ST. MICHAEL'S HOUSE
Services For People With Disabilities

Seeing the Person, Shaping the Care: Supporting People with Intellectual Disabilities in Hospital with Progressive Illness

Muireann Ní Riain
CNS Acute Hospital Liaison

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Contents

- Who are St. Michael's House?
- Who are people with intellectual disabilities?
- Why do they go to hospital?
- Experiences in hospital
- Reasonable adjustments - Supporting People in Hospital
- Hospitalisation Journey with Progressive Conditions
- Supporting Planning for People with progressive Conditions
- Liaison support available

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2600

Service Users

86

Residential Homes

3

Respite Services

35

Day Services*

16

ASD Services

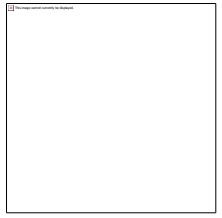
14

Training Centres

7

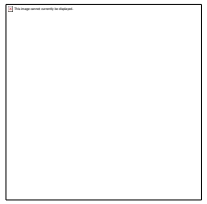
Special National Schools

1



Purpose Built Leisure Centre

5



Social Platforms

1,943

Staff in St. Michael's House

*Including main day services (6), Local Centers excl. ASD services (20) and Hubs (9)

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People with Intellectual Disabilities

- Complex population
- 1.4% of Irish Population (CSO 2016)
- Affects how a person learns and how a person communicates
- Can have complex range of challenges in
  - Understanding and processing new or complex information
  - Learning new skills
  - Coping independently
  - Physical and medical needs
- Wide spectrum of support needs from living independently to requiring 24/7 full nursing supports

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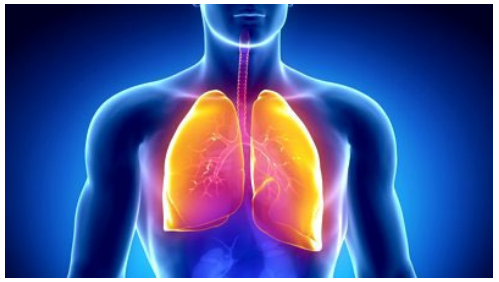
Health and People with Intellectual Disabilities

- Differing pattern of health than general population
- Increased prevalence of medical conditions and co morbidities (Emerson et al 2012, McCarron et al 2011, McCarron et al 2014, Landes et al 2021)
- Access to healthcare difficulties is complex
- Evidence of premature mortality/ Avoidable deaths that could be avoidable by good healthcare (CIPOLD; Heslop et al 2014; White et al 2024)



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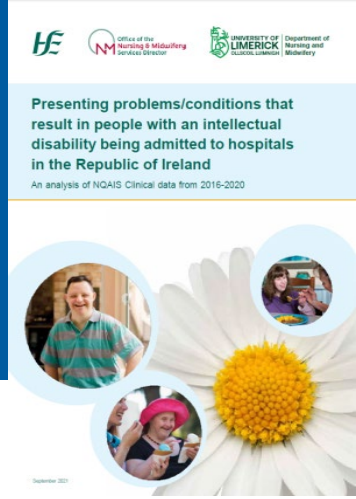
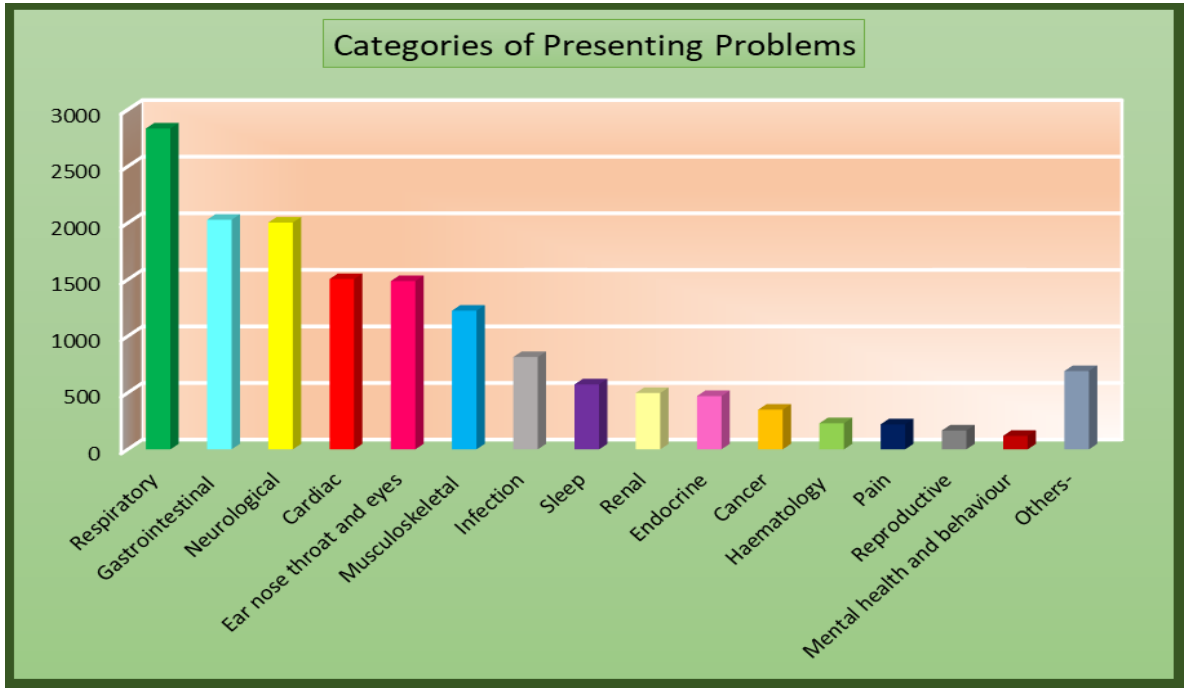


NQAIS Analysis 2016 –2020



Presenting Problems (Adults & Children)

- Respiratory (RTI/ Pneumonia/ Pneumonitis (food/ vomit))
- Gastrointestinal (Nausea &Vomiting/ Gastroenteritis/ dental caries/ constipation)
- Neurological (Epilepsy/ convulsions)

Doody, O., McMahon, J., Lyons, R., Moloney, M., Hennessy T. and Ryan,
R. (2021) *Presenting problem/conditions which result in people with an intellectual disability being admitted to acute hospitals in the Republic of Ireland: An analysis of NQAIS clinical data from 2016–2020. Limerick: University of Limerick and Office of the Nursing and Midwifery* Service Director, Health Service Executive, Ireland

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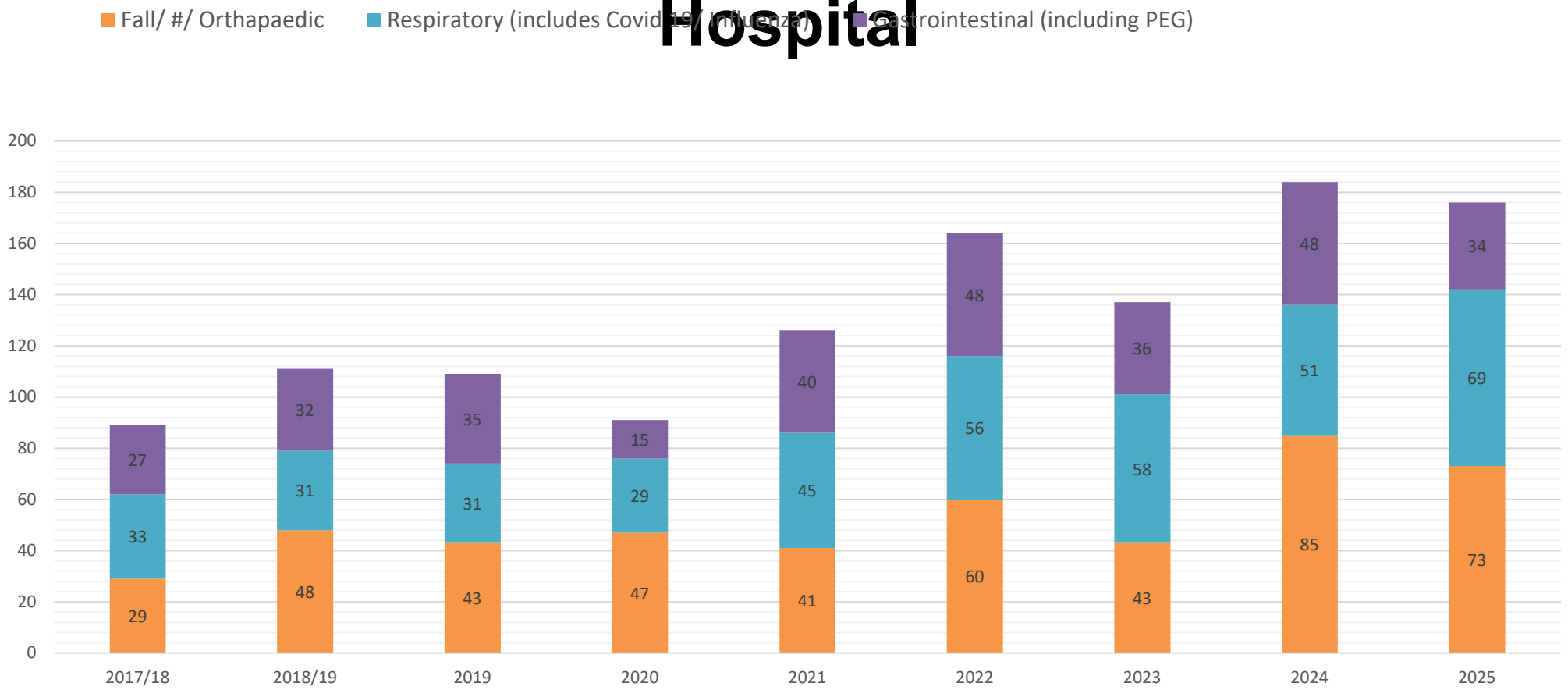
SMH Reasons for Presentations to Hospital



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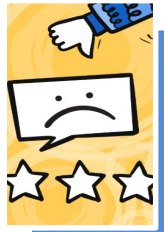
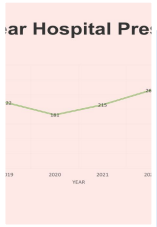
Challenges in Healthcare Provision



Very poor experiences

Lack of effective advocacy

Difficulties Accessing Services



Longer stays in hospital and evidence of inadequate care provision (Sheehan et al 2016)

Health Inequalities and poor healthcare

Lack of reasonable adjustments (Heslop et al 2013)

Diagnostic Overshadowing - **Seeing the disability not the illness**

Lack of organisational awareness and accountability for needs (Tuffrey-Wijne et al 2013)

Rights in Healthcare - “Everyone has the right to make decisions about their own treatment and care”.

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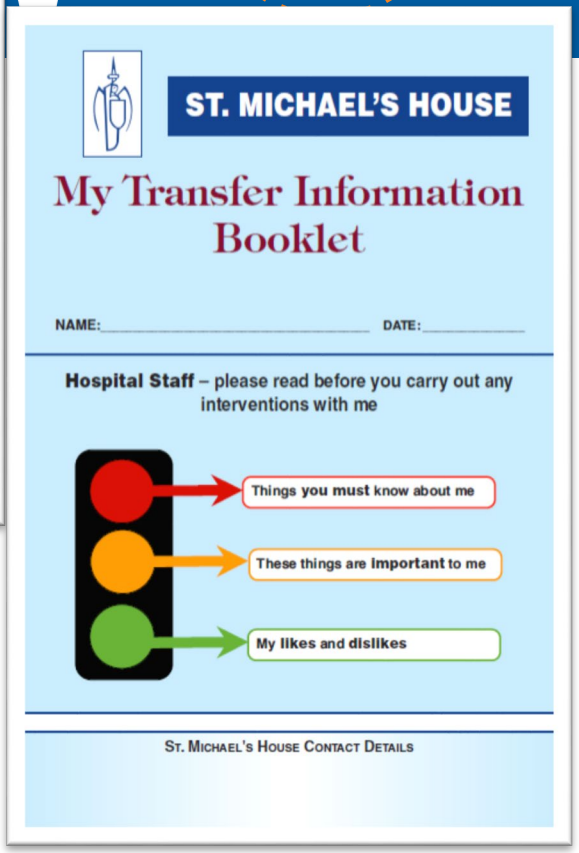
Reasonable Adjustments



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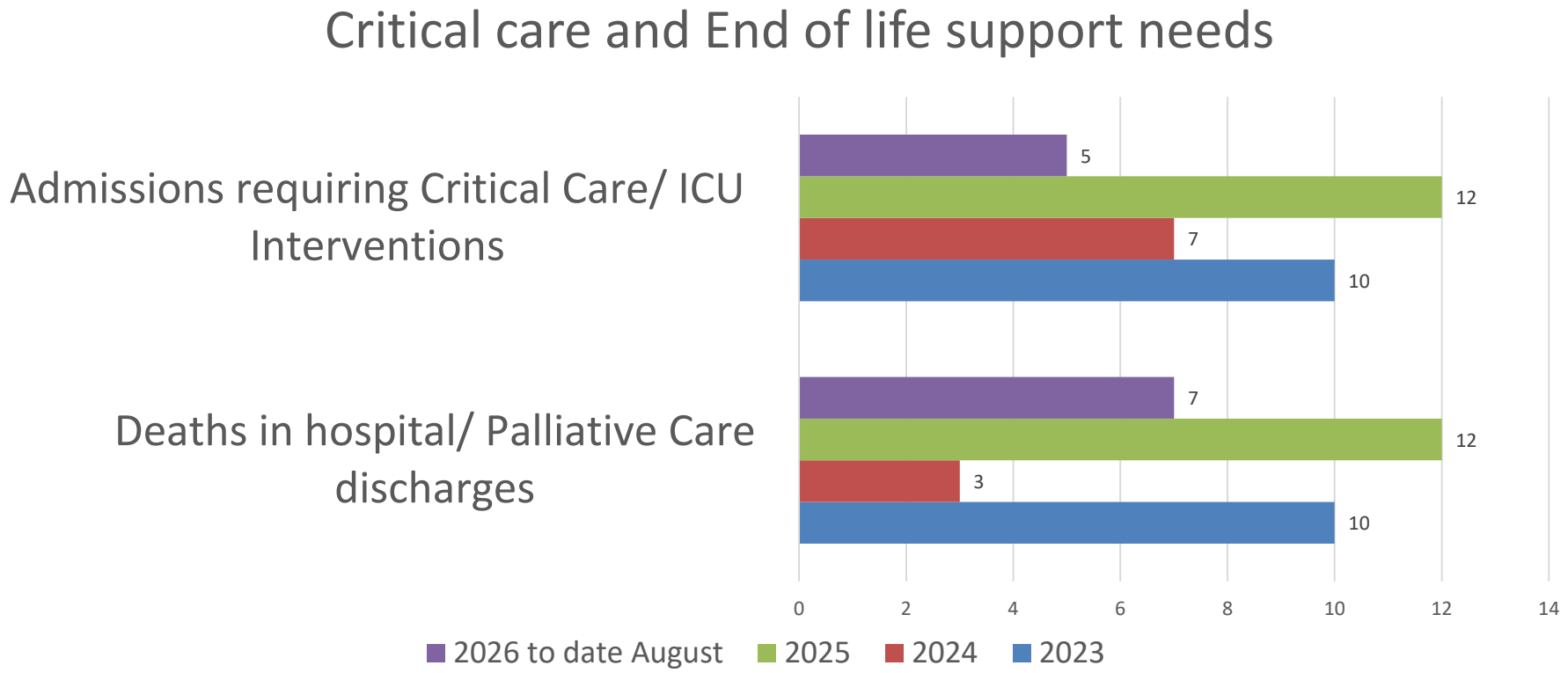
Hospitalisation Journey with Progressive Conditions



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Supporting People as their Condition progress

Goal – having the conversations at the right time for where their condition/ illness is to support the quality of life they want and as needed towards a good end of life in a calm supported manner

What can obstruct or hinder this–

- Ongoing hospitalisations and acute interventions that have minimal impact on a person quality of life until they arrive in ED and are told the person will not be going home
- Assumptions made that a person with intellectual disability does not have a quality of life when outside the acute system
- Blanket DNR in place or that it is expected that a person should be DNR
- Poor communication of the levels of medical interventions/goals of care for a person and due to that poor understanding of differences and impacts on a person
- Not having a conversation
- Start of conversations in hospital but no follow up plan or pathway in place to follow through

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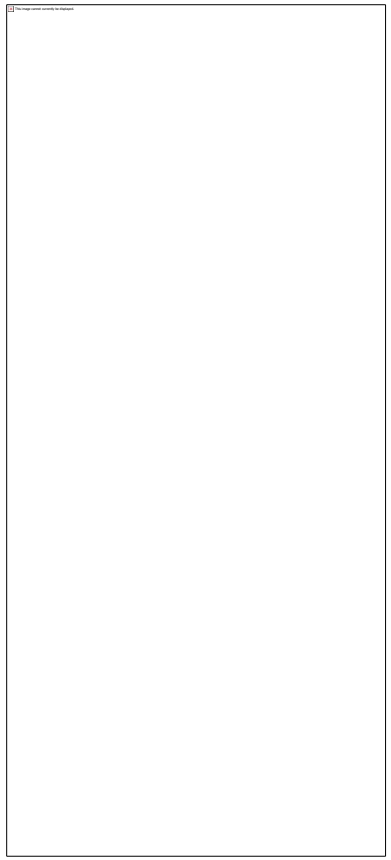
Martina



- Lady with mild/ moderate intellectual disability with unstable insulin dependent diabetes
- Multiple hospitalisations for diabetes management in her life and as she aged co morbidities increased and overall decline in her condition was seen
- Issues with infection, mobility secondary to lymphoedema leading to increase of hospitalisation frequency
- CNM in her home worked on getting Advanced Healthcare plan in place as the lady was verbally saying she did not wish to continue into hospital
- Liaison with the hospital about her long term management but no engagement about her future health presentation or acknowledgement of the impact of her condition on her quality of life with multiple discharges home with changed needs and no advanced care planning
- Final admission into hospital with significant antibiotic interventions and critical care at HDU level with no response so end of life supports were commenced.
- She dies in hospital with family and SMH staff supports with her but was that where she wanted to be??

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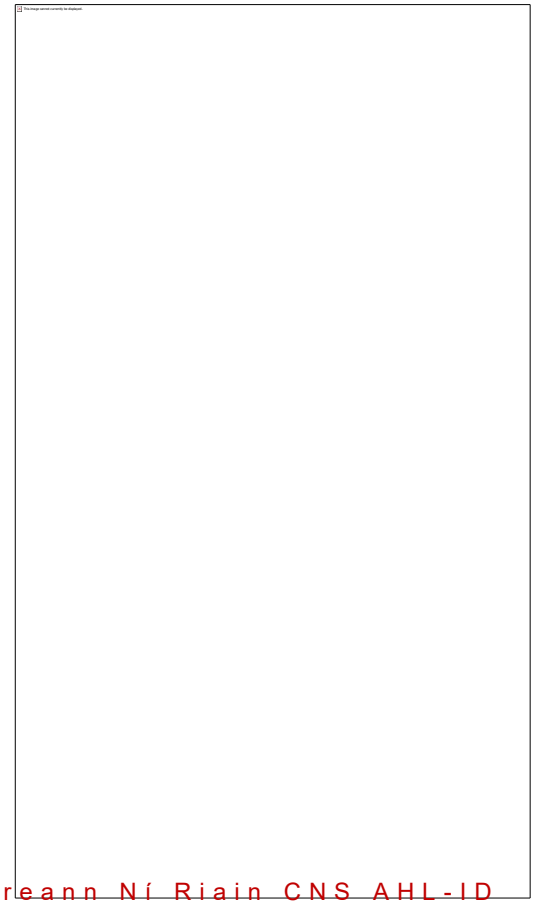
Martin



- Genetic condition with associated intellectual disability and complex epilepsy
- Recognised life limiting condition which was supported by paediatrician in childhood and transitioned to adulthood supports with neurology input from acute care
- Full support in SMH residential and day services with life interests
- Nurse support day to day with wider clinical input as needed and modifications to care as he grew and developed
- Regular hospitalisations in his life for epilepsy management and associated issues i.e. respiratory distress/ infection.
- CNS AHL involvement for nearly 10 years

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Martin

2017/2018

Recognition of life limiting condition, ongoing hospitalisation and ongoing risk of possible SUDEP - he was well at the time of discussion

Advanced Care Directive in place for SMH but DNR but for ongoing hospitalisation for IVAB

2019 – 2021

Multiple visits to hospital with seizure management/ aspirations, challenges in maintaining medication and nutrition

2021

Gastrostomy inserted primarily for AEDs and as required nutrition

2021 – 2024

Ongoing hospitalisations but severity not as acute and quality of life maintained but observed to be deteriorating with decreasing mobility and less interest in oral diet.

Increasing aspirations so main nutrition via gastrostomy with oral tastes when able supported by SLT and MDT

2024-2025

Increasing acute hospitalisations with shorter lengths in between and definite poorer quality of life/ involvement in activities.

Family receiving calls from ED about acuity/ seriousness

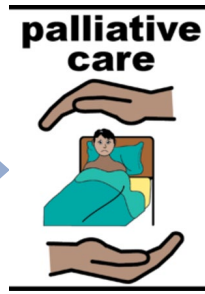
Late 2024/ Early 2025

SMH MDT with family — NPO and recognition of deterioration but ongoing hospitalisation agreed

Mid 2025

Final hospital admission with discharge support with Community Palliative Care

Died in his SMH home with family and SMH staff supporting him



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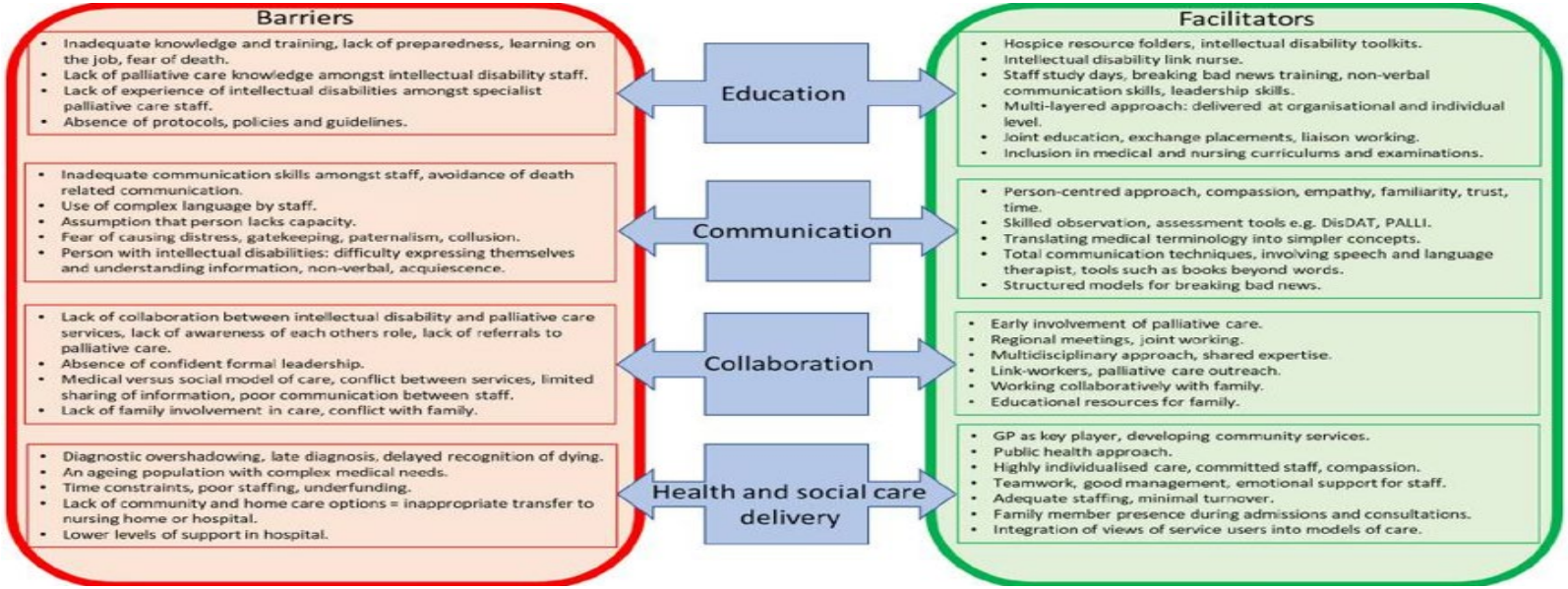
Palliative Care and People with Intellectual Disability

- MOST likely to go well: Access to hospital when needed.
- LEAST likely to go well: Involving the person in decisions; working together with other services. (Tuffrey Wijne, I 2021)



(Adam E et al 2020)

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Things to consider

- Progressive illness and life limiting conditions can progress for some time with very acute phases and long periods of stability
- People with intellectual disability are resilient and adapt to new quality of life many times
- Families have been on a cliff edge on numerous occasions so consideration needs to be given
    - Who has spoken to them before and what expectations do they have?
    - Review of hospitalisations – what is happening during admissions
    - Review of lived impact on quality of life and involvement in their community in between each hospitalisation
- Step by step approach i.e. are there interventions that will improve quality of life for the moment/ symptoms management
- Provide clear information about the different goals of care available i.e. A Palliative Care involvement/ DNR does not mean end of life
- Involve all supports including community care
- Someone living in an intellectual disability residential community home may have more pathways available to them versus them living at home
- People with Intellectual Disability and their capacity for involvement in the conversation

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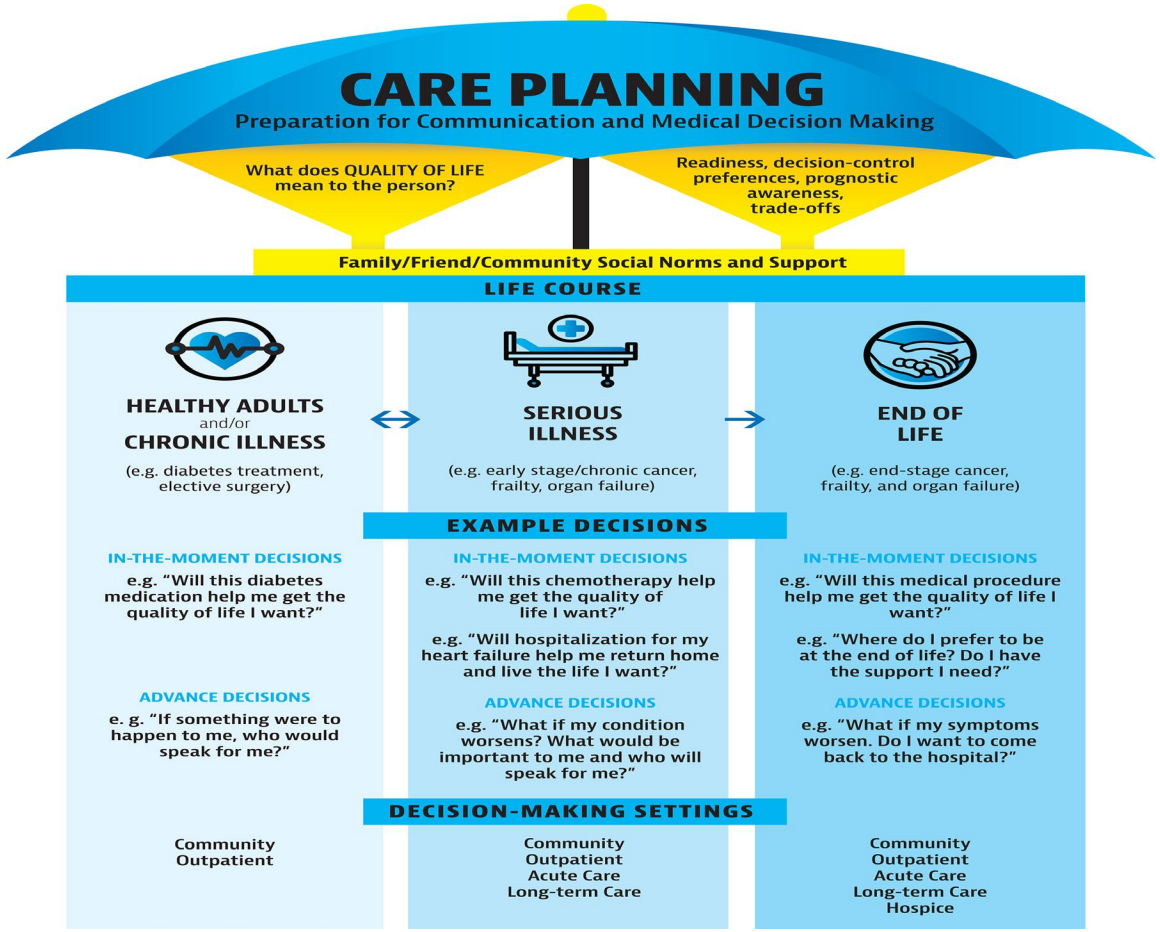
The care planning umbrella: The evolution of advance care planning



- What does Quality of Life meant for the person?
- Readiness, Decision control preferences, prognostic awareness, Trade offs

(Hickman et al 2023)

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Acute Hospital/ Intellectual Disability Liaison Support

- Responsiveness
- Building Relationships
- Collaboration
- Communication

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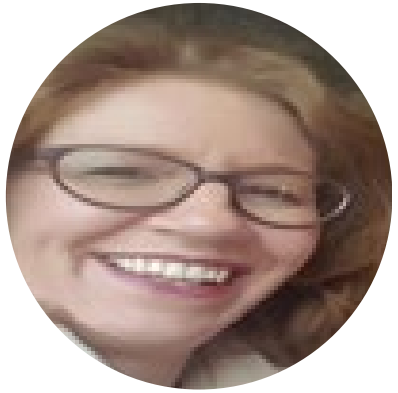
Acute Intellectual Disability Liaison Nurses in Ireland

Christine Carragher

CNM2 Intellectual disability Liaison

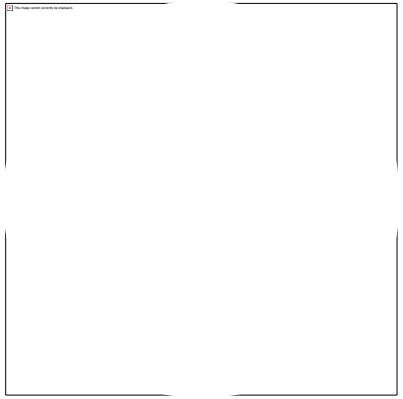
OLOL Drogheda



Muireann Ní Riain

CNS Acute Hospital Liaison – Intellectual Disability

St. Michael's House



Amy Young

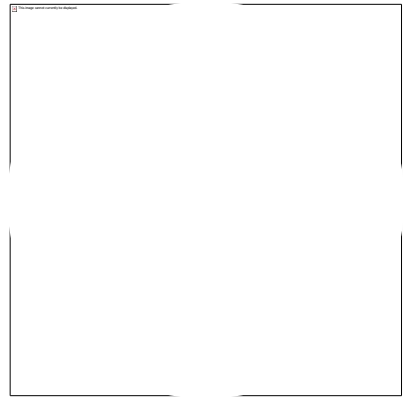
CNS Acute Hospital Liaison – Intellectual Disability

Horizons Cork

Sarah-Jane Boyle

CNM2 Intellectual Disability Liaison

Tallaght University Hospital



Vacancy

St. James Hospital

CNM2 Intellectual Disability Liaison

"The application of the knowledge, skills and expertise of the Registered Nurse in Intellectual Disabilities of the distinct needs of people with intellectual disabilities at the point of pre-attendance, attendance and discharge within the general hospital environment to enable and facilitate safe and effective, compassionate, person centred care." (Brown, 2016 p.21)

https://www.learningdisabilityservice-leeds.nhs.uk/get-checked-out/resources/your-health/palliative-care/

Adam E, Sleeman KE, Brearley S, Hunt K, Tuffrey-Wijne I. The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. Palliat Med. 2020 Sep;34(8):1006-1018. doi: 10.1177/0269216320932774. Epub 2020 Jun 17. PMID: 32552409; PMCID: PMC7596767.

Tuffrey Wijne, I (2021) https://eapcnet.wordpress.com/2021/10/09/the-challenges-and-triumphs-of-developing-a-survey-on-palliative-care-for-people-with-intellectual-disabilities-around-the-world/

Hickman SE, Lum HD, Walling AM, Savoy A, Sudore RL. The care planning umbrella: The evolution of advance care planning. *J Am Geriatr Soc*. 2023; 71(7): 2350-2356. doi:10.1111/jgs.18287

Doody, O., McMahon, J., Lyons, R., Moloney, M., Hennessy T. and Ryan,
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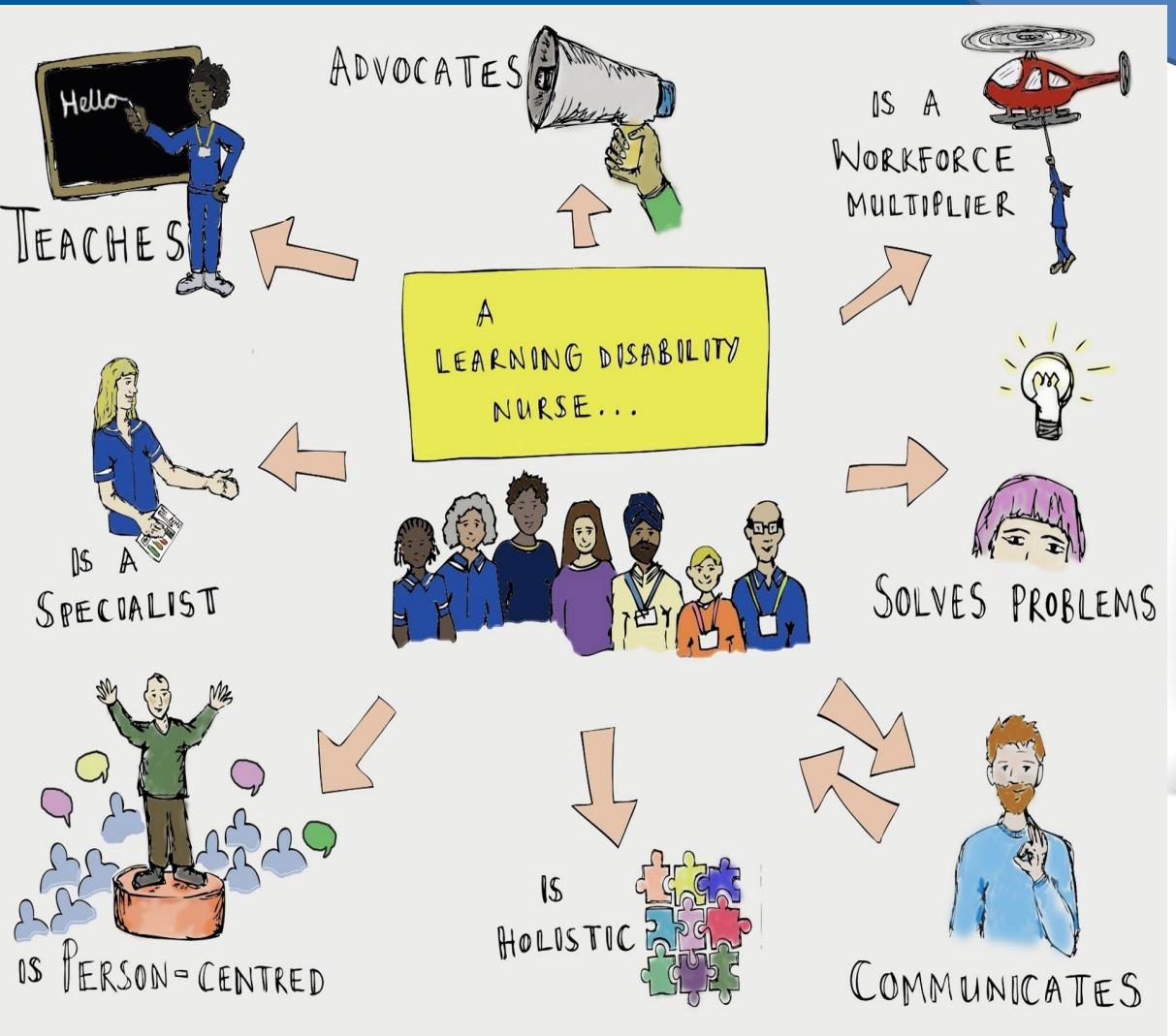
"Engagement in the establishment stage of a relationship produces better care outcomes and is the basis of a meaningful alliance"
(McAllister et al 2013)



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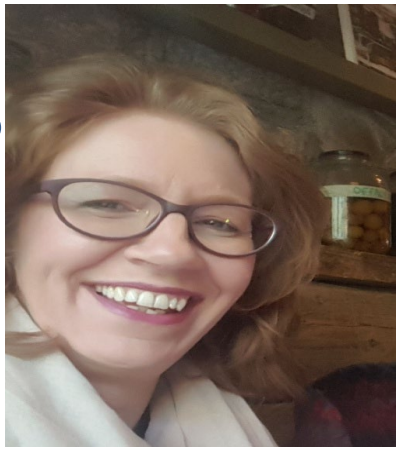

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