

SUPPORTING AGEING IN PLACE FOR PEOPLE WITH INTELLECTUAL DISABILITY AND DEMENTIA

National
Intellectual Disability
Memory Service

Evelyn Reilly,
Advance Nurse Practitioner - Dementia.
Daughters of Charity Disability Support Service
National Intellectual Disability Memory Service

OVERVIEW

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- Increased longevity in people with ID
- High risk of dementia
- Complexities in supporting ageing in place
- What are the essential prerequisites to support people –case study from Daughters of Charity Disability Support Services

Supporting People with Dementia to Age in Place



Tuesday 11th May 2021 11.00am

@nidmsirl @ageingwithid
#dementia #nidmsmasterclass

Down Syndrome and Life Expectancy

25

Life expectancy in 1983

60

Life expectancy today

People with Down syndrome are graduating
HIGH SCHOOL and COLLEGE, WORKING and CONTRIBUTING
TO SOCIETY more than ever before.

Learn more at www.ndss.org.

ndss



Ageing with Down Syndrome

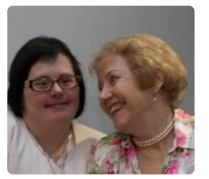


THIS IS A SUCCESS STORY

Opportunities to:

- Promote lifelong health and wellbeing
- Maintain independence
- Reorient services
- Mainstream the ID agenda

High rates of morbidity and mortality and we need to address health inequities



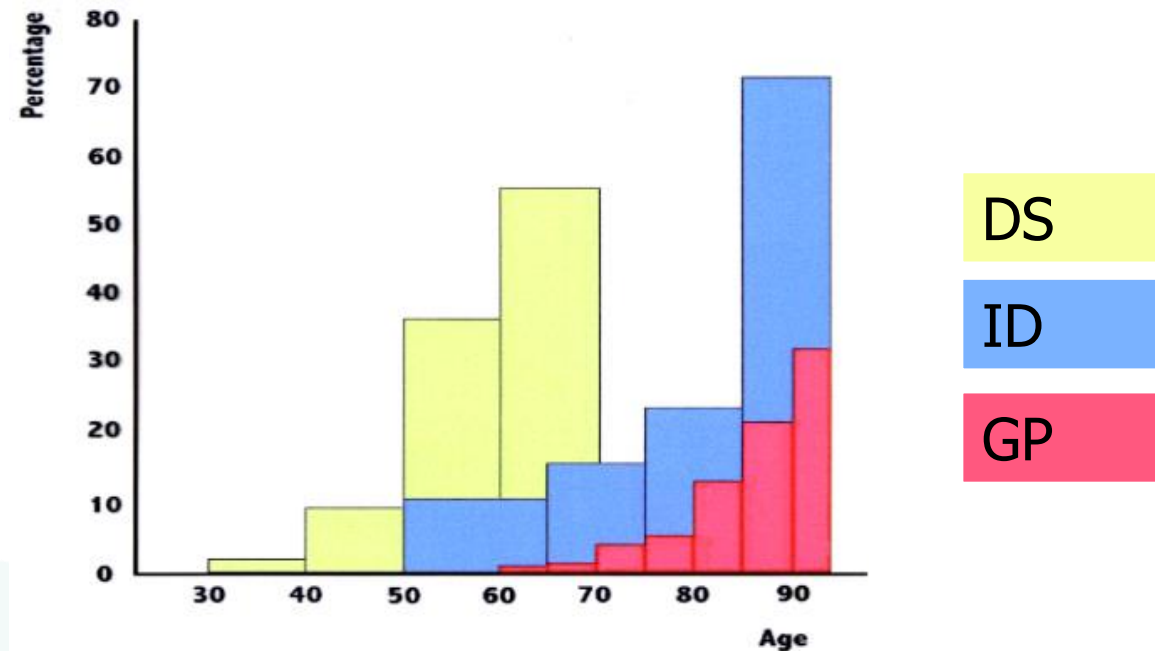
Optimising Wellbeing for People with Down syndrome

Ageing Through a Quality of Life Model



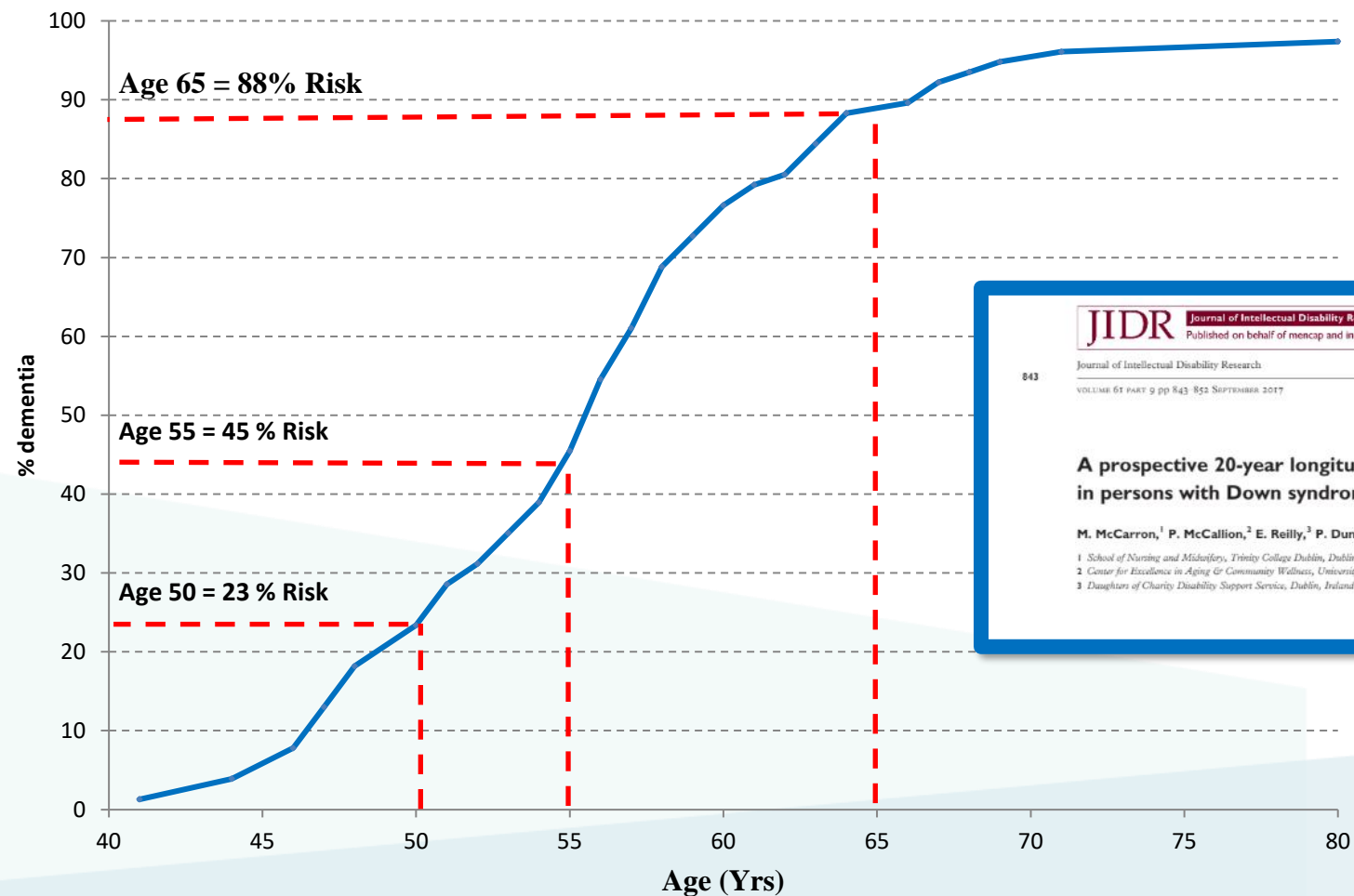
Cognitive Ageing

For people ageing with ID and Down syndrome



- The incidence of dementia could be up to **five times higher** than in people without ID (Strydom *et al*, 2013)
- **Much higher rates** in people with Down syndrome (McCarron *et al*, 2014, 2016; Strydom *et al*, 2010)

Risk Trajectories By Age

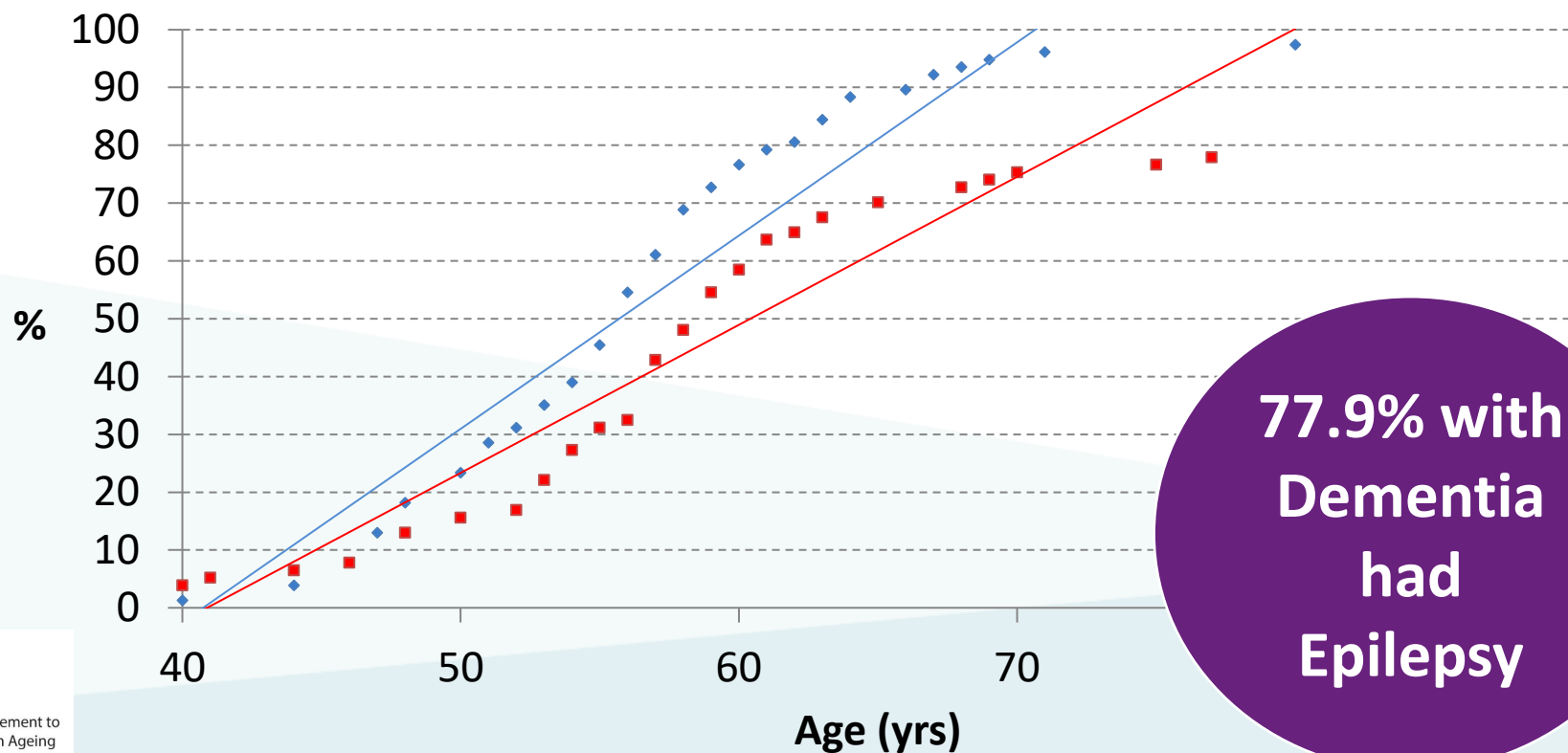


Dementia & Epilepsy

This often becomes a
tipping effect for
someone having to
move home

Life Time Prevalence

♦ LTP Dementia ■ LTP Epilepsy



77.9% with
Dementia
had
Epilepsy



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

- The concept of 'Ageing in Place' 'is a concept with multiple meanings.
- It implies the ageing of people within familiar environments
- It is based on numerous assumptions about the person's self-determination, least restrictive environment, the value of home, and the quality of life'

Ageing in Place



- Home is a place not only ‘where our heart is’ but also where we have a history and where our social connections are built.
- **Ageing in place** can refer to a person’s preference to age in what they see as ‘their own home’.

Ageing in Place



- In the broader sense '**Ageing in Place**' can be considered as not just the physical home but the local community or social circles, where people also have a '*place*'.
- If people do have a sense of place within their home, social networks and local community, then where possible, keeping people within (or connected to) this place is likely to improve a person's quality of life as they age.

Need for Planning



Developing a Strategic Plan: Lessons from the Daughters of Charity Disability Support Service

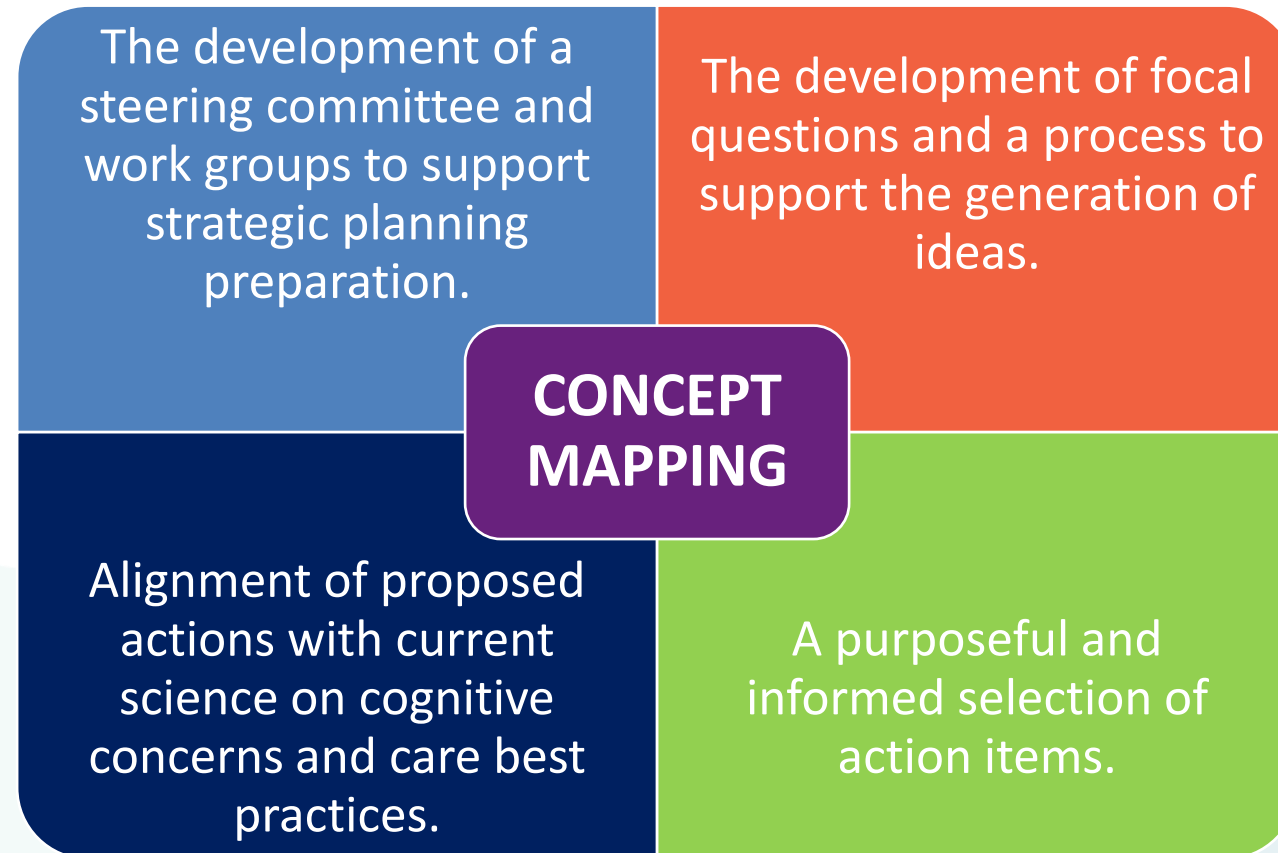
The Need for Strategic Planning: Some Key Questions

- Knowing the **mix of services** needed and how they will **change** over time?
 - Determining the **best location** for services?
- Being clear about **what we are trying to achieve** with the services we provide?
 - Developing **sustainable services**?
- Developing **dementia-specific day and residential programs**?
 - Developing a **Strategic Plan** on dementia care ?

- Critical to the strategic planning process is a thorough **strategic analysis**

- Planners, however, often decide to plan only from **what they know now**.
This makes the planning process much less strategic and often based upon guesswork.

Concept Mapping: Phases

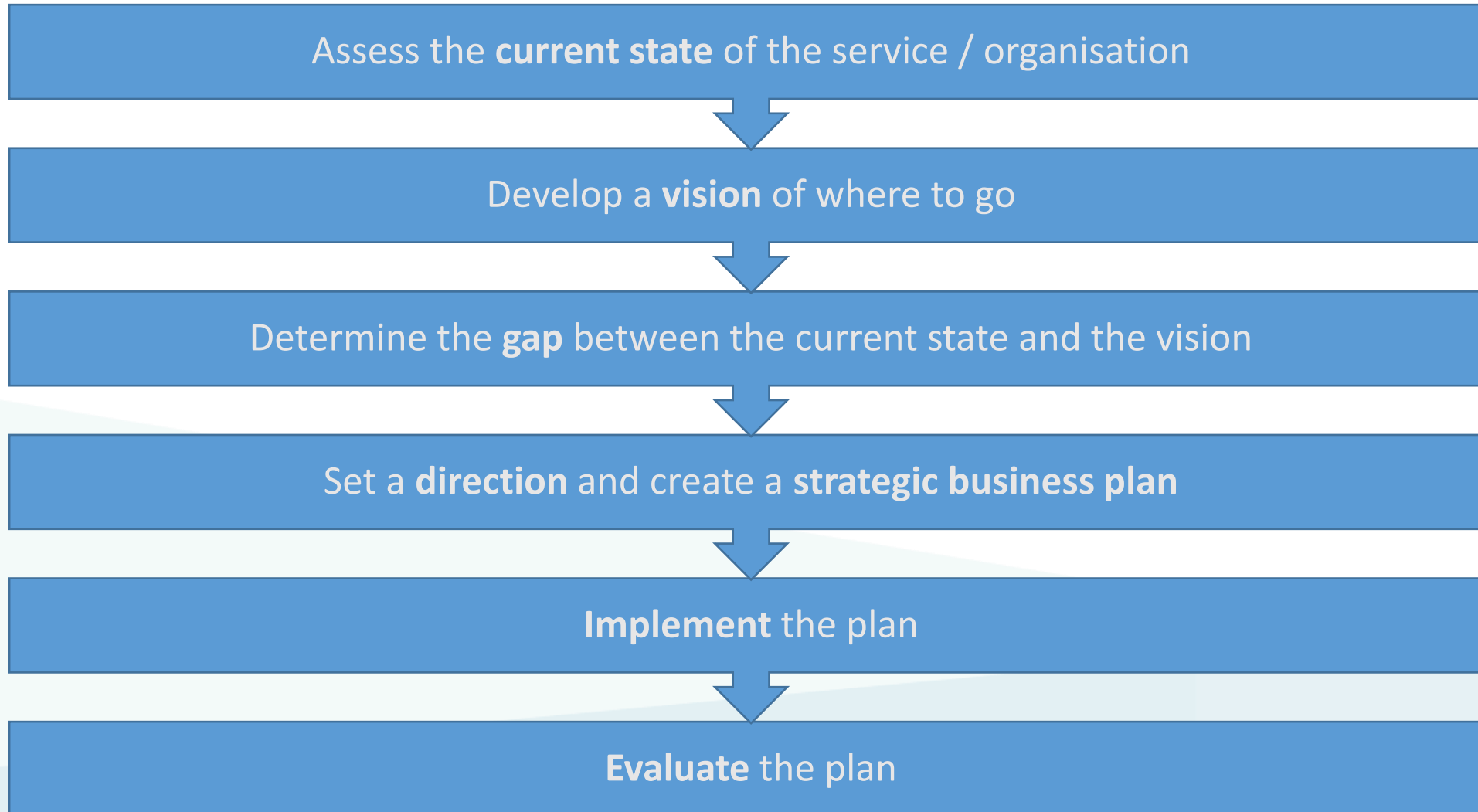


Intellectual disability and dementia practice

McCarron et al 2014

@nidmsirl

Planning for Success



Five steps: Realising the Strategic Vision

1.

Providing clearly defined **purposes for the service** with **realistic goals** and objectives and **specified timeframes** developed to reflect the service's capacity for implementation.

2.

Ensuring **effective communication** of the vision and the goals to all stakeholders within the service.

3.

Planning focused use of **existing resources** to advance the vision.

4.

Measuring progress from an established baseline with data collection, communications and continuous **quality improvement** mechanisms.

5.

Requiring **efficiency and effectiveness** in the design and delivery of dementia-related strategies

Ageing in Place at the Daughters of Charity Service

The Vision

“Consistent with the overall vision and mission of the Daughters of Charity Service, there will be **comprehensive, seamless delivery of services to address the holistic needs** of person with dementia, and of their peers, families and staff carers.”



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Thank you

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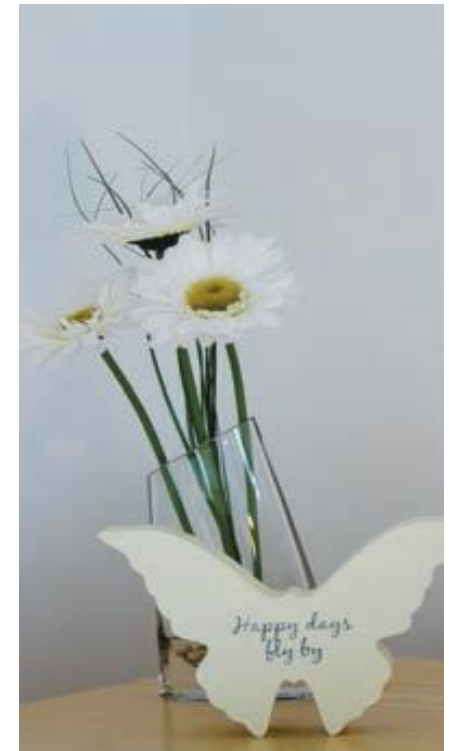
Pamela Dunne
Clinical Nurse Specialist in Dementia
National Intellectual Disability Memory Service/
Daughters of Charity Disability Support Services

Making Vision a Reality

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“Vision without action is merely a dream.
Action without vision just passes the time.
Vision with action can change the world”

Joel Barker



Strategic Planning for dementia at the Daughters of Charity Disability Support Service (McCarron et al 2003)

What do you want that you don't have <i>(Achieve)</i>	What do you want that you already have <i>(Preserve)</i>	What don't you have that you don't want <i>(Avoid)</i>	What do you have now that you don't want <i>(Eliminate)</i>
Suitable environment	Ageing in place	Restrictive environments	Relocating clients with dementia into non - specific dementia settings
Competent care/ Staff Education and Training	Strong relationships amongst staff and service users	Mini institutions for persons with dementia	Crisis decision making particularly at end of life
Peer and family education	Competent Nursing Care.	Transfers to generic hospitals/ nursing homes.	
Staff consistency across the service	Spiritual care		Fragmented approach to dementia care
Increased family involvement	Policy and Service advisor on dementia		Inappropriate environments
A Dementia Specific Day Service	Person centred ethos		Inappropriate day programmes
Clinical nurse specialist/advanced nurse practitioner in dementia	Care provided within the service		Negative impact on quality of life for other clients in home setting
Memory Clinic and dementia screening and assessment	Multidisciplinary support		

National Policy and Strategy for Dementia



Implementing Policy for Dementia Care in Ireland



THE IRISH NATIONAL DEMENTIA STRATEGY

Tús Áite do
Shábháilteacht 1 Othar
Patient Safety 1 First



A commitment to Age in Place

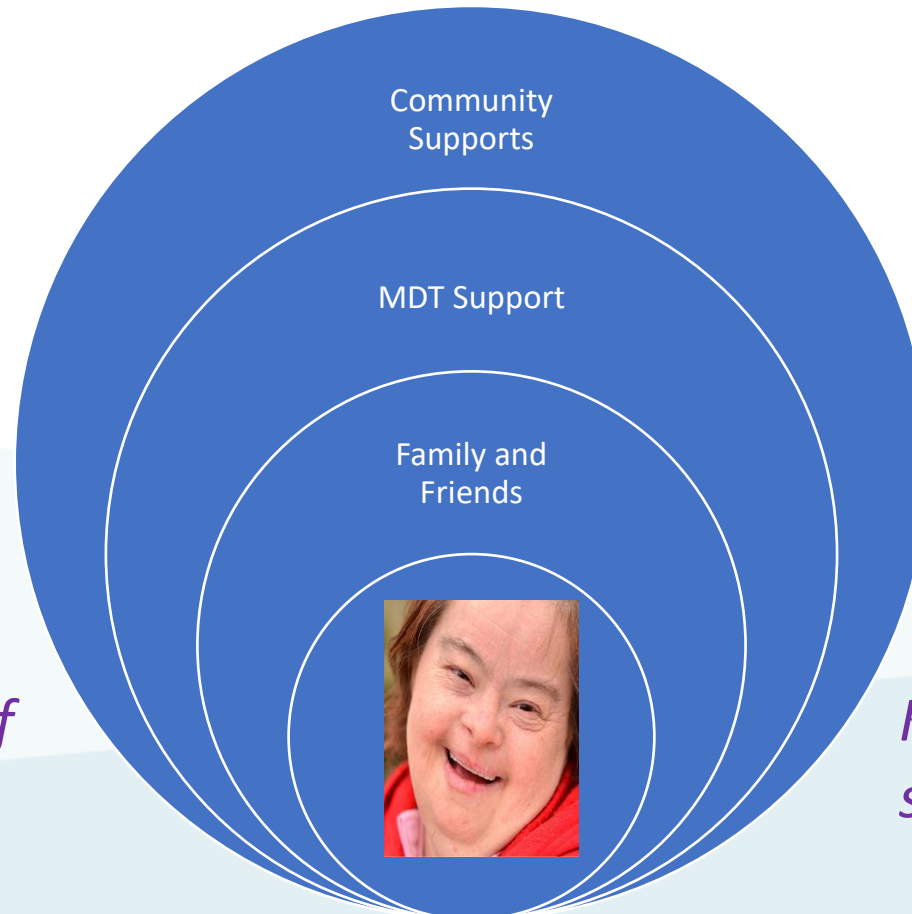
- The Daughters of Charity service is committed to supporting people with dementia to remain in their own homes for as long as possible.
- Many people with dementia continue to live in their home with support from the multi-disciplinary team for many years after diagnosis.
- When it is no longer considered feasible to give care with safety or with comfort ,a co-ordinated approach to transitioning to a higher support setting is vital.

Building Circles of Support

MDT Support

Occupational Therapist
Physiotherapist
Dementia Nurse Specialist
Speech and Language Therapist
Psychologist
Social worker
Doctor
Pharmacist

Each Person's experience of dementia is as unique as their fingerprint



Community Supports

Memory Clinics
HSE - Public Health Nurse
The Alzheimer's Society
Family Carers Ireland
Palliative care services
Voluntary organisations
Dementia Understand Together

Know what services and supports are available to help

Anticipating Challenges

Understanding the progression of dementia and common challenges

- Memory, thinking, orientation
- Dependence in ADLs
- Eating and drinking
- Communication
- New onset epilepsy
- Emotional, social behaviour
- Incontinence
- Mobility

Planning Ahead

Environmental modification

National Disability Authority's Centre for Excellence in Universal Design – National Disability Authority (2015)

Social environment

Optimising physical health, cognition, activity and well-being

Advance Care Planning

Advance care planning is a process of discussion and recording. It may take place over more than one conversation –The Irish Hospice Foundation

**Plan for the probable,
work for the possible,
hope for the future**

Ronan Smith, member of
Irish dementia working
group, Alzheimer's society
of Ireland

Implementing the Vision

Developing Standards of Care



Supporting Care in the Community

Case example

- Anne had baseline screening for dementia aged 40years
- At the age of 48 she was diagnosed with Alzheimer's dementia
- Anne remained in her home supported by her familiar staff with lots of family involvement
- She experienced significant challenges including negotiating the behavioural and psychological symptoms of dementia
- She experienced lots of life events shared with those she loved – her 50th birthday celebrated in the local community.
- Anne was supported through the advanced stage of dementia. She passed away surrounded by family and staff in her home aged 55 years.



Sample of 12 adults with diagnosis of Alzheimer's living in Community residential services in 2020

Profile of resident	Year of diagnosis	Stage of dementia
57 year old woman with DS	2008 (12years)	Advanced stage dementia
64 year old woman with DS	2014 (6 years)	Advanced stage
82 year old woman – ID	2014(6 years)	Mid stage- increase in falls / frailty
57 year old gent with DS	2019 (1 year)	Mid stage with co-morbidity
56 year old lady with DS	2016 (4 years)	Mid stage. Engaged in community
52 year old woman with DS	2016(4 years)	Mid stage. Frontal temporal symptoms
59 year old woman with DS	2014 (6 years)	Mid stage . Engaged in community
60 year old with DS	2009 (11 years)	Advanced stage dementia
84 year old -ID	2010(10 years)	Advanced stage dementia
59 years old - DS	2014 (6 years)	Mid stage dementia
51 year old woman with DS	2018(2years)	Mid stage
57 year old lady with DS	2012 (8 years)	Advanced stage dementia

And Sometimes....

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There are times when despite our best efforts the home outstrips its capacity to give care with safety and with comfort.

The Daughters of Charity through its Strategic plan has given a commitment to the continued care of the individual where possible within the organisation

Willow View and Meadow View were designed based on the principles of best practice in dementia environments

As envisioned within the Dementia Strategy the importance of dementia capable environments supported by staff who have the knowledge and skills to support complex care needs

Serious consideration is always given when contemplating moving home



Supporting Care in the Community

The person with ID:

Their perspective: Ascertaining the person's will and preferences

Their value on relationships and the importance to them in sustaining these



The relatives perspective:

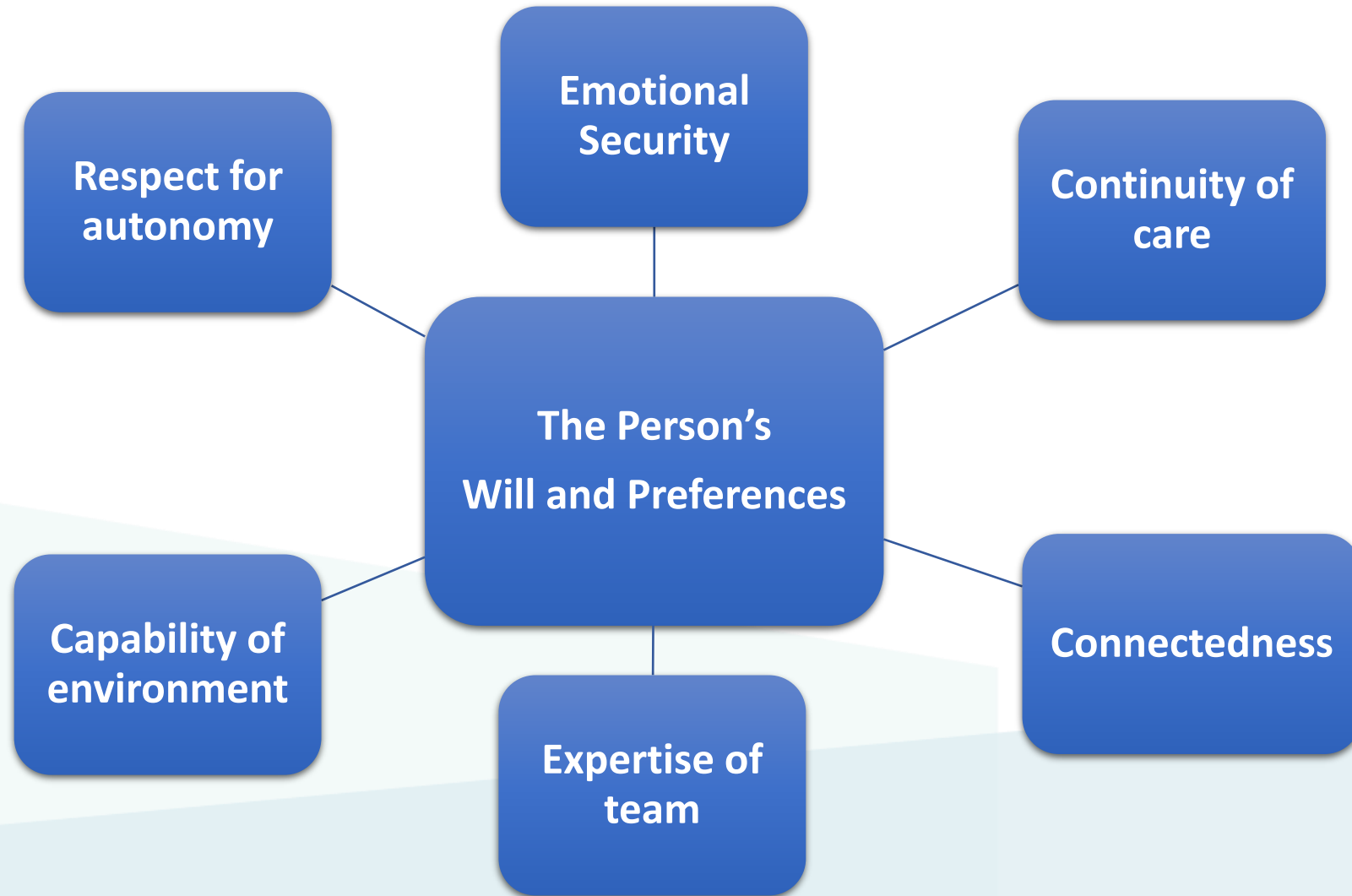
Relatives also attach importance to the person with ID being in their usual home and familiar friends and environment



Staff and health professional perspective:

Staff often have built up close bonds and relationships with the person over many years

Moving Home: Important Considerations



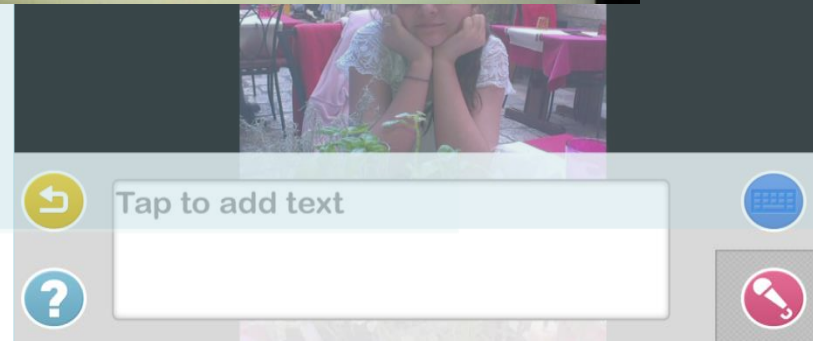
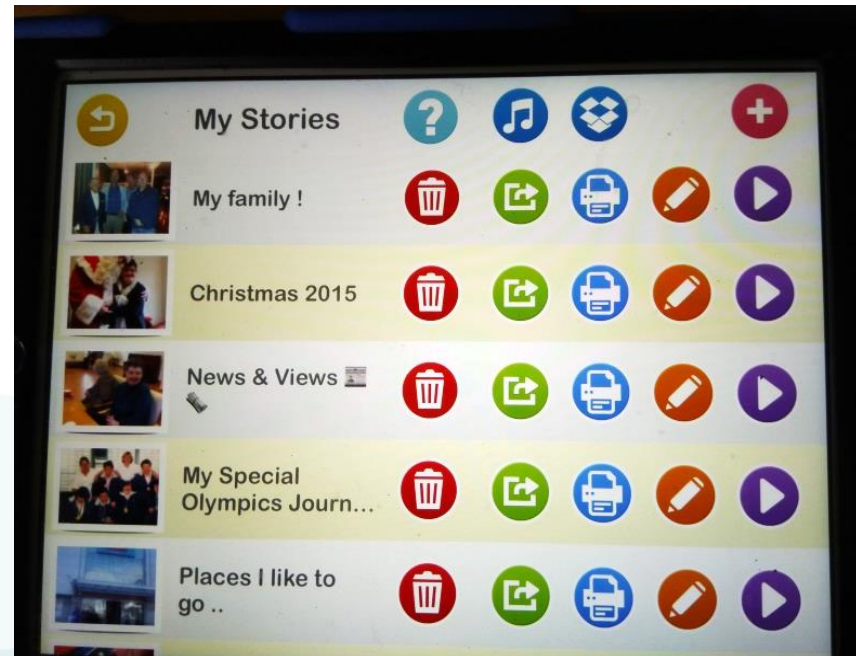
Maintaining a sense of connection and getting to know me through life stories

“It helps me to keep my memories”.

Example Chapters:

- My Childhood
- My Family/friends
- Significant Life Events
- Special Achievements
- Special People and Places
 - Likes/dislikes
 - Music
- Conversation Prompts

Add narrative and voice recording to photos to build meaningful memories



Capturing preferred music

Moving Home: Important Considerations

My Transition Plan

The following components of the transition plan are tailored to meet the individual needs of the person using the transition process as outlined.

Name:		D.O.B:	
My Transition Journey Start @		Proposed Moving in Date:	
My Key Workers in Residential and Day Services are:			
My Key MDT Support are as listed and have been notified of my impending move:			

My Family

Key support family members	Who was Contacted:
Family input into shared decision making and forward planning	

Achieving Excellence in Dementia Care

Moving Home: Important Considerations

Continuity – Promoting well-Being and Social Connectedness

My Friends I want notified of my move are:

Visits to my new home

Making the home familiar to me and preparing my new bedroom

Date	Action	Completion Date/ Person's Responsible	Observations

Moving Home: Important Considerations

Getting to Know me

My New Key worker from my new home will visit me in my current home

Date	Action	Completion Date/ Person's Responsible	Observations

To help others to get to know me 'My Life Story' will be completed by current staff with family/friends input. The template of 'My Life Story' is available from the Memory Clinic.

Supported Move

Date	Staff support from home is	Hours assigned today	Comments

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Moving Home: Important Considerations

Personalising my room
to reflect who I am



My own room, my own
bathroom, my own things



Moving Ideas into Action: A Dementia Specific Home



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