Meeting the needs of persons with intellectual disability and dementia

Award Winning Approaches to Care and Assessment

Prof Mary McCarron,
Dean of the Faculty of Health Sciences
Trinity College Dunlin Ireland

Authorship: McCarron, M., McCallion, P., Reilly, E., Burke, E., Dunne, P. & Wang, BW.
Changing Demographics of People with an Intellectual Disability

Of the people with moderate, severe or profound intellectual disability, the proportion aged 35 years or over increased from 29% in 1974 to 38% in 1996 when NIDD data were first reported, and to 49% in 2013 (Kelly & O’Donohoe, 2014)
Comparative Rates of Dementia
Down’s syndrome, L.D., General Population

Holland, 2011
Point Prevalence of dementia among Down syndrome-IDS TILDA

Prevalence of dementia among people with Down syndrome
WAVE 1: 15.8%
WAVE 2: 29.9%

The prevalence of epilepsy increased from 19.2% to 27.9% for those with Down syndrome
McCarron et al 2014

For further information visit:
www.idstilda.tcd.ie
Ageing and Dementia: A Strategic Challenge

- Changing Demographics
- Ageing population with Down syndrome
- Challenges to the current service model
- A need to restructure residential and day programs
- A need to up-skill staff at all levels in the organisation to respond to changing needs
Planning to Respond

• Assess the current state of the service/organization
• Develop a vision of where to go
• Determine the ‘gap’ between current state and the vision
• Set a direction, business plan
• Implement the strategic plan
• Evaluate the plan
Concept Mapping Phases

1. The development of a steering committee and workgroups to support strategic planning preparation

2. The development of focal questions and a process to support generation of ideas

3. Alignment of proposed actions with current science on cognitive concerns and care best practices and

4. A purposeful and informed selection of action items

(Trochim’s 1989)
Developing an issue-based Strategic Plan

• Comprehensive strategic analysis
  Ageing demographics
  Current and predicted prevalence of dementia

• Analysis of Staff training and support needs

• Focus group interviews with staff, clients and family members

• Formation of a strategic planning working group

• Creating a Vision and Explicit Mission

• Development of Dementia Specific Strategic Plan + Business

In responding to the needs of persons with dementia in your area identify:

1. What do you want that you don’t have *(Achieve)*

2. What do you want that you already have? *(Preserve)*

3. What don’t you have that you don’t want? *(Avoid)*

4. What do you have now that you don’t want? *(Eliminate)*
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.”
Vision: A Seamless Service

Key components of a dementia specific service:

- Early screening and diagnosis and good clinical support through the memory clinic model
- A continuum of residential options to support the changing needs of persons at different stages of dementia
- Appropriate day programs
- Training and education programs for staff, family and peers
- Research to guide practice and policy
The Memory Clinic is now extending its services to other organizations and collaborating with generic dementia services offering specialist advice and supporting dementia assessment and care.
Investigating Dementia
A 14 Year Longitudinal Perspective

Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Mental health

A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome

M. McCarron,¹ P. McCallion,² E. Reilly³ & N. Mulryan³

¹ School of Nursing & Midwifery, Trinity College Dublin, Dublin, Ireland
² University at Albany, Albany, NY, USA
³ Daughters of Charity Service, Dublin, Ireland

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Understanding Cognitive Decline: Diagnostic Workup

**Physical**
- Vital signs
- Full physical examination
- Complete blood count - FBC, E/LFT, ESR, TFT, Folate
- & B12, U&E, drug levels etc.
- Mental Health

**Neuro-imaging**
- CT, MRI (depending on feasibility)

**Neuro-Psychological Testing**
- Informant and objective based measures
Risk Trajectory According to Age
Mortality

Survival curve

Cumulative Survival

Time in years

Median
Implementation:
Comprehensive Education Program

• Comprehensive staff education

• Resource onsite pack – research informed and evidence based

• Peer training curriculum

• Bi-annual information evenings for families – training delivered if dementia symptoms suspected or confirmed

• Dementia specific standards to guide practice with training on their implementation

http://www.docservice.ie/includes/documents/Dementia%20Publication%202011.pdf
Developing Standards for Care

Standard 1: Appropriately Trained Staff and Service Development

People with dementia receive care and support from staff who have the prerequisite knowledge and skills to perform their role effectively.

Standard 5: Promoting Well-Being and Social Connectedness

Each person with dementia is encouraged and supported by staff to participate in their own personal care at whatever level they are capable of. The person’s preferences, privacy, dignity, and well-being are key principles which underpin all care activities.

Standard 6: Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs

All people with intellectual disability have access to a memory assessment service specializing in baseline screening, dementia assessment and diagnosis in persons with intellectual disability.

Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards

A Guide to Practise

McDermott, M & Reilly, C. 2010
“Vision without action is merely a dream. Action without vision just passes the time. Vision with action can change the world.”

Joel Barker
A Dementia Specific Service for People with ID in Ireland
A Quality Environment for Person Centred Dementia Care
A dementia care unit...
No...someone’s home...
The environment as therapeutic intervention
“What a beautiful idea to have the house laid out this way...it’s like they have their own private apartment, their own personal space and yet they are able to be involved in everything else that’s happening in the house if they wish.”

(Family Member)
Rounded corners, places to sit – thinking about safety and wayfinding
Able to sit together at mealtimes
A kitchen that welcomes
Bright, warm and homely spaces
My home where I live with dementia
Responding to needs and concerns in mid-stage dementia

Addressing complex nursing and palliative needs of late stage dementia
“...the other house just became too distressful for her, despite staff’s efforts and they were wonderful... she was very troubled, you could tell by the distress on her face”
(Family member)
Personalised care at all levels of the organisation

Opportunities to succeed and use retained abilities

Engagement in valued life activities
Enjoying The Conservatory
When members from the same family are living with dementia:

A two bedroom apartment
Heart of the home, the hub and cornerstone of daily life: The kitchen, dining and living areas
A large curved kitchen island - two levels - staff able to engage face to face... and discreetly supervise...
Still my kitchen – opportunities to empower and support,...
Dining In Style – maintaining a sense of family around the kitchen table

Baking, cooking, managing one’s own kitchen
Activities, joy and things remembered
The Living Area: Social connections and quiet personal spaces
My own room, my own bathroom, my own things
An En-Suite Bathroom
Gardens and Therapeutic Outdoor Spaces
Combining a Healing/Sensory & Horticultural Garden
Peaceful and tranquil, yet supporting social activities and meaningful communication
Recreational therapists and volunteers support music, art, cooking, gardening.
Maximise awareness and orientation, promote feelings of, and actual safety and security, provide opportunities for significant social contact...

(Cohen and Wiseman, 1991)
“The move was so well planned; it resulted in zero stress for all of us, staff here getting to know them before the move, staff from the house coming with them and settling them in, having that familiar face just really helped.”

(Family Member)
“I had sleepless nights at the thought of my sister moving into care, and nightmares at the thought of the move, how wrong I was.

I could never have imagined that there was a place like this, it’s like coming into a new world...

the content feeling, I know she is so safe, so happy, so well cared for. It’s a beautiful home; the staff are wonderful. The last day I was with her she was cooking rice crispy buns..so happy, it’s just a dream come true.”

(Family member)
Music:
http://www.purple-planet.com