psychosocial Restraint]
- ☐ Quality of Life Issues

.....

Upholding Will and Preference



- ❑ The role of the advocate is to get to know the person and support them to have their wishes, will and preferences kept at the centre of the decision making process.
- ❑ Advocates support the person to be directly involved in decision-making processes which affect them and must aim to present information in ways that assist the person to make their own informed decisions and choices. (Advocates are never decision makers for the person)
- ❑ Advocates work to support a person's right to take considered risks and experience failure.
- ❑ Advocates must not be influenced or compromised in carrying out their role by any other party and cannot do anything the person does not want them to do.
- ❑ Advocates adopt a 'Will and Preference' V 'Best Interests' approach.

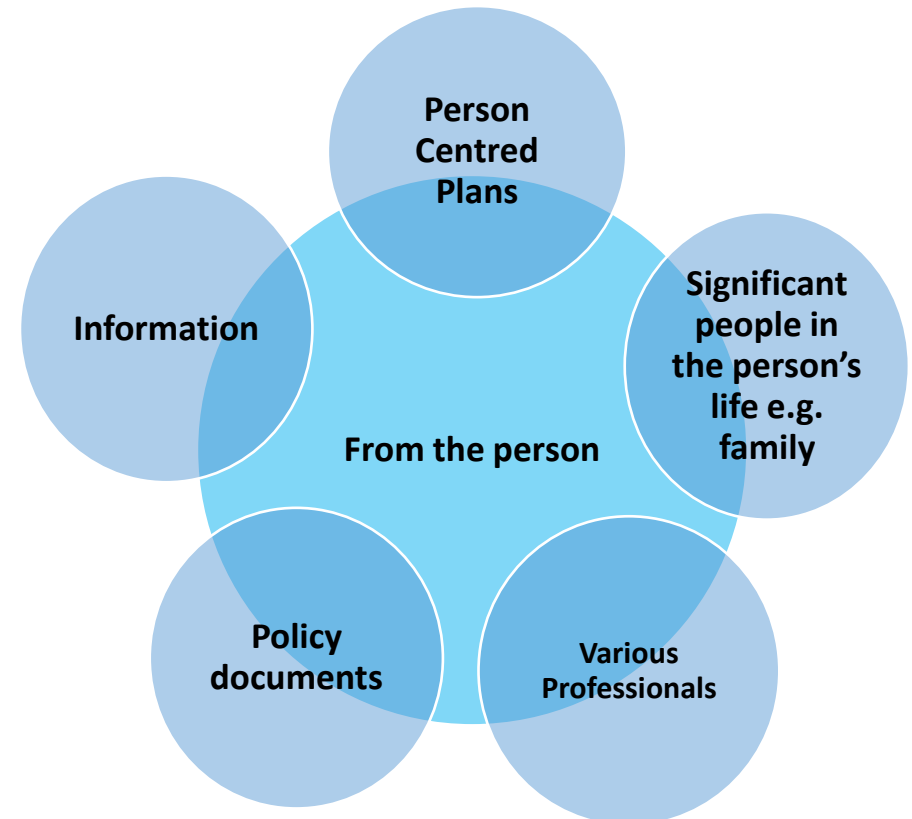
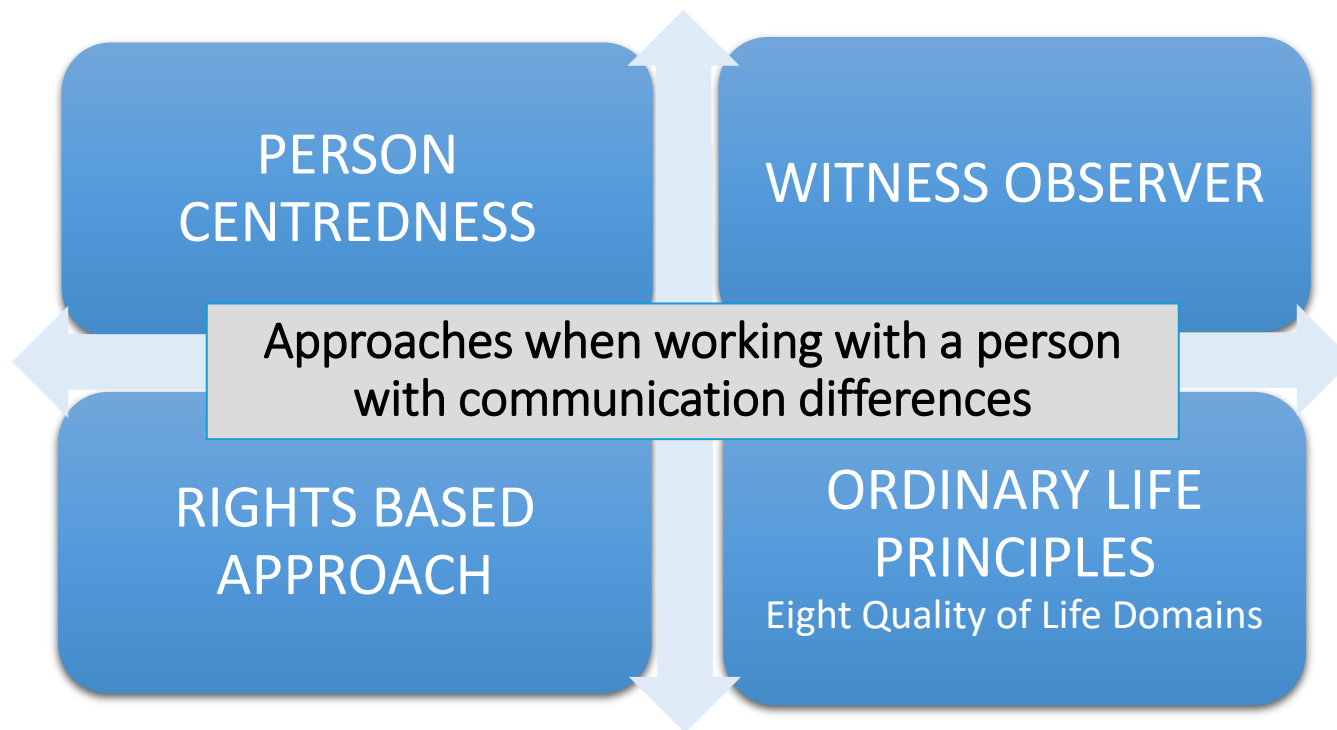
Upholding Will and Preference



- ☐ Advocates ensure that fair process has been followed for the person.
- ☐ Advocates explore the different avenues of recourse open to a person when a rights violation has occurred- i.e. complaint mechanisms, taking legal action, Escalating a concern to HIQA, the Ombudsman, the Irish Human Rights and Equality Commission etc.
- ☐ Advocates consider if the person is empowered or disempowered in each situation.

Working with those with communication differences

In a case where the person is not in a position to articulate their will or preferences the advocate uses 4 internationally recognised approaches to ascertain the person's will and preference.



Sue's story



- Sue, a person in her 20's with ASD had been **living in a large residential setting** for over a decade until the service closed down & she was moved to an emergency placement in a rented house with support staff from a care agency.
- The **staff had no training or experience in supporting people with ASD** and the team had **limited input from multi-disciplinary team** with expertise in ASD.
- All this led to a **restrictive service** being provided to the person. Many of the doors in the house were locked and furniture in the house was minimal and bolted down. The person spent most of the time in one room and was accompanied by two staff at all times.
- Sue would engage in a behaviour where she would collect items and store them in a box. Staff would remove the items on health and safety grounds. **Sue's behaviour was generally viewed as difficult** by those working with her.
- **Sue only left the house for 'drives'** or when she would go to her parent's house for short visits. As far as Sue's parents were concerned Sue was safe and protected in her home and they were too elderly for her to live with them. They were happy for staff to do whatever they saw fit to keep her safe. Sue had no other family members to advocate on her behalf.

PERSON CENTREDNESS

- Built up picture of lifestyle, preferences, needs
- Spoke to people who knew Sue, Read reports .
- Staff spoke negatively of Sue being 'bold', saw behaviours as controlling and attention seeking
- Parents insights to person/life story, likes/dislikes. (flowers/fragrances/activities)
- No assessment. Service being provided without knowing support needs. Needs poorly understood.

WITNESS OBSERVER

Time with person, observations, see and record, number of meetings across time.

Observations

2 staff at all times, restrictions, locked rooms, sparse home, no activities, no structure, isolated rural setting, communication style (e.g. tap chest/vocalisations) - Lamh, indicate unhappiness with people (push/walk away).

*Accountability for this work is key

IS PERSON EMPOWERED OR DISEMPOWERED?

HUMAN RIGHTS BASED APPROACH

Identifying if person's rights are respected, protected, fulfilled. Gathering relevant information.

Rights issues identified:

Restrictive practices, chemical restraint. Sought review of medication. Led to review and emphasis on assessment. Representation for appropriate supports.

ORDINARY LIFE PRINCIPLES

8 domains of quality of life

1.Skills/abilities, 2.Community presence, 3.Continuity, 4.Choice & influence, 5.Individuality 6.Status & respect, 7.Relationships, 8.Well-being

Findings:

Multiple quality of life issues – used to raise questions of decision makers.

Outcome:

- The advocate asked questions of decision makers to draw attention to the inadequate nature of the service. This resulted in alternatives being considered. A potential service was identified and the advocate's observations were used to develop a transition plan and person centred plan.
- This work led to a positive outcome for the person. They were placed in a far less restrictive service, with appropriate supports and with a focus on promoting the person's abilities. The result of which was that the person showers and dresses independently, can make breakfast with minimal supports, engages in a service in the community, goes shopping with support and many other meaningful activities.

Policy Environment



NAS participates in the policy sphere in the following ways;

- Disability Consultative Forum of Department of Employment Affairs and Social Protection
- Expert Group on ADM at National Disability Authority
- HSE National Disability Consultative Forum
- Quality Assurance Oversight Committee for Decision Support Service
- Steering Group for National Patient Experience Survey
- Safeguarding Ireland
- Citizens Information Board pre-budget submissions and social policy
- NAS regularly submits to public consultations (safeguarding etc.)

Áras Attracta- NAS Role

NAS has played an active role on the ground in Áras Attracta

- Three NAS advocates worked with residents in Áras Attracta as part of “A Day in the Life Exercise” for the Independent Review Group Report into Áras Attracta (McCoy Report)
- McCoy Report found an expansion of the NAS service to residents of Áras Attracta would be beneficial

What matters most

Report of the
Áras Attracta Swinford
Review Group

July 2016

Web- advocacy.ie
National Line: 0761 07 3000

