

# Getting to the core of the Act- Will and preference, support, unwise decisions, risk and liability- reflections on practice

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## 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).

# Mission statement

The National Advocacy Service for People with Disabilities (NAS) provides an independent, confidential and free advocacy service that works exclusively for adults with disabilities. Our role is to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and have limited informal or natural supports. We act as a catalyst for change through collaboration, capacity building and representation to make the rights of people with disabilities a reality.

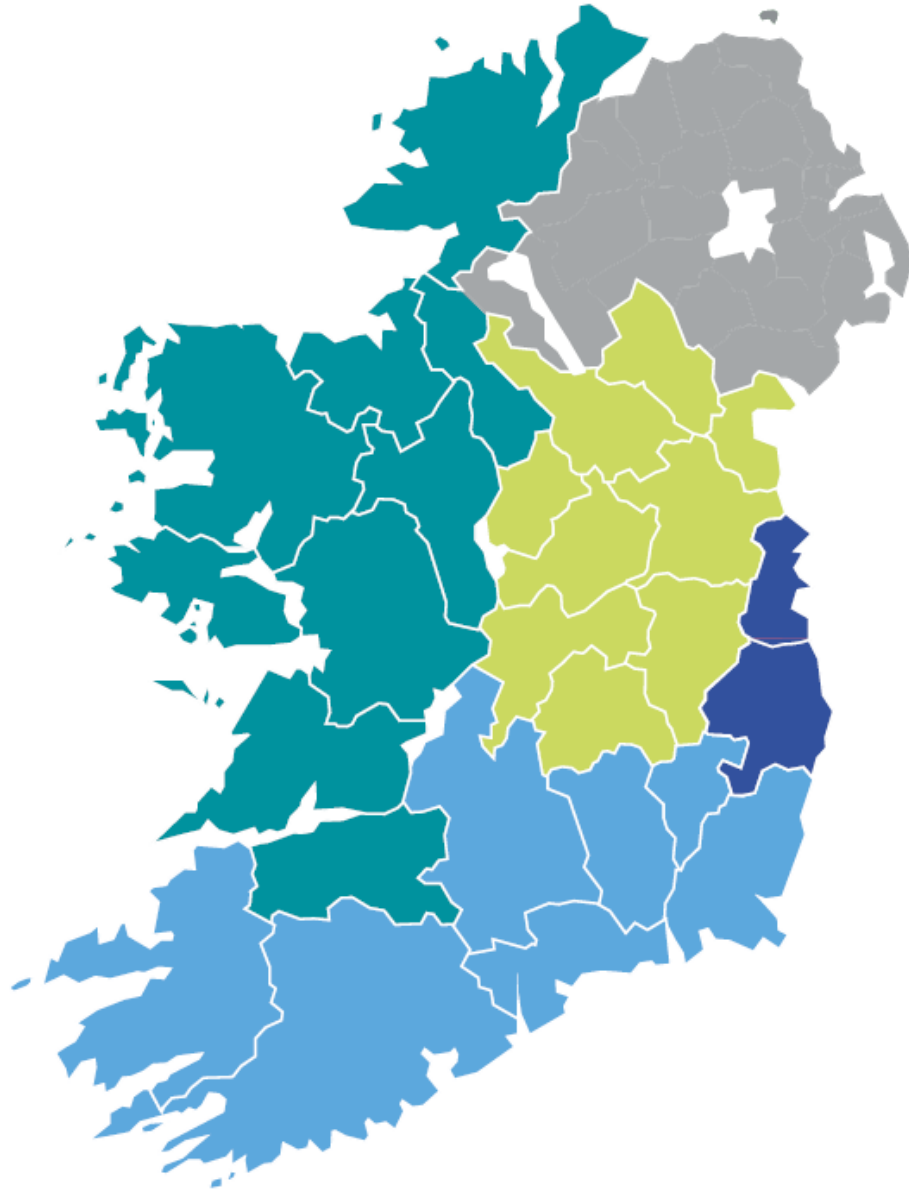
# About the National Advocacy Service

- 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
- NAS also launched a new, independent Patient Advocacy Service in October 2019 ([patientadvocacyservice.ie](http://patientadvocacyservice.ie))



# Patient Advocacy Service

- NAS launched a new independent Patient Advocacy Service in October 2019
- We have a team of patient advocates helping patients of public acute hospitals to make a complaint about the care they have experienced
- Service is free, independent and confidential
- Funded by Department of Health
- [Patientadvocacyservice.ie](http://Patientadvocacyservice.ie) national line: 0818 293 003



- 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

# NAS Work 2018

NAS provided full representative advocacy support in **916** cases in 2018

**7%**  
increase  
on 2017

NAS closed **461** cases, having achieved positive outcomes for clients

NAS provided information, advice, one-off interventions and short-term advocacy in **3,025** initial enquiries in 2018

**8%**  
increase  
on 2017

The NAS national phone line received **1,953** calls, up from 1,263 in 2017



# NAS Referral Process

Supported by a Service Provider	28%
Health Professionals	23%
Supported by a family member	14%
Supported by their Disability Service provider	12%
Initial contact made by the person	11%
Other	9%
Citizens Information	3%





# Types of Disabilities

People with...	2017	2018
Intellectual Disability	43%	45%
Physical Disability	30%	31%
Mental Health	24%	24%
Learning Disability	18%	17%
Autistic Spectrum	12%	12%
Sensory Disability	7%	8%
Acquired Brain Injury	2%	8%

# NAS Issue Categories 2018

**Housing:** includes homelessness, inappropriate residential placements such as young people in nursing homes, lack of choice in terms of residential placements, decongregation, 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.



housing  
**50%**



health  
**22%**



justice  
**12%**



parenting with  
a disability  
**8%**



Birth, family and  
relationships  
**7%**



Social Welfare  
**6%**



Money and Tax  
**4%**



Education, social  
life, employment  
**7%**

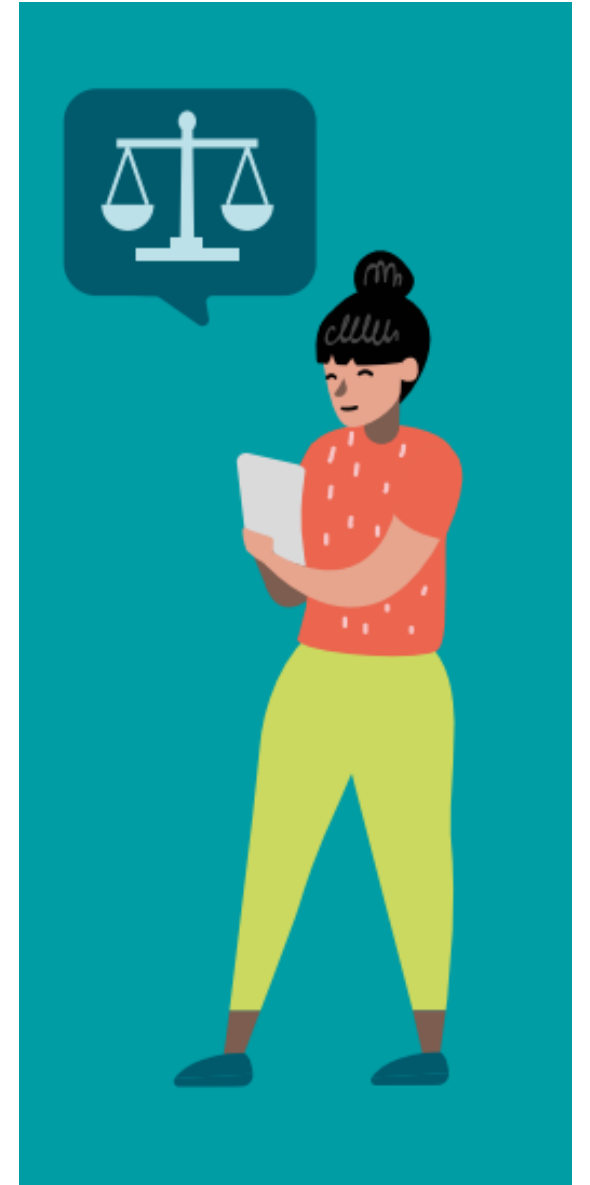
# NAS and Assisted Decision-Making



- NAS practises the Guiding Principles of the ADM in our work
- Advocates ensure that the will and preferences of individuals are heard
- Emphasis on facilitating different communication styles

# Introduction to and Purpose of Assisted Decision-Making (Capacity) Act 2015

- Regulates assisted decision making
- Regulates substitute decision making
- UN CRPD principles in Irish Law
- Establishes Decision Support Service
- Abolishes Ward of Court



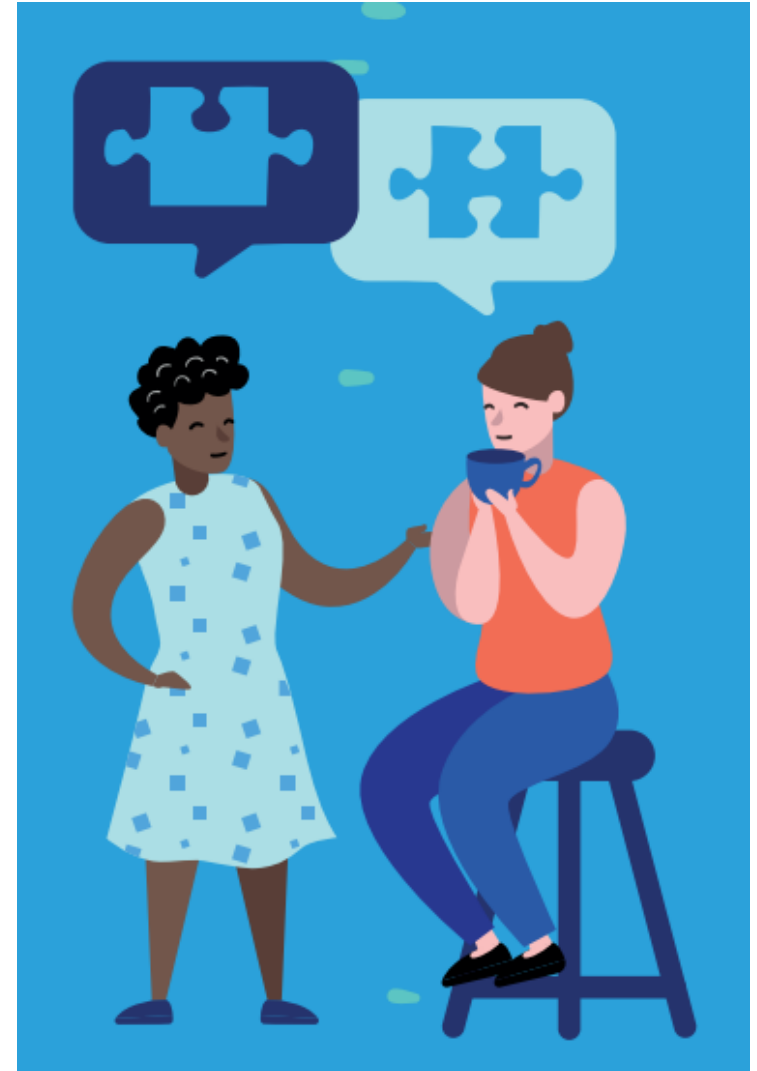
# Guiding Principles of Assisted Decision-Making (Capacity) Act 2015



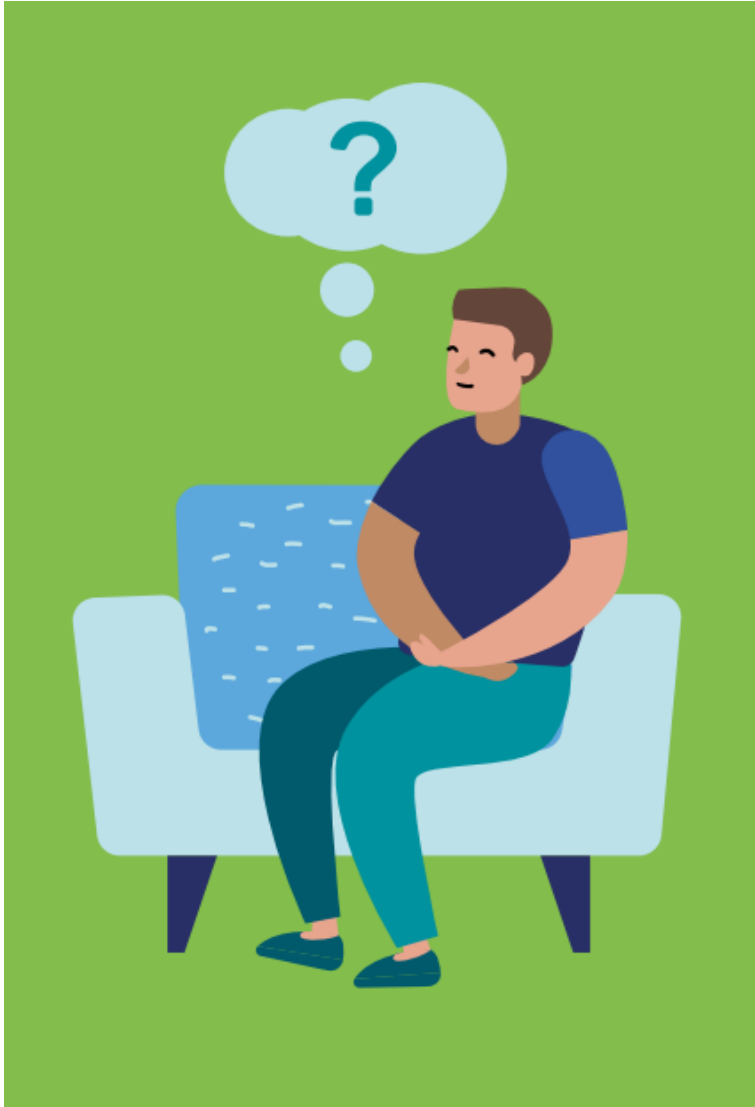
- All persons have equal legal rights, some may need assistance to exercise their rights (UN CRPD, ECHR, Constitution)
- Act creates presumption of capacity
- Act Adopts functional approach to assessing capacity
- There are 9 guiding principles in Part 2, Section 8 of Act

# Supporting Capacity

- **Principle 1:** Presume that the person has capacity to make a decision unless you can prove contrary
- **Principle 2:** Every effort (all practical steps) should be made to support the person to make their own decision
  - Ensure all relevant information available and accessible
  - Choose best time and location
  - build decision-making capacity



# Unwise Decisions and Risks



- **Principle 3:** Respect the person's decision even if it seems unwise
  - A unwise decision is not adequate reason to challenge capacity
  - Risks: cause for concern if the unwise decision is clearly irrational or out of character, or if it puts the person at significant risk of harm or exploitation (safeguarding issue)





## Guiding Principles cont.

- **Principle 4:** Do not intervene unless necessary
- **Principle 5:** Least restrictive approach and respecting the dignity, privacy and autonomy of the person
  - Minimise restriction
  - Respect autonomy
  - Intervention **proportionate** and **time limited**



## Guiding Principles cont.

- **Principle 6:** Permit, encourage and facilitate, give effect to their present and past will and preferences, and act in good faith for the benefit of the relevant person
  - This is **NOT a best interests** approach
- **Principle 7:** Consider the views of others that may be helpful



## Guiding Principles cont.



- **Principle 8:** Consider the urgency of the intervention, and likelihood of recovery
- **Principle 9:** Only obtain and use information in relation to the decision to be made

# Case Studies

## Risk, Unwise Decision- Moving Beyond the traditional approach



# Yvonne- Decision around Appropriate Housing



- Yvonne in her 50s, used to live in congregated setting, recent years in a community house.
- Entered hospital after a stroke, service stated they couldn't meet her needs after
- Pressure mounted to do Fair Deal and enter nursing home
- Advocate became involved, emphasised to all parties (HSE, hospital, family, service provider) that Will and Preference of Yvonne was community-based living
- Advocate challenged suggestion nursing care required
- Suggestions Yvonne lacked capacity to decide re; her own wellbeing, advocate escalated case with HSE to act on Yvonne's instruction that she didn't want to live in nursing home
- 1 year later, a suitable service was found and Yvonne in a new bungalow

**This case study shows the benefits of having an independent advocate on the side of a person to firmly ensure that their will and preferences are recognised and respected.**

# Jessica- Autonomy, Choice and Risk



- Jessica lived in congregated setting, needed assistance with meals
- Speech language therapist advised soft foods diet, risk choking
- This was against will and preference of Jessica
- Capacity assessment undertaken to demonstrate Jessica understood risk
- NAS advocate assisted Jessica to express will and preference for chopped food
- Service ignored stated wishes relating to diet
- Advocate assisted Jessica to engage services of a solicitor, sought independent review, agreeing to medical examination
- Following review, service agreed to chopped food diet again, and to allow Jessica eat out in restaurants when she wished
- **This case study shows a person with a disability can face a broad consensus on an issue amongst the health care professionals that work with them that is contrary to their will and preference.**

# Case Study- Respecting Will and Preference



# Jamie- Will and Preference in healthcare decision



- Jamie in his 40s, has an intellectual disability living a group home, had a life threatening illness some years ago
- Medical team recommended a procedure to avoid return of illness, family stated they didn't want Jamie to have the procedure, Jamie not informed
- An independent advocate assisted Jamie to find out his medical options
- Jamie expressed opinion he did not want the illness to return, and advocate helped Jamie communicate his will and preference
- Advocate pointed out that family have no role in consenting or refusing a medical procedure
- **ADM principles applied here- Jamie should not have been considered lacking capacity to make decision until all efforts made to allow him to express his will and preference**, in this case allowing Jamie to work with an independent advocate



[Advocacy.ie](http://Advocacy.ie)

National Line: 0761 07 3000

