

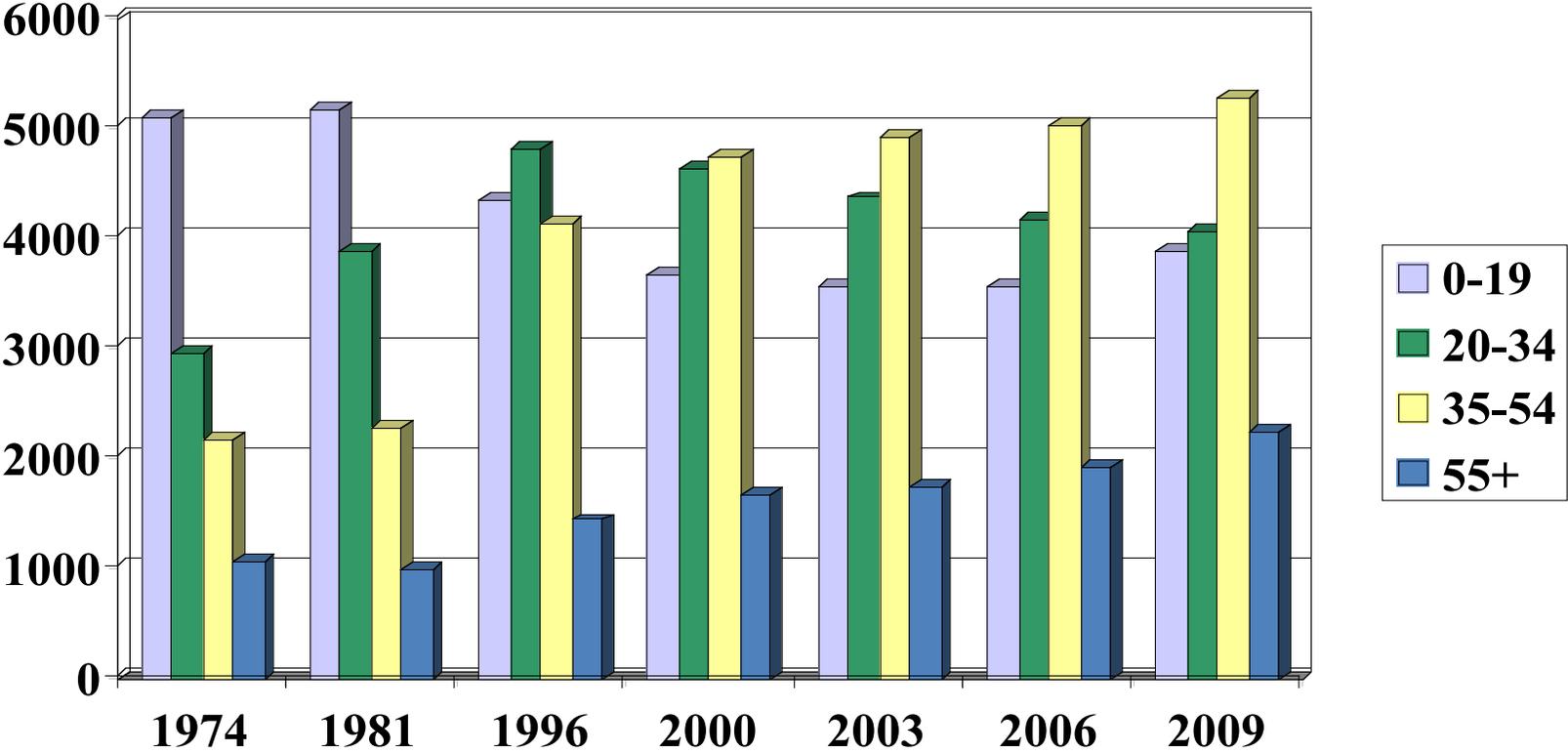


# Screening, Assessment, Diagnosis Treatment and Support for People with Intellectual Disability with Dementia Through a Memory Clinic Model

Mary McCarron PhD

# Demographic Trends

Moderate, Severe and Profound 1974, 1981, 1996, 2000, 2003, 2006, 2009



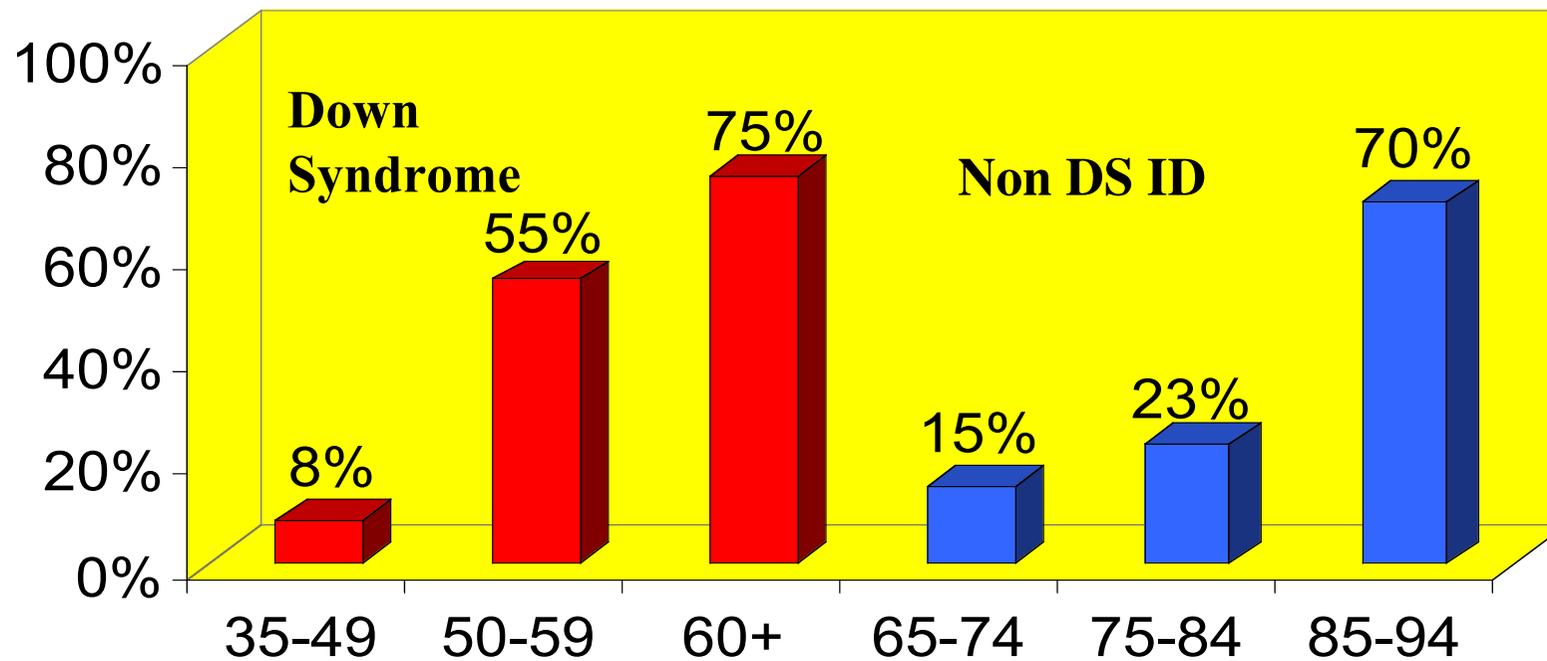
National Intellectual Disability Database, 2010. Health Research Board, Ireland

# Dementia in Persons with Down syndrome

- \* It has been universally agreed that the prevalence of Alzheimer's type dementia in persons with Down syndrome exceeds that of the general population:
- \* 15%- 45% of persons with Down syndrome over the age of 40 years

(Prasher & Krishnan 1993)

## Prevalence of Dementia in People with Down Syndrome & People with Intellectual Disability



Lai, F. Williams, R. 1989 Archives of Neurology; Cooper, SA. 1997 JIDR

## **Assessment and Diagnosis: Sources of difficulties**

- Cognitively and emotionally functions at an earlier developmental level with difficulty in using standardized assessment procedures
- Lack of experience and education of generic health care professionals in dealing effectively with people with ID and standardised assessment tools in the generic population of little value
- Communication difficulties and inability to self-report feelings/difficulties
- Physical problems often overshadow other problems such as mental health difficulties
- Assessment not part of general routine. Poor baseline records and frequent staff changes
- Medical and environmental issues

# **Rationale for the Establishment of a Memory Clinic Daughters of Charity Service**

- Ageing Demographics
- Pilot site for Longitudinal Study on dementia in persons with Down Syndrome
- Strategic Plan to address dementia care Concerns
- Need for prudent management of scarce resources
- To support the development of joint working and partnerships with generic services

## **Vision for care and Support for persons with dementia at the Daughters of Charity Service**

- That persons at risk of dementia would be diagnosed early and that early intervention including personalised supports and a capable and trained workforce would improve the quality of life and death for persons with dementia;

.....additionally and that each person would be supported to live in the home or community of their choosing for as long as possible.

# Principles underpinning the Memory Clinic

- To establish a baseline for all persons with Down Syndrome while they are healthy from which change can be monitored
- To facilitate comprehensive diagnostic work up and consensus diagnosis of all persons with DS with suspected symptoms of dementia
- To provide reactive screening for all persons with ID after concerns have been raised
- To ensure quality support for persons confirmed with a diagnosis of dementia throughout the continuum of the disease
- To ensure quality support for staff, peers and family carers
- To develop a minimum data set to support;
  - comprehensive longitudinal follow up
  - to predict and guide current and future service need
  - to provide standards of good practice which can be benchmarked and audited

# Memory Clinic: Summary of Key Activities

**Baseline Screening and Dementia Assessment:** 144 with Down syndrome > 35 years reviewed and screened and 50 presented with symptoms of dementia following a comprehensive diagnostic work up.

## **Staff training:**

- Formal – 4 Days Course; offered twice per year with a maximum of 20 participants, from all areas of the service.
- Formal – 1 Day Course; Offered once per year, specifically targeting frontline Nursing staff.

## **On Site Consultation (offered daily):**

- Communication, Environment, Understanding Behaviours , Feeding/Hydration Issues, End-of-Life Issues

## **Peer Training:**

- Usually carried out in the Home Setting and aimed at enhancing understanding of the person's changing personality and declining skills.

## **Family Information Day/Evening:**

- Twice yearly, focused on ageing in persons with Intellectual Disability

# Memory Clinic – Key Personnel

- Professor Mary McCarron – Policy and Service Advisor on Dementia
- Ms. Evelyn Reilly – Clinical Nurse Specialist
- Dr. Niamh Mulryan – Medical Director

# Associate Personnel

- Dr. Jean Lane – Senior Physician
- Dr. John O'Brien - GP
- Ms. Sallie Matthews – Social Worker
- Dr. Andre Van Rensburg – Psychology
- Ms. Vanella David – Speech and Language
- Mr. Cardwell Muvungani - OT
- Ms. Melinda McCabe – Physiotherapy
- Ms. Margo Brennan – Dietician
- Sr. Stella Bracken – Spiritual Care
- St. Francis Hospice

# Memory Clinic Key to Supporting Longitudinal following and understanding change over time

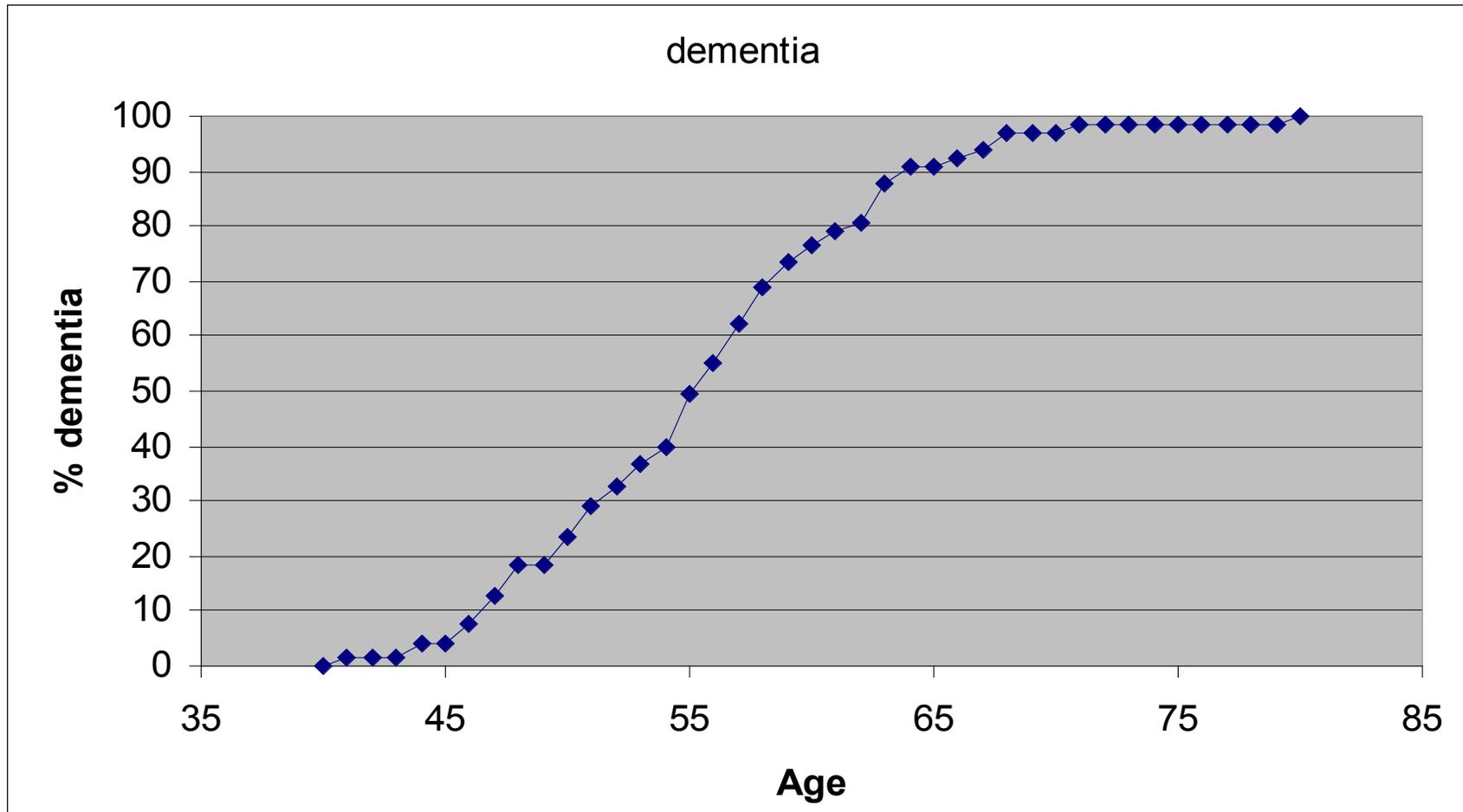
Sub sample; 14 year longitudinal follow up of 80 persons with Down Syndrome

- Combination of Informant-based and Objective test instruments:
  - Down Syndrome Mental Status Examination (DSMSE) (Haxby, 1989)
  - Test for Severe Impairment (TSI) (Albert & Cohen 1992)
  - Daily living Skills Questionnaire (National Institute For Ageing 1989)
  - Dementia Questionnaire for Mentally Retarded Persons (DMR) (Evenhuis et al 1990)
- Clinical screen and diagnostic work-up

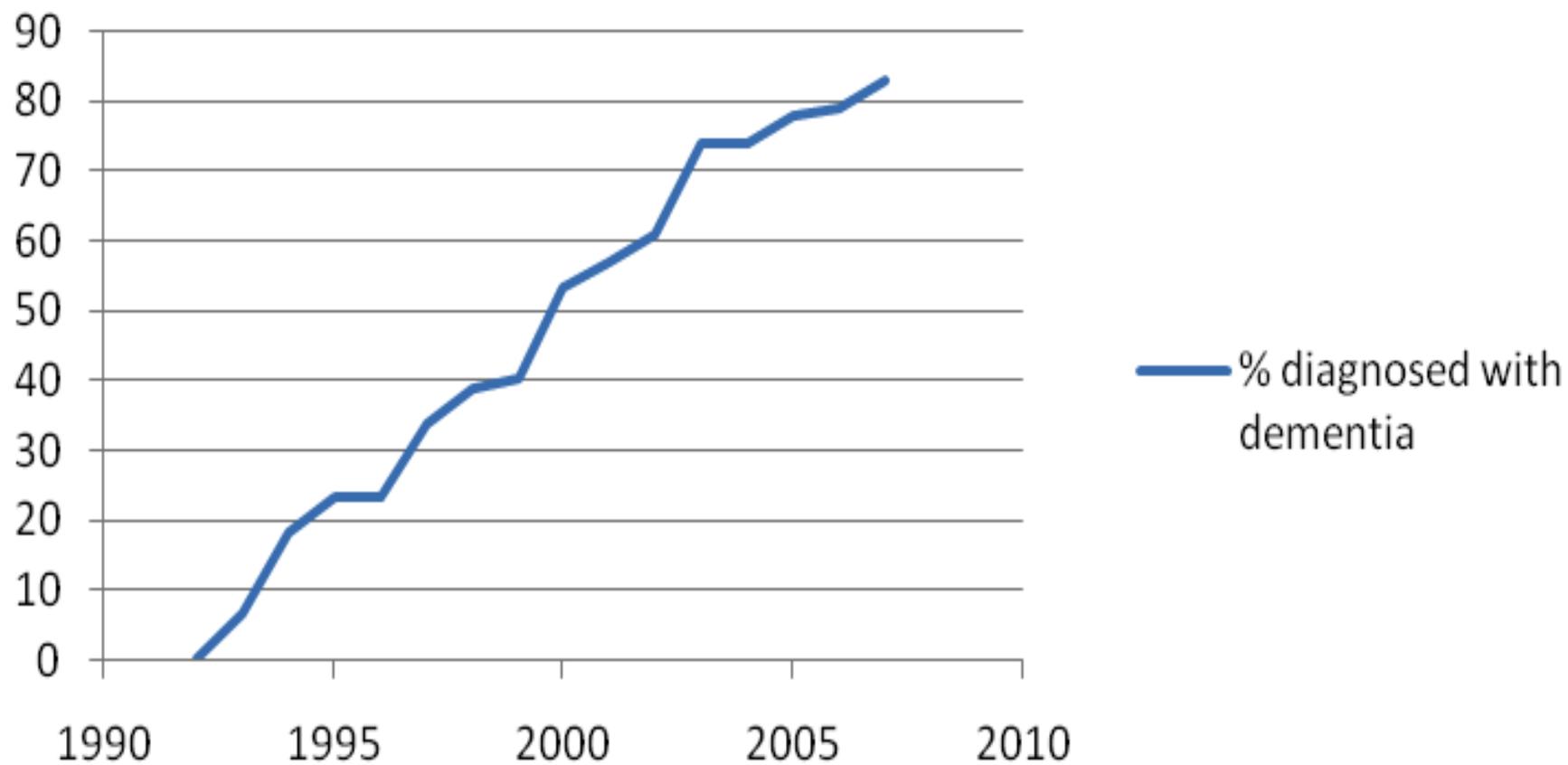
# Demographics

- 77 people with Down Syndrome; All Female
- Moderate ID (62) Severe (15)
- > 35 years at first assessment (1996)
- 64 (83%) developed dementia; 13 (16.9%) no dementia
- Mean age of dementia diagnosis was 55.1 years (SD= 7.2)  
Range: 41-80.
- Persons with Dementia were significantly older than persons without dementia 52.1 years vs 43.9 years ( $t=3.5$ ;  $df = 75$ ;  $p=0.001$ )

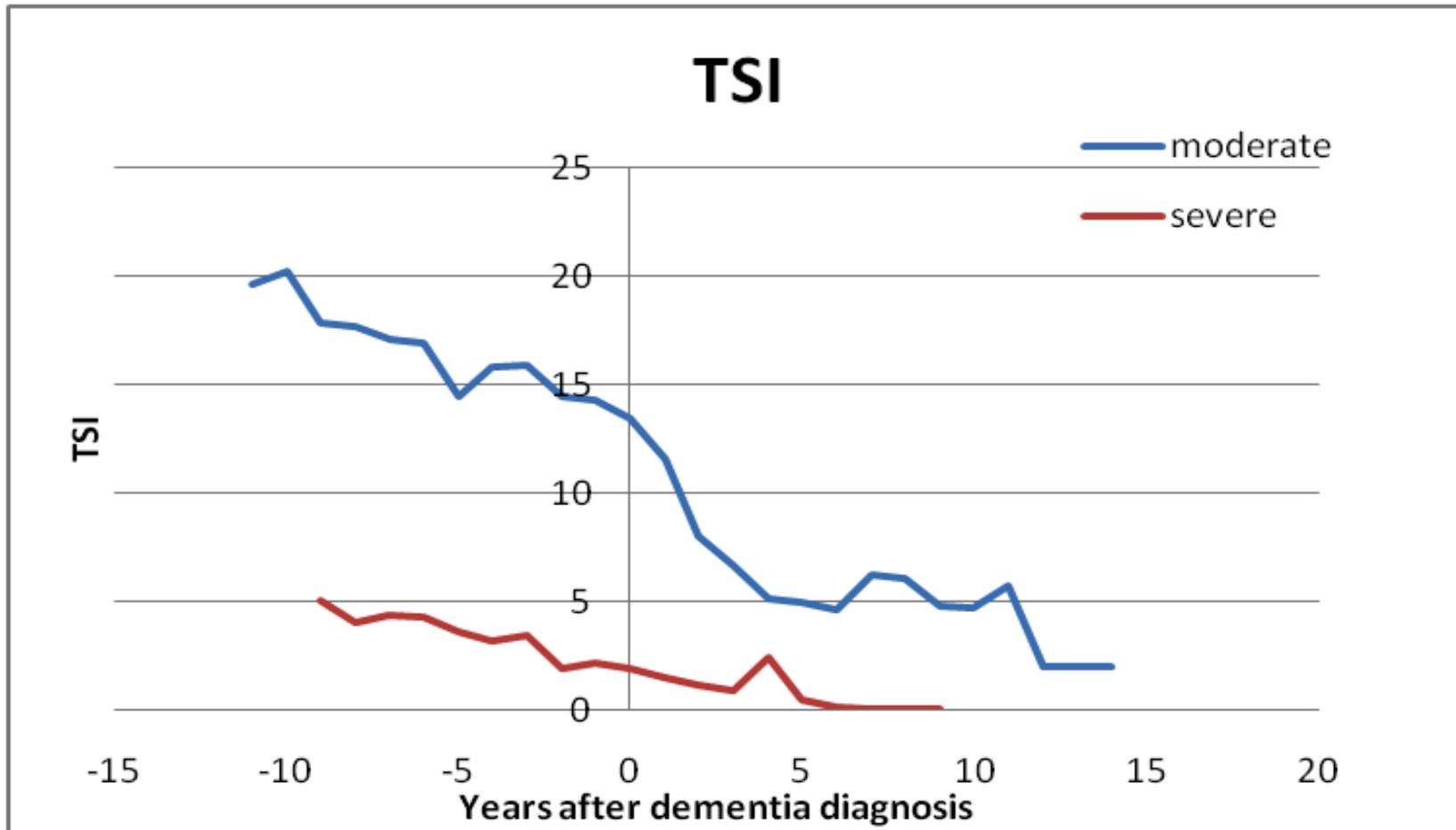
# Risk of developing dementia by age



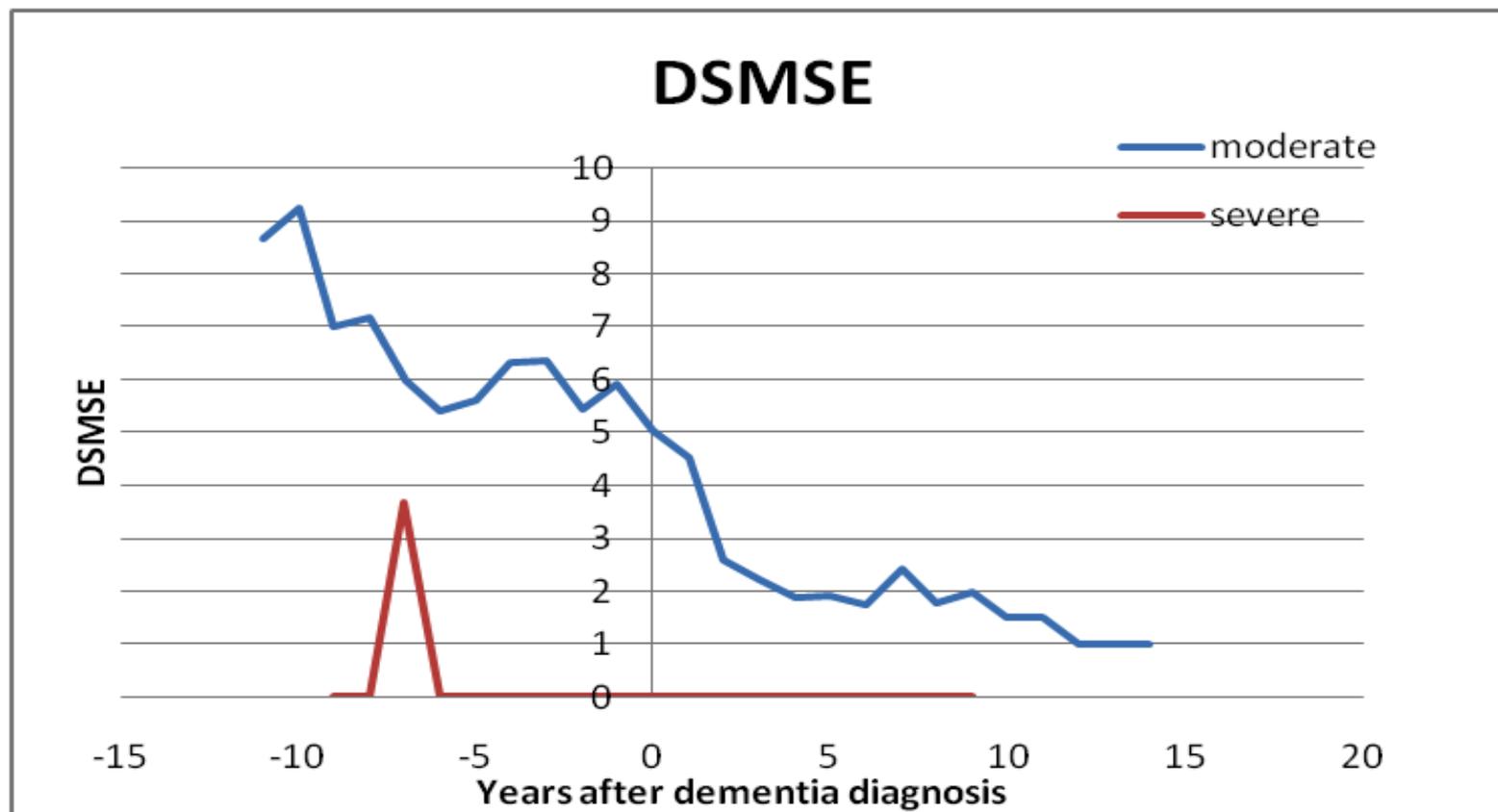
## cumulative % diagnosed with dementia by year



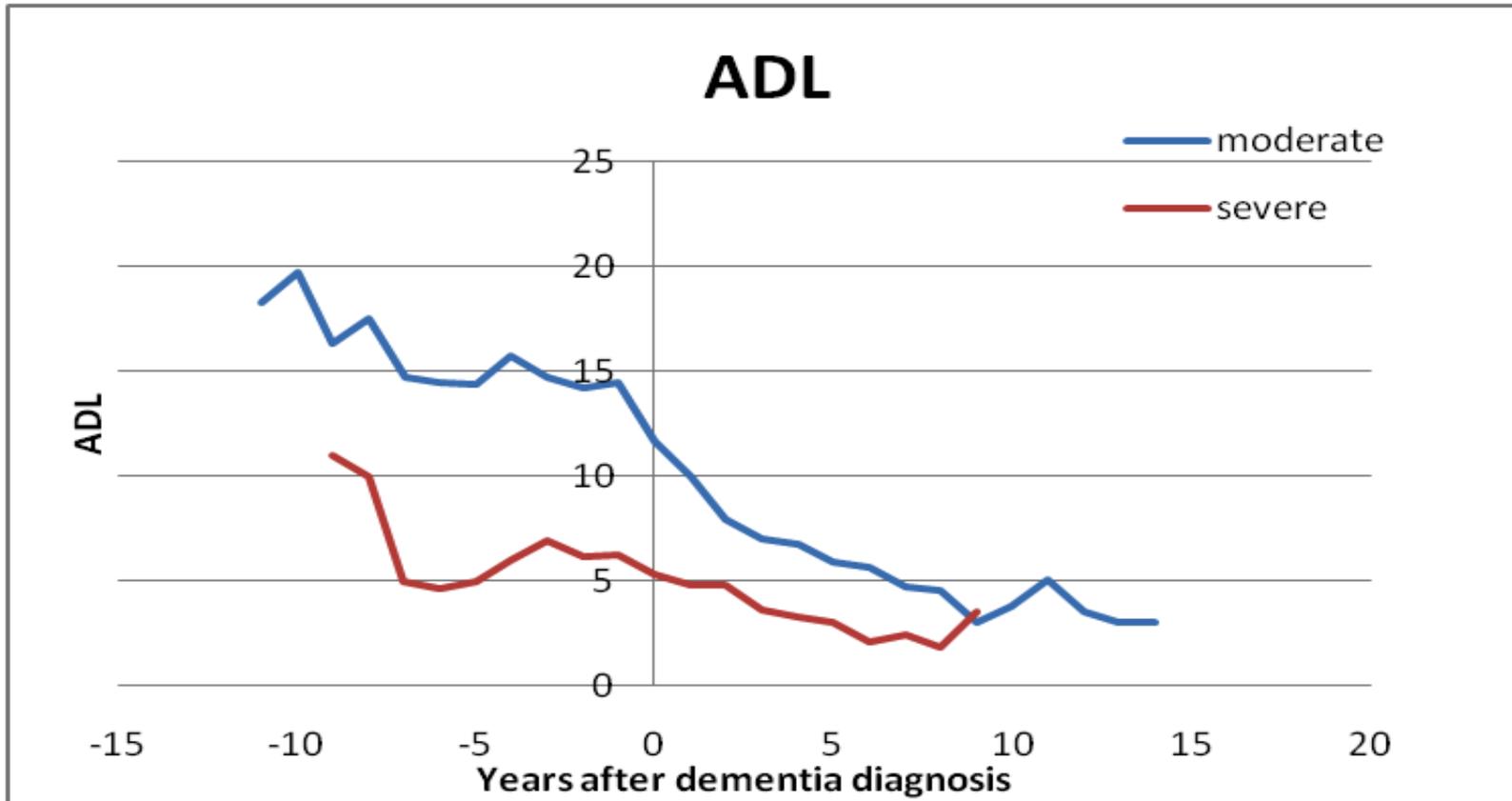
# TSI score vs. years before dementia diagnosis for those with moderate and severe disability



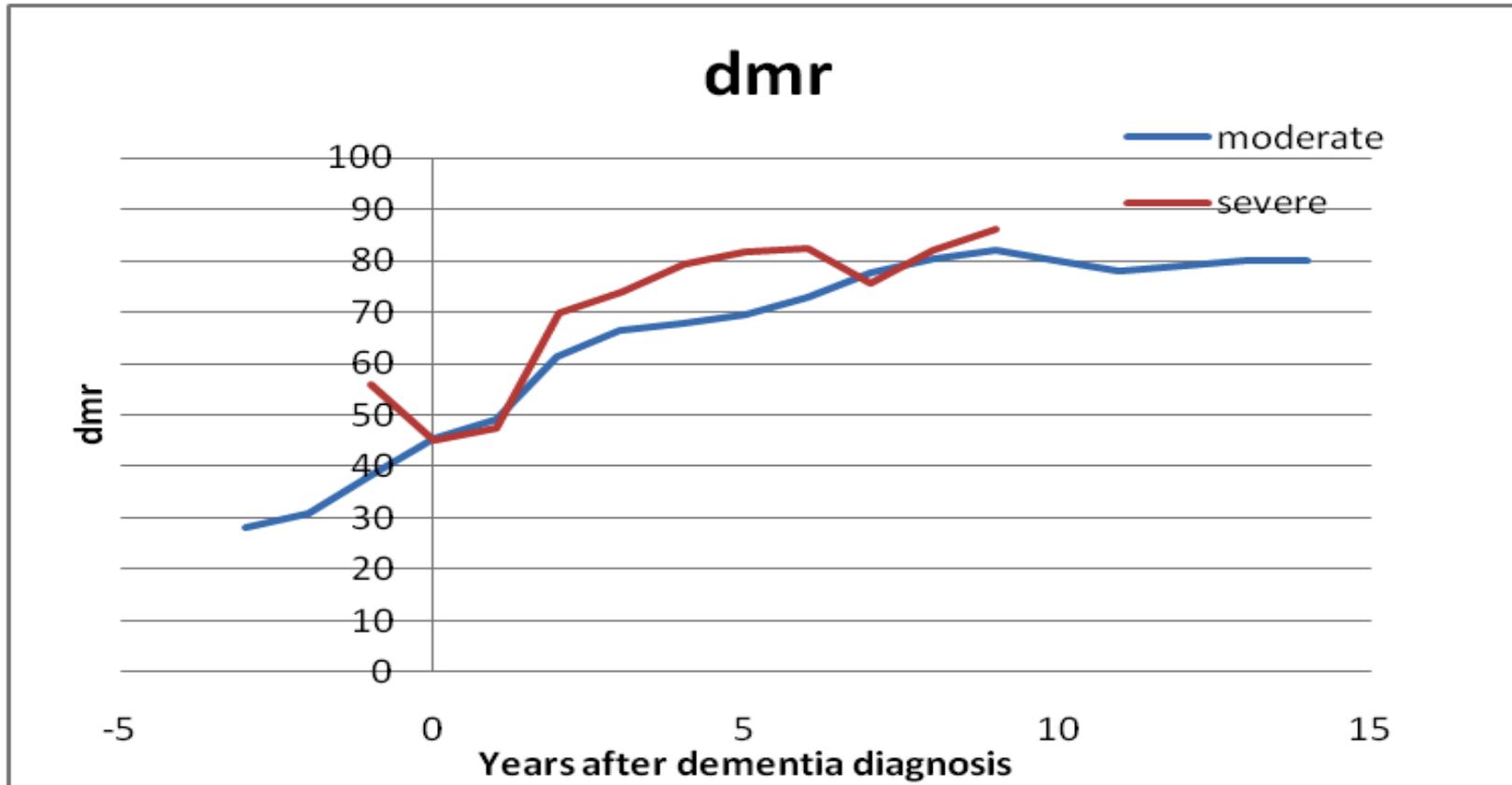
## DSMSE score vs. years before dementia diagnosis for those with moderate and severe disability



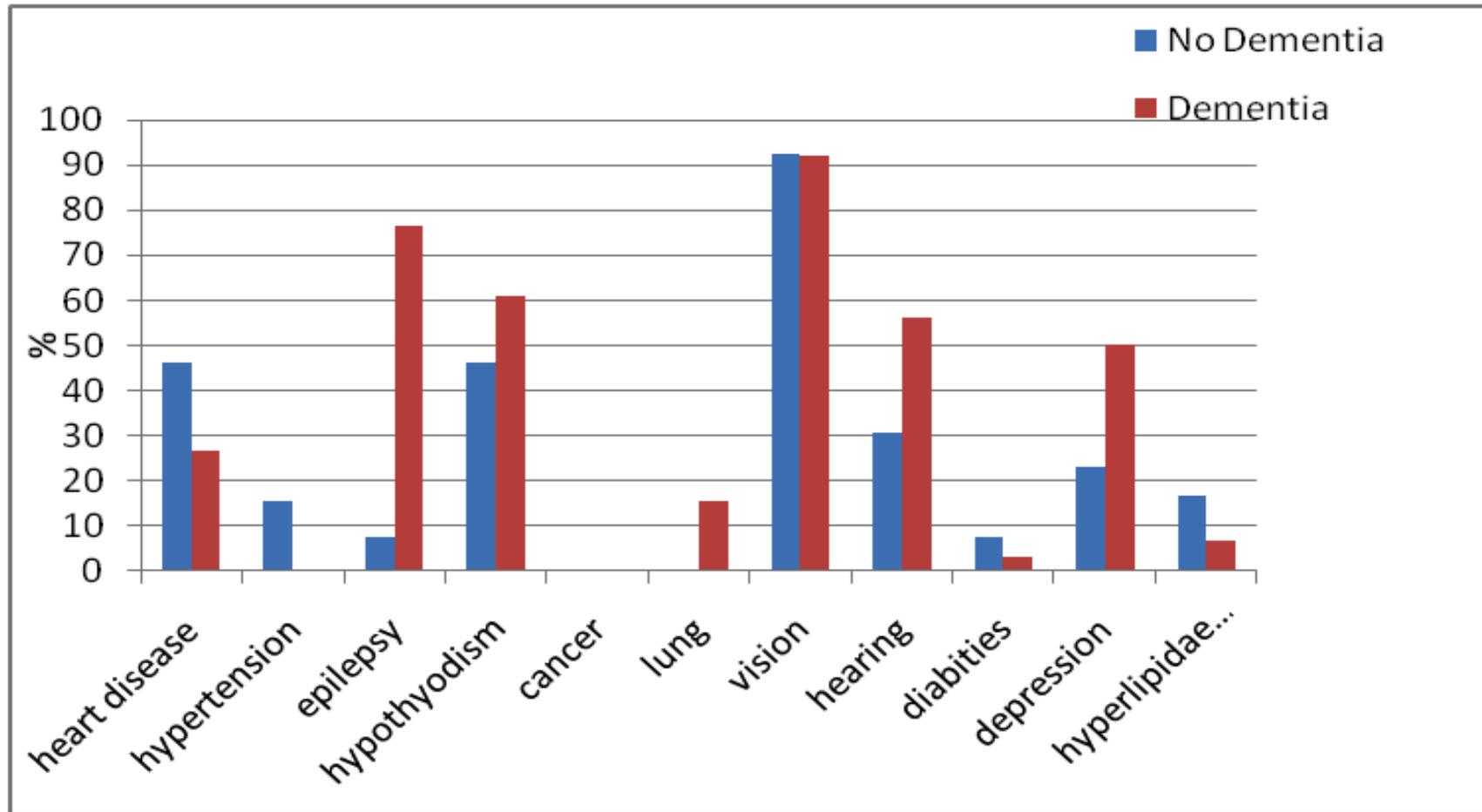
# ADL score vs. years before dementia diagnosis for those with moderate and severe disability



# DMR score vs. years before dementia diagnosis for those with moderate and severe disability



# Health co-morbidities in persons with and without dementia



## **Vision: A Seamless 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 and family
- ✓ Research to guide practice and policy

***To ensure quality care and support for persons confirmed with a diagnosis of dementia throughout the continuum of the disease –Development and roll out of Dementia Specific Standards***

# Developing standards for care

Standard 5:  
Promoting Well-Being and Social Connectedness

Each person with dementia is supported to maintain relationships with those who are important to them in their family, homeservice, and local community

29

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

Daughters of Charity Service

Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards  
A Guide to Practise  
McCarron, M & Reilly, E. 2010

TRINITY COLLEGE DUBLIN  
CREANTRY NA TRIONNACH, BALE ATHA CLAYTON  
THE UNIVERSITY OF DUBLIN

15

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.

7

Standard 2:  
Memory Assessment Service

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

11

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 4:  
Communication and Behaviour

The personhood and well-being of the person is maintained through effective communication approaches.

23

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

**-- Joel Barker**