



PRINCIPLES OF ASSISTED DECISION MAKING – REFLECTIONS FROM PRACTICE

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GENERAL INTRODUCTION TO OUR SERVICE

- St. Michael's House (SMH) – A Section 38 community based voluntary provider of services for people with an intellectual disability.
- Serves the Greater Dublin area in 170 locations.
- 1,920 Service Users – 1,061 of whom are adults.
- Two short case examples to illustrate factors we have traditionally considered in situations where a complex decision needs to be made.





CASE EXAMPLE 1:

Summary of the request for support:



This request was received in 2012.

- Couple attending SMH day service approached staff and asked if they could share a room on an upcoming holiday with the unit.
- How staff offered support to the couple
- Empowerment v Protection.





STEPS TAKEN IN 2012

- Met with couple to discuss the request
- Staff asked their consent to discuss with PAIRs
- 'Capacity check' - informally
- Family & residential involvement
- Training / education (including information on contraception)
- Support for staff going on the holiday

- One issue - SU was concerned about informing family who were unaware of the relationship.
- Organisation made the decision to support the request and respect SU wishes re family.





OUTCOME

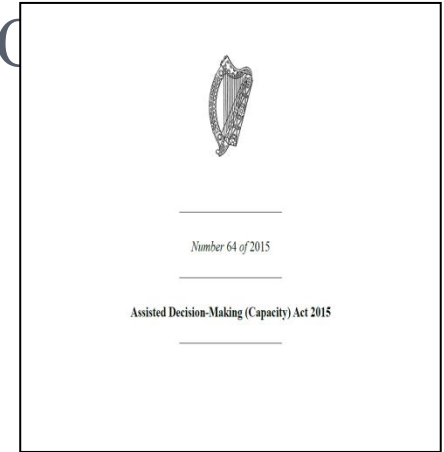
- Lady was encouraged to discuss this with her mother which happened – positive result.
- Holiday was really successful
- Staff felt very supported as they were supporting the couple following policy.





WHAT WE WOULD DO DIFFERENTLY IN LINE WITH ADM - GUIDING PRINCIPLES

- **Assume capacity.**
 - Staff would act as Capacity Enhancers.
- **Maximising capacity** and supporting decision making
- Support the couple's **will and preference** which was clearly stated.
- **No interventions unless necessary** – request supported by unit staff without needing to refer to PAIRS.
- Limit **scope of interventions.**





CASE EXAMPLE 2

- 49 year old gentleman in full time residential care
- Friendly engaging man – very close to his Dad
- Diagnosis of ASD and communication predominantly echolalia
- Regular fluctuations in respiratory status and history of aspiration pneumonia
- Loves going out for a coffee
- Values his independence





THE CONFLICT

- Videofluoroscopy - aspiration on Regular, Grade 1 and Grade 2 fluids
- Recommended Grade 3 thickened fluids (similar to the thickness of room temperature honey).
- Significant impact on Quality of Life
 - Communicating distress
 - Risky behaviours
 - Impacting on ability to engage with daily activities
 - Activities restricted
 - High level of supervision at all times





HOW WE USED TO ACT

- Best interest
- Withdrawal of care



This case was 2 years ago- trying to move towards ADM principles although not fully there yet

In 2018:

- Listened to the person's perspective
- Gather views from people important to the person.
- Think in terms of Will and Preference
- Support 'unwise' decisions
- Come up with a solution that suits the individual



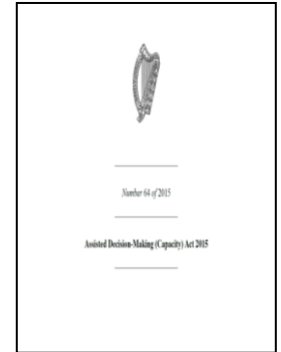


THE OUTCOMES

- Drinks regular fluids
- Gentleman is more content
- On prophylactic anti-biotic
- Regular review from Dr. and the team
- Staff are provided with regular training to increase safety at mealtimes
- No perfect solutions
- People close to the person feel that we are acting in line with his Will and Preference



WHAT WE WOULD DO DIFFERENTLY IN LINE WITH ADM- GUIDING PRINCIPLES

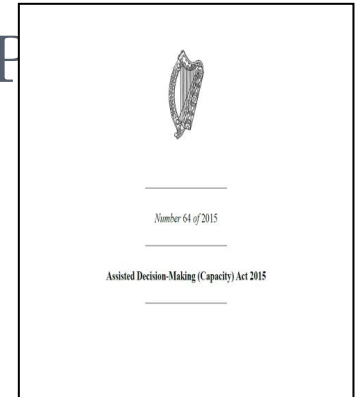


- Intervene only **when necessary**- least restrictive and respect the person's rights
- What is an 'unwise 'decision- **bias, risk, rights, choice?**
- **Support decision making** - all forms of communication are valid. People with complex communication difficulties can make their **will and preference** known with the right supports
- Supporting people to make their own decisions is an **emotive area** for many staff working in disability services. A cornerstone of delivering person-centred services. Develop staff support structures





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WORK DONE... MORE TO DO!

WHAT WE CAN
CONCLUDE IS MORE
WORK NEEDS TO BE
DONE.

QUOTE-ID.COM

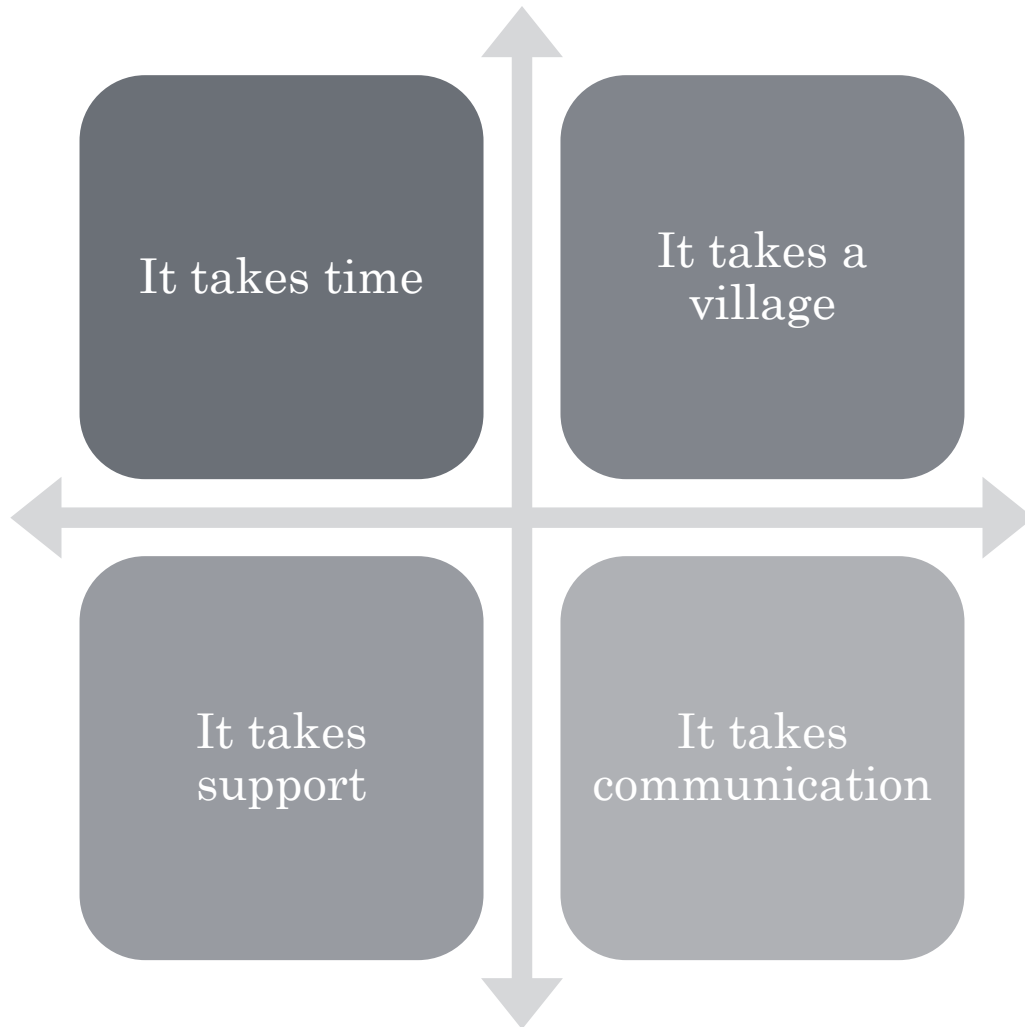
Bill Nelson
American Politician

- Reviewed the ADMCA and identified the opportunities and challenges for each stakeholder group (Service Users/ Staff/ Families)
- Established a Multi-Disciplinary Steering group
- Researched- What decisions are currently made and what supports are in place?
- Reviewed current organisational policies and practices to identify what changes are needed
- Developed a Work Plan (using implementation science)





USING THE ACTIVE IMPLEMENTATION FRAMEWORK TO GUIDE US:





KEY QUESTIONS AND MORE QUESTIONS...

- Can we use existing structures and systems to imbed ADM principles?
 - How do we know and record will and preference?
- Culture eats strategy for breakfast- how can we win hearts and minds?
 - Start with the adults who receive services
 - Build case stories and examples
 - Positive risk taking
- How do we respond now in the absence of commencement of the ACT?
 - Support decision making when possible
 - Refer to the advocacy services as needed
 - Wardship as a last resort



WORKING IN PARTNERSHIP

Themes

St. Michael's House

Assisted Decision Making (Capacity) Act (ADM) 2015

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People make decisions all the time.
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Sometimes staff support service users in St. Michaels House to make decisions.
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The ADM Act will help people when they need support making decisions.
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Person Centred Plans will make sure people can make their own decisions or get the help they need to make a decision.
- DRAFT TBC**



Service users must get information about their decisions in a way that they can understand.
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 This Easy to Read Poster was produced in conjunction with Noyle Road Easy Road Consultation Group.

