From policy to practice – Consent, Assisted Decision Making and tools for practice:

# The role of advocacy in supporting decision-making, particularly during COVID-19


## NAS Regional Manager: Joanne Condon


NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES


# Article 12 UNCRPD

## -Removes barriers to Personhood-

- Dispel the Fiction of Rationality
- Irrational choices and bad decisions are a reality for all of us
- Dignity of Risk - Right to make bad decisions

NATIONAL ADVOCACY SERVICE
FOR PEOPLE WITH DISABILITIES

- Upholding the centrality of will and preference and personal autonomy in decision-making for people with disabilities has for many years necessitated the support of Independent advocates.
- NAS has much experience in supporting people to make their own decisions.
- Experience in establishing people's will and preference.

# About the National Advocacy Service

- Established 2005 as pilot projects, national company since 2014
- Funded and supported by the Citizens Information Board
- CIB statutory obligation to provide advocacy and a representative advocacy service for people with disabilities *(Comhairle Act 2000 & Citizens Info Act 2007)*
- Fully professional, independent, free and confidential service
- 50 paid, professional staff across Ireland
- NAS also launched a new, independent Patient Advocacy Service in October 2019 (patientadvocacyservice.ie)

# 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.

# 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).

# 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% |

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 Issue Categories

**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 choices, consent issues and meaningful engagement in defining treatment plans, mental health related issues.

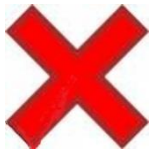
**Justice issues:** include Ward of Court cases, wills and probate, personal injuries claims, rights of residence and criminal cases.

**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.

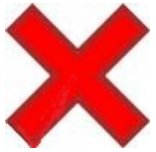
# NAS Advocacy code of practice: upholding Will and Preference

- 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.

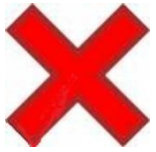
# Good practice: Things an advocate will not do:



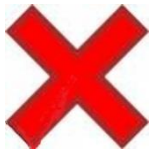
- Tell the person what to do



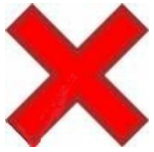
- Tell the person what decisions to make



- Make decisions on the person's behalf



- Give legal advice



- Act without the person's permission

# Case Studies
# -Covid19-

# Advocacy Issues: Covid-19

**Housing:** Homelessness, swift moves to inappropriate residential placements such as young people in nursing homes, lack of choice and involvement in moves, Restrictions to movement/liberty. 'Next of kin' decision making to remove people from services.

**Quality of Life**: Withdrawal of day services/Impact to routines/Job loss, loss of respite services, Withdrawal or reduction in home support services/PA services. Curtailment of meaningful daily activities. Complex safeguarding scenarios, curtailed visits with family/friends, isolation, domestic violence.

**Health issues:** Treatment decisions, consent issues, emergency hospital admissions, swift discharges from hospital, DNAR decisions, Covid-19 testing, self-isolation, window visits, disruption to critical mental health services, increased use of PRN medication.

**Justice issues:** Ward of Court cases, delayed court hearings, remote interim capacity assessments, waiting lists for free legal aid.

**Parenting with a Disability**: curtailment of access, online/phone access only with children, Court hearings postponed/delayed.

# Joy – Emergency admission to hospital

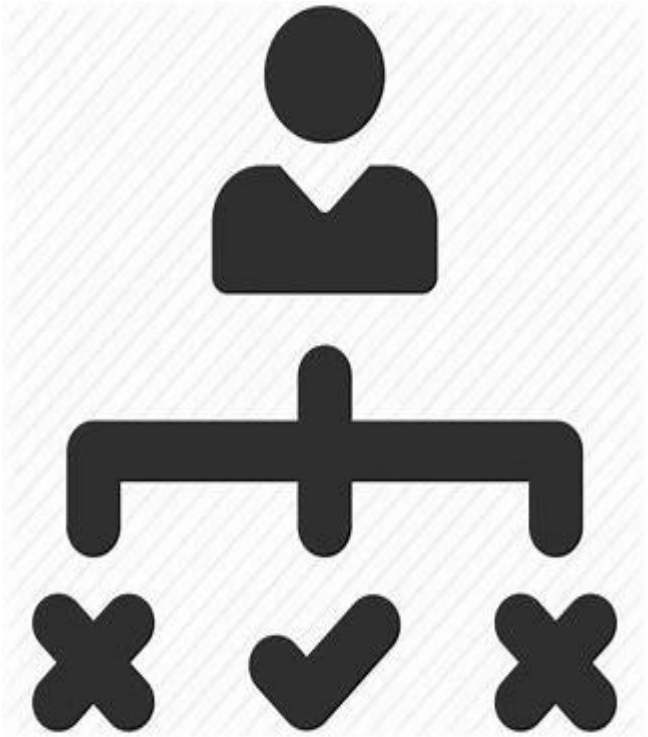
- Joy is 48, has a physical & I.D, lived with her sister Amy.
- Joy was admitted to ICU in April due to **suspected Covid-19.** Tested negative, but diagnosed with a number of other serious medical issues.
- Hospital wished for **sister to attend meetings and make decisions** for Joy in relation to treatment, DNAR and onward placement and were ignoring Joy's expressed request for Amy not to be involved.
- The Advocate pointed out that **family have no role in consenting or refusing** a medical procedure and helped to communicate Joy's rights and wishes in line with the HSE Consent Policy.
- Hospital then wished to **discharge Joy to a nursing home.** She had lived in a NH previously, which she hated and expressed that she would abscond if she was moved there. Hospital sought to have a **capacity assessment** carried out so that Joy could be returned to the NH if she tried to leave once moved there by aiming to demonstrate that she did not have the capacity to make decisions.

# Joy – Emergency admission to hospital

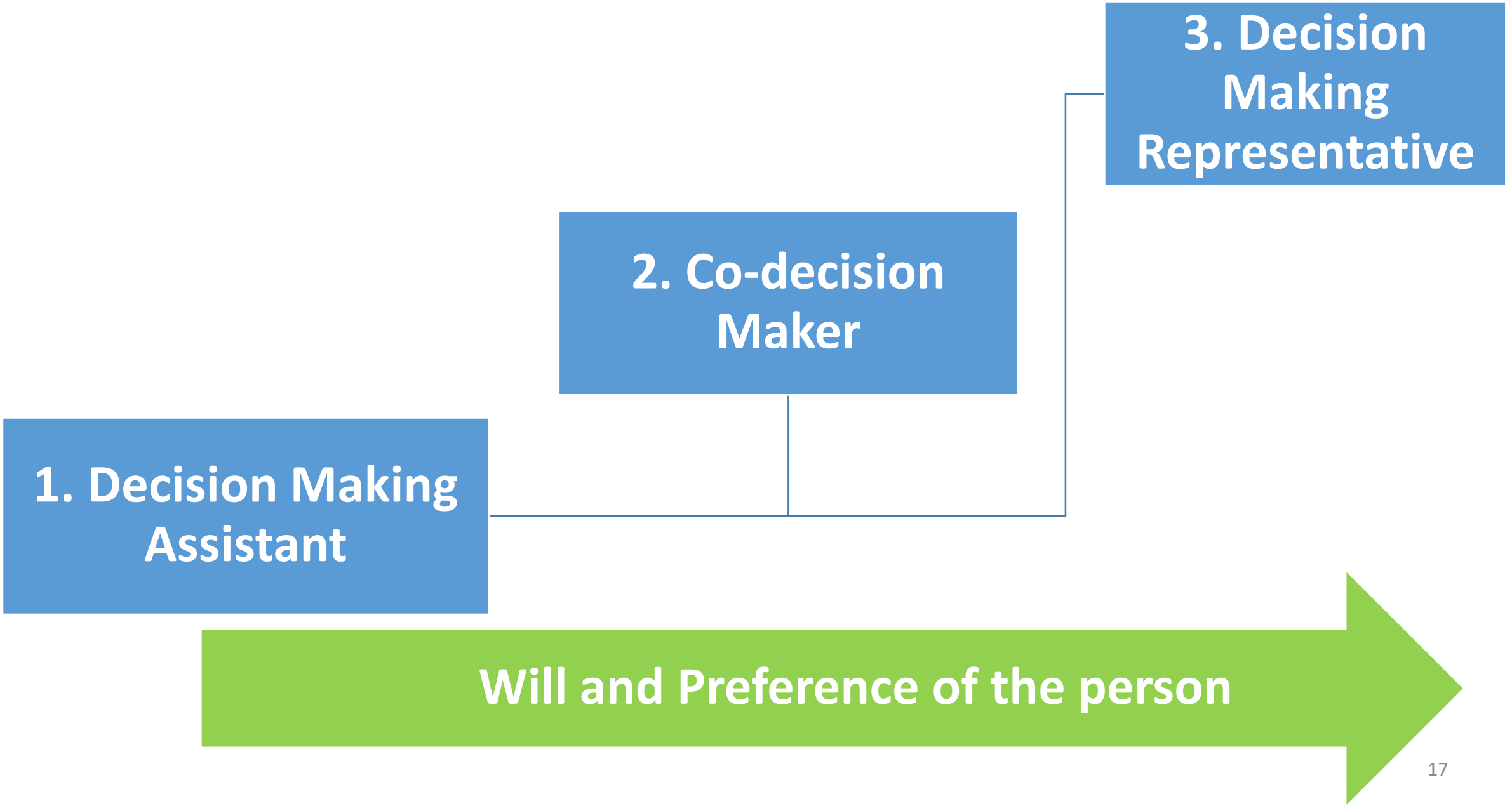
- The Advocate upheld Joy's **right to presumption of capacity** and sought for a Speech & Language Therapist to become involved to support Joy **to communicate her will and preference.**
- The Advocate also highlighted that the least restrictive range of options **(proportionality)** had not been explored and upheld the person's human rights by highlighting the FREDA principles to those involved.
- The person was supported by the advocate to seek out specialist supports and an up to date needs assessment to help determine what options might exist for the person with regard to living **options after discharge** from hospital.
- The correct process was followed to establish a **DNAR** for the person by her consultant and **Amy was not invited to meetings** in keeping with Joy's wishes.

**ADM principles applied here - Joy should not have been considered as lacking capacity to make decision until all efforts were made for her to express her will and preference. Interventions were not proportionate and capacity was not assumed. Best Interest decision making was evident.**

# Where does Independent Advocacy fit with Supported Decision Making & the ADM (Capacity) Act?



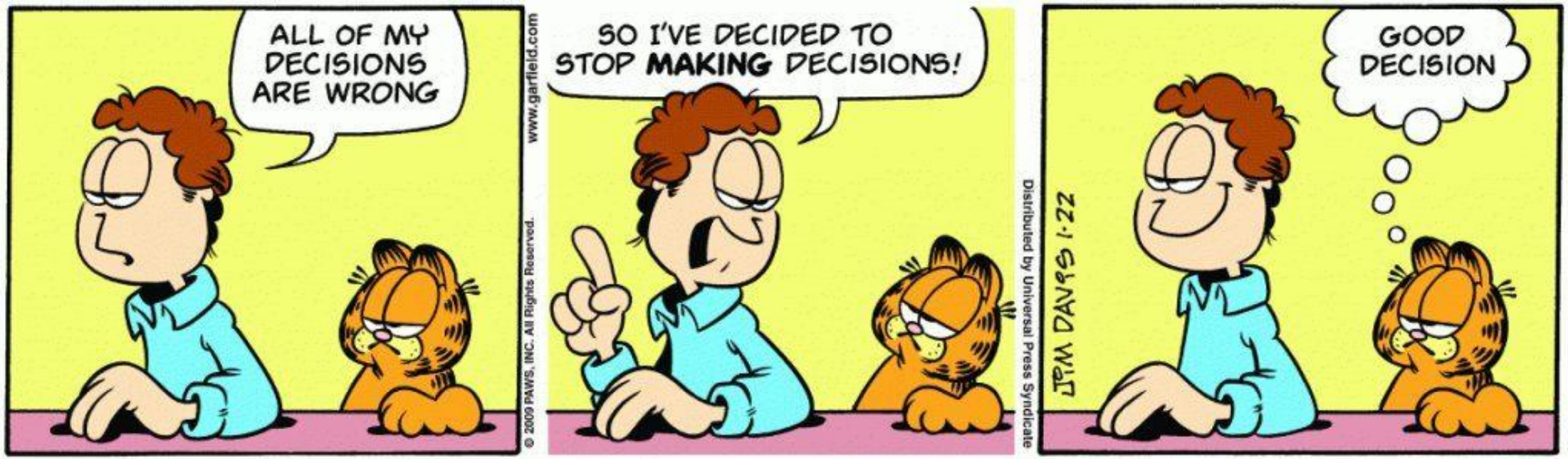
# FORMAL DECISION-MAKING SUPPORT OPTIONS

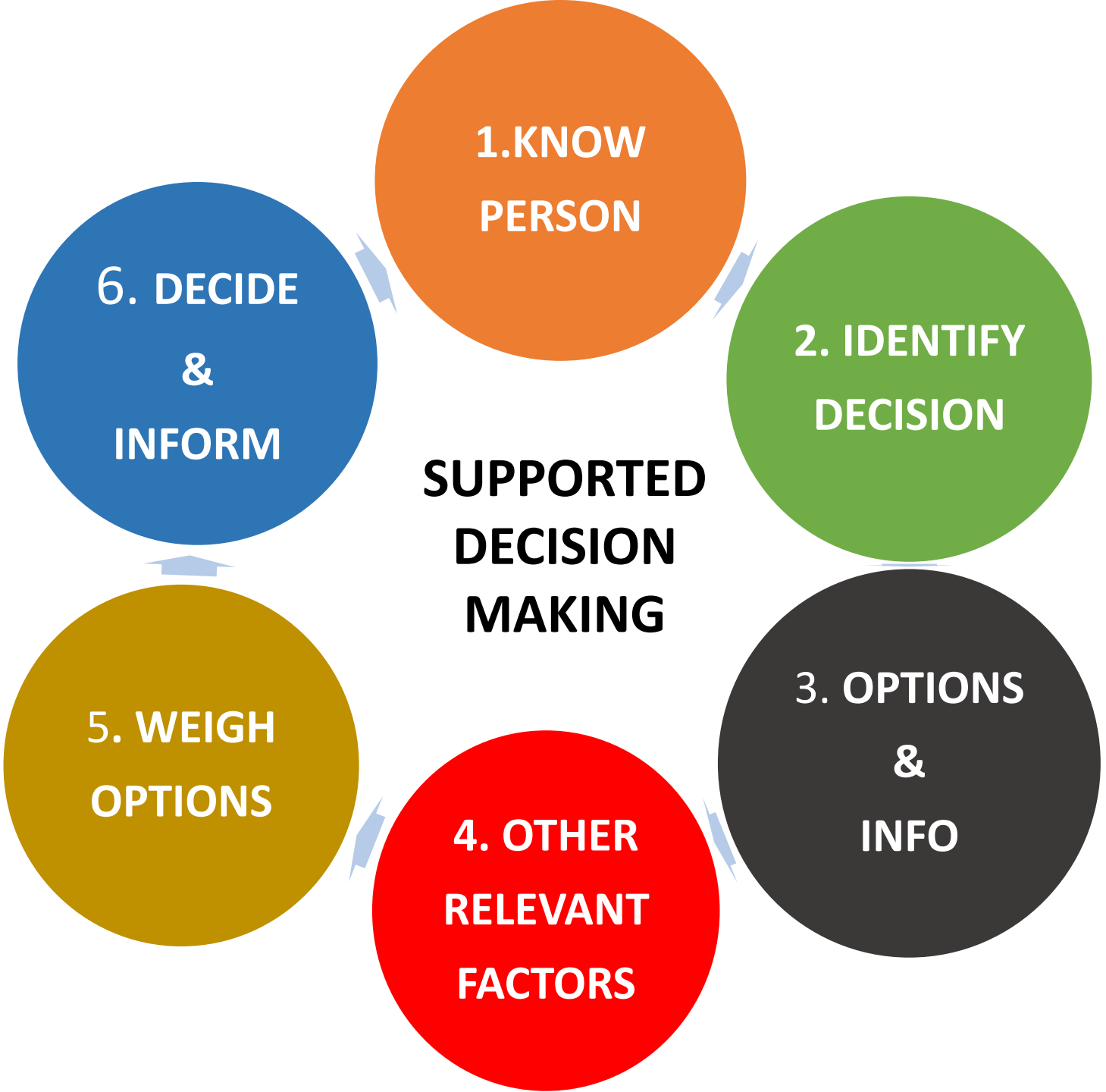


# Advocacy issues that could arise for those with decision supporters under the ADM

- ❑ A decision-making supporter is helping with decisions that are not included in the agreement
- ❑ Where due process has not occurred (tokenism)
- ❑ Where intervention has occurred but was unnecessary / prolonged
- ❑ Where proportionality has not applied
- ❑ Person's right to unwise decisions is not being respected or coercion exits
- ❑ Where misrepresentation of/over-riding of will & preference occurs
- ❑ Ill treatment has occurred by decision making support person
- ❑ Support to raise such complaint to the Decision Support Service where necessary

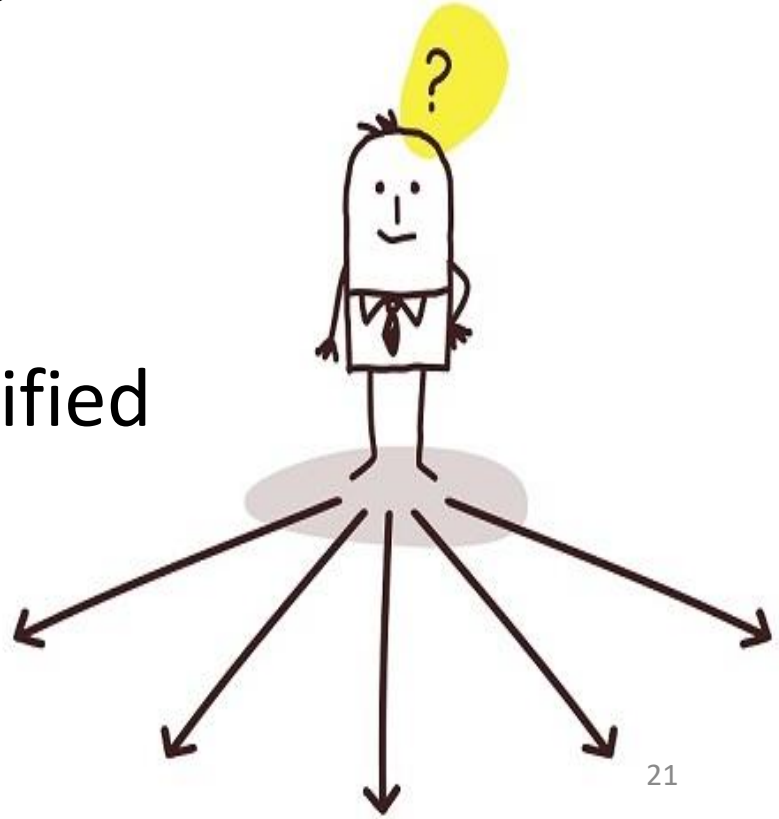
# The supported decision making process -What is involved?-




1.KNOW PERSON
2. IDENTIFY DECISION
3. OPTIONS & INFO
4. OTHER RELEVANT FACTORS
5. WEIGH OPTIONS
6. DECIDE & INFORM
SUPPORTED DECISION MAKING

# INGREDIENTS FOR SUCCESSFUL SUPPORTED DECISION MAKING

- Individually tailored
- The quality of the relationship
- Start with small decisions and work up to big ones
- Links similarities to previous decisions made
- Practice makes perfect
- Document the process
- Account for how will & preference was identified
- Opportunity to experience
- Process empowers and supports
- Not falling back into ‘Best Interests’



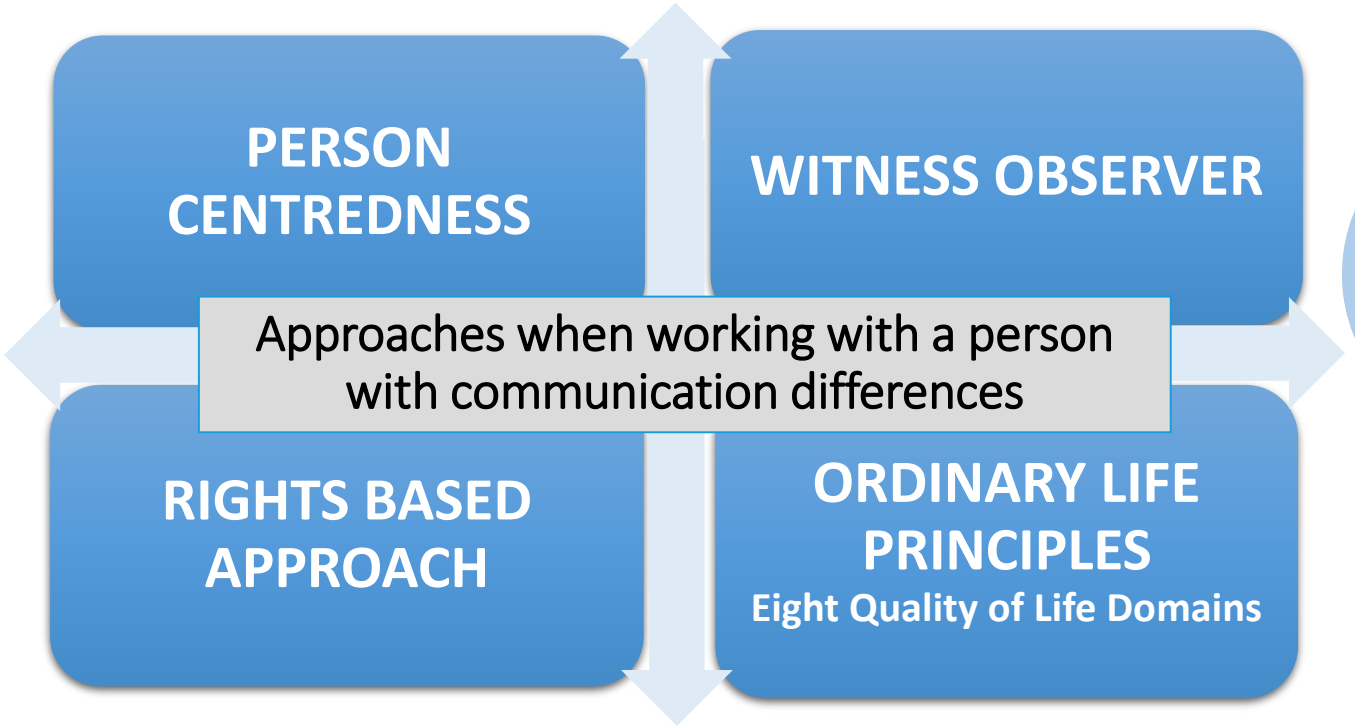
# Jane's Story: Representing will & preference

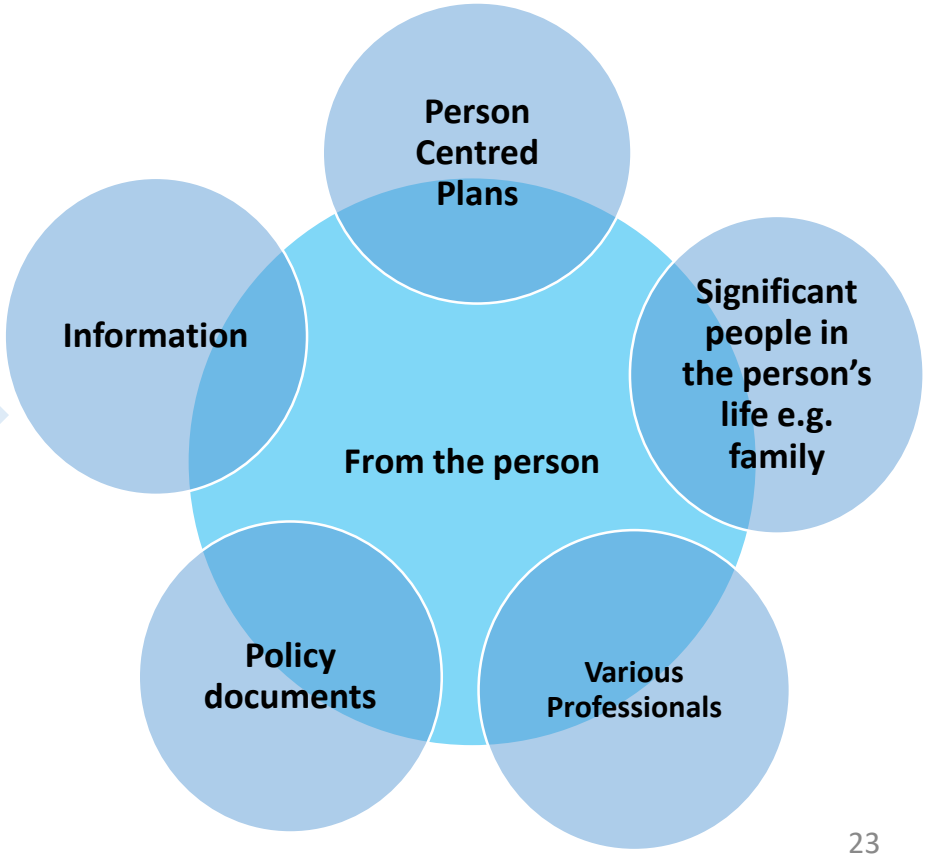
- Jane is 40 and has an intellectual disability. Lived all her life in a rural community with parents. Inherited the family home when parents died. **Ward of court** for many years. (Lunacy Act)
- Jane contacted NAS as she was unhappy about how her committee was making decisions about her life **without regard for her wishes.**
- Jane's committee began to make decisions about her property, money and life without speaking to her. They felt it was too high risk for Jane to live independently and that it was in her **best interests** to live in a residential service. They wanted to sell Jane's home.
- Jane was **supported by her advocate to represent her will and preference** to keep her home and remain living there by writing to the President of the High court to ensure her voice was heard.
- The advocate also assisted Jane to engage with various professionals who could help Jane identify the **supports she would require to live independently.**
- Jane's **will and preference was upheld** and she was able to continue living independently in her home with additional appropriate supports in place to enable her to manage her finances and household tasks.

**This case study highlights the role of the advocate in ensuring the voice of the person is heard when decisions are being made about their life and how representing the person's will and preference can lead to more positive outcomes for the person.**

# Supporting the will and preference of 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.




"I'M SORRY. WHAT OTHER OPTIONS ARE THERE?"

# Advocacy.ie

# National Line: 0761 07 3000