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

# Tools to support decision-making capacity: what works in practice

## Ascertaining will and preference with people who need support with decision making

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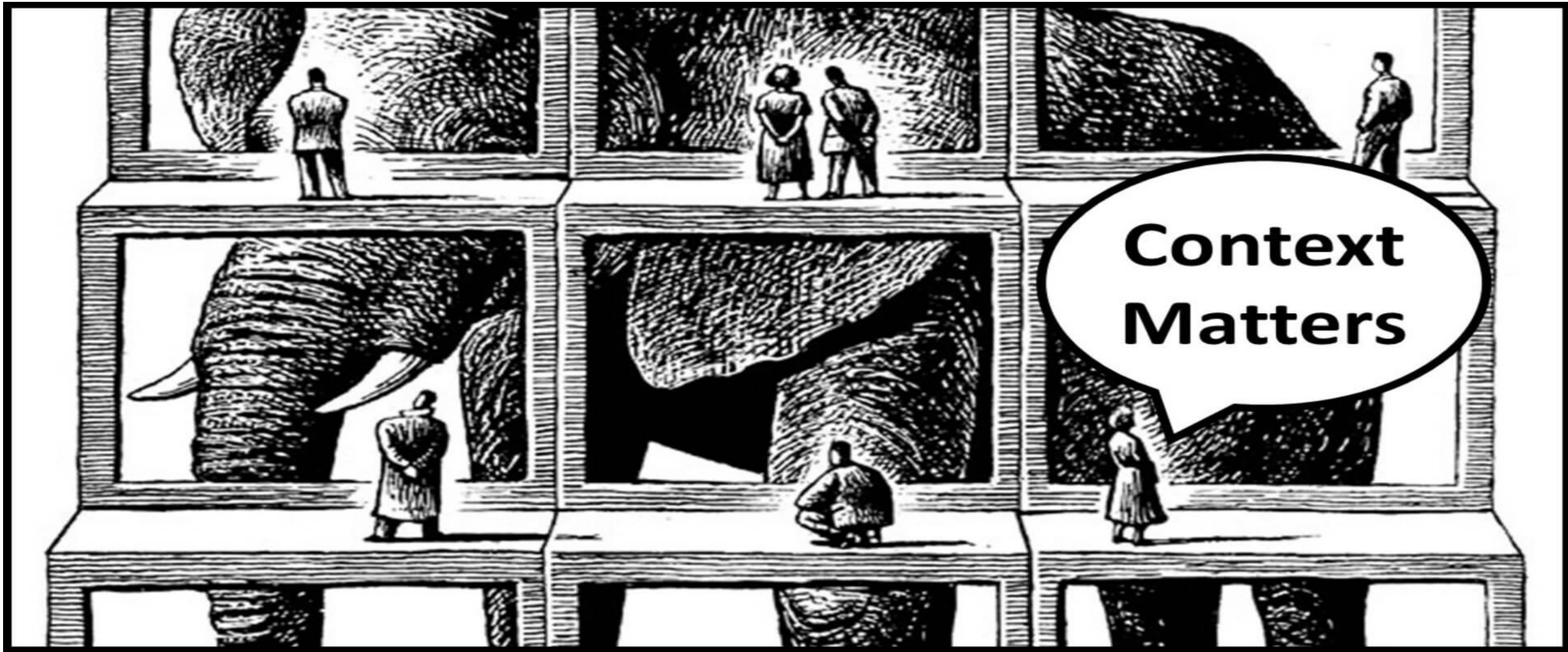
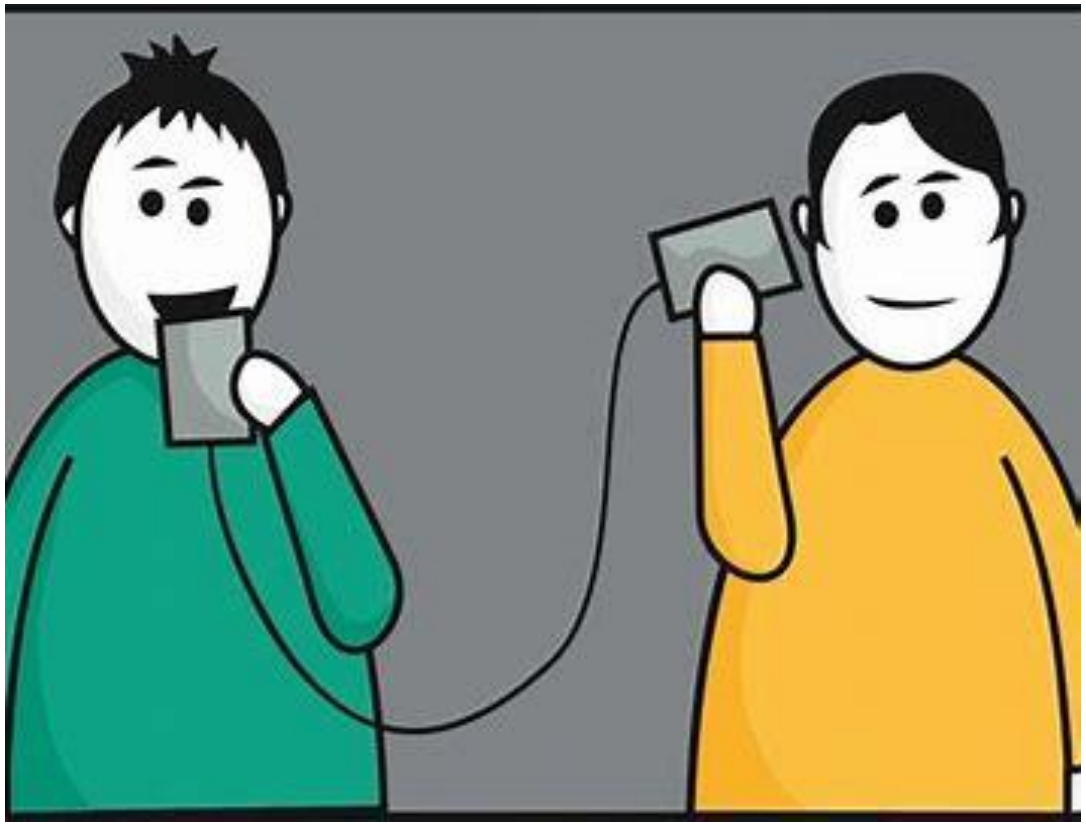
NATIONAL ADVOCACY SERVICE FOR PEOPLE WITH DISABILITIES

**The UNCRPD's supported-decision making model recognises that <u>ALL</u> people have the right to make decisions and choices about their own lives.**

*Arlene Kanter*

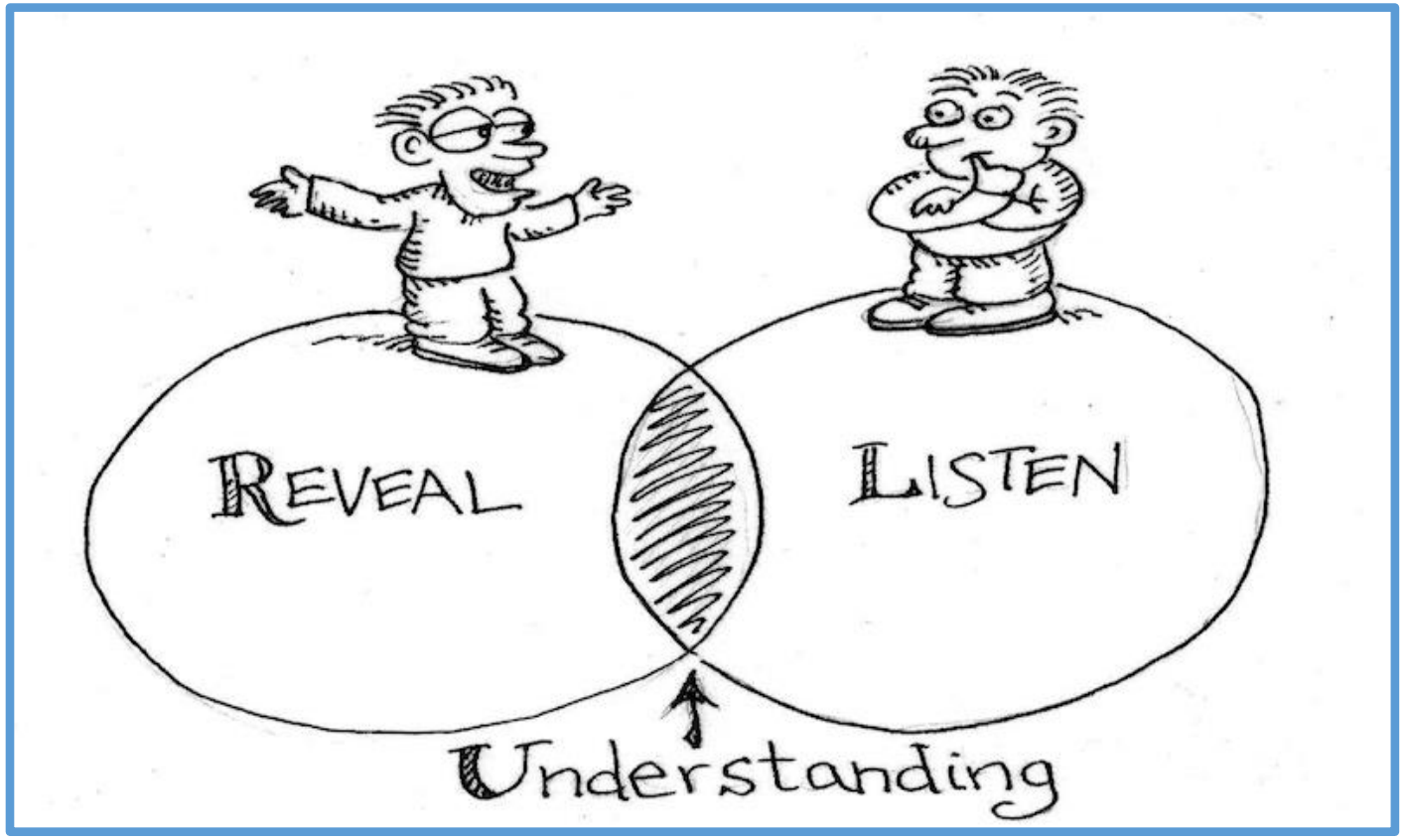


# Supporter responsiveness is key



A supporter's willingness to see the person beyond their disability is found to impact their responsiveness to the expressions of preference of those they support *(Watson, 2016)*

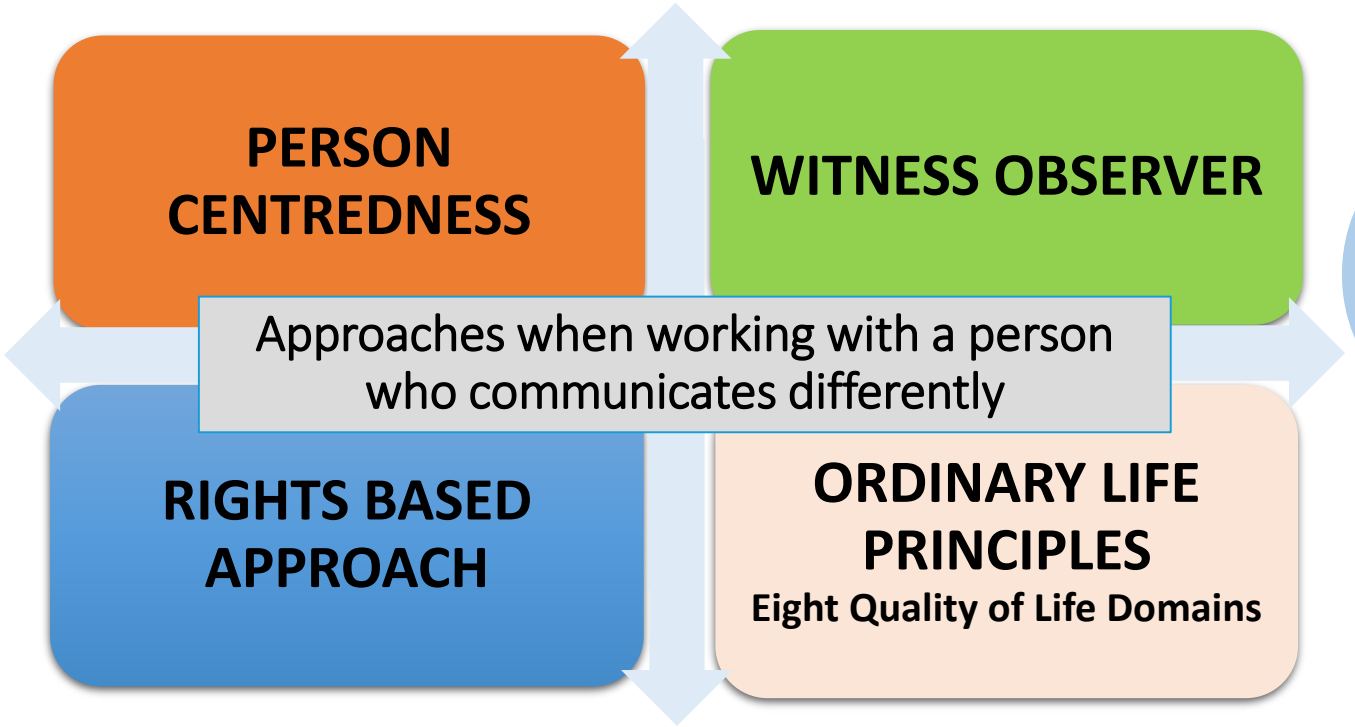
# The question is not does the person have the capacity to communicate will and preference

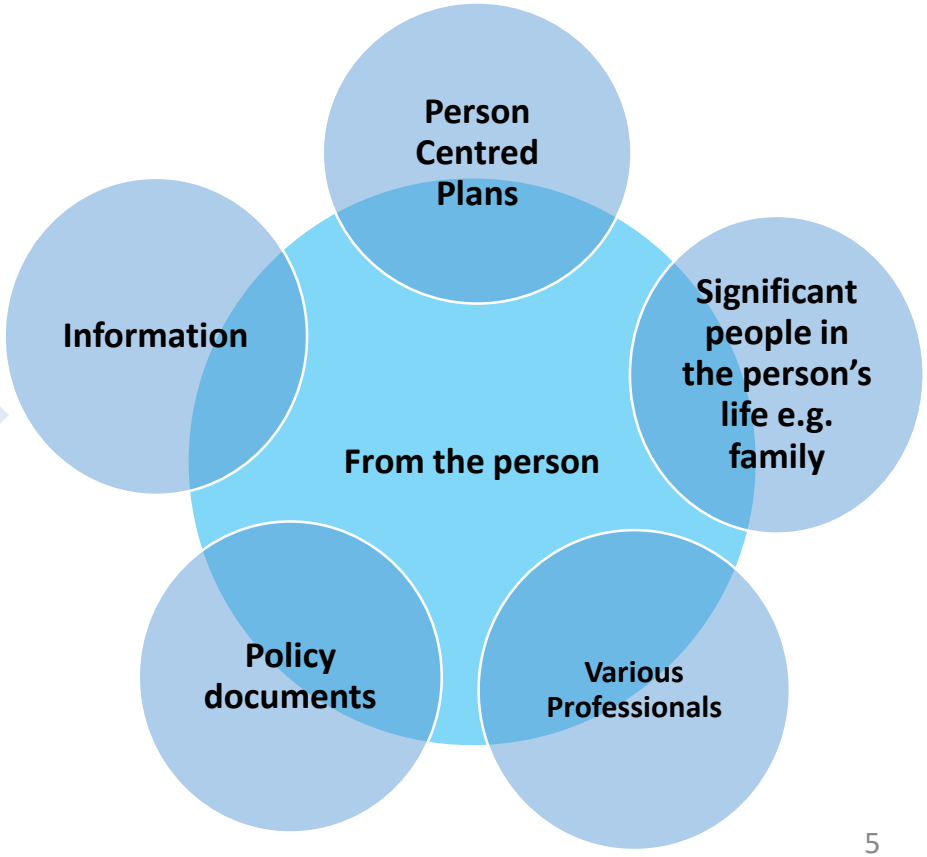



# But do we have the capacity to establish the person's will and preference?

# Supporting the will and preference of those who communicate differently

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 (restrictive OT recommendations) *healthy cynicism
- 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.

# What was the outcome?

- It was accepted that the person required a **new service and appropriate supports** and a potential service was identified and **information gathered by the advocate was used to inform** a transition plan and person centred plan.

- The person **obtained a service which was far less restrictive, with appropriate supports and with a focus on promoting their abilities.**

- The person now **showers and dresses independently** (their love of fragrances was an enabler to supporting capacity to be built!), can **make breakfast** with minimal supports, engages in service in the **community**, goes **shopping** with support and many other **meaningful activities**. Leads a far more meaningful and 'ordinary' life.

## SUPPORTER RESPONSIVENESS

- Deficit view of person
- Decisions made for person
- Poor quality of life
- Misunderstood
- Needs unmet
- Focus on ‘safety’
- Focus on stopping behaviours
- Restrictive practices
- Chemical restraint
- Focus on protection

- Person’s will and preference, needs communicated with decision makers.
- Decisions based on these: new service
- Person’s rights upheld
- Strengths based approach
- Challenge assumptions
- Focus on understanding what behaviour is communicating
- Focus on Quality of life
- Promotion of abilities
- Focus on support & capacity building
- Dignity


**Decision making representatives are bound by the ADM (Capacity) Act to give effect to the person's will and preference in the decisions being made.**

But there is nothing in the Act that requires the decision making representative to meet the person and nothing that sets out frequency of meetings that should occur.