TRINITY COLLEGE DUBLIN
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# *Ageing, health & frailty: opportunities & challenges*

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# The Challenge of Ageing

- A Success Story
- How little we know about ageing
- Promoting life long health
- Maintaining independence
- Postponing disability
- Reorienting services

# Building a Picture of Ageing with Intellectual Disability in Ireland: Preliminary Findings from IDS-TILDA

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Professor Mary McCarron, Principal Investigator

# The differences in the demography of ageing for people with ID

- People who enter the ageing process with ID may have their primary identification as a disabled person already firmly established (Gilson & Netting 1997, p. 292).
- They may have different life experiences from non-disabled people: fewer social supports, lack of an employment history, few assets for retirement, and [in some cases] pre-existing high dependency (Bigby 2002, p.232).
- People with disabilities often age within a service system rather than external to it (Bigby 2004, p. 244).
- For highly dependent people with disabilities, the loss of parental carers in mid-life will be a significant factor.

# Issues that are different

- Life long disability rather than newly onset disability in old age
- Relatively small additional disabilities may have large impact on independence
- Long term out of home placement for some
- Reliance upon family caregivers who are themselves ageing
- Services systems who never expected to provide old age care


Legislation, Policy, Institutions, Attitudes
Community Based Government & Non-Government Service Organizations
Community, Organizations, Clubs, Societies
Family, Friends, Acquaintances
Individual

# Special issues in healthcare, healthy ageing and intellectual disability

- Specific populations of people with ID have particular health risks e.g.,
  - Syndrome-specific
  - Associated developmental disabilities arising from CNS compromise
- Increased longevity of persons with ID may lead to growing risk of acquiring adult and older-age associated conditions

# Healthcare of People with ID

- Higher health care needs but less access to health care services
- Likely, on average to have 5 undiagnosed conditions at any given time- UTI’s, sight and hearing problems
- Higher level of mental health problems( up to 60% dual diagnosis, 3x schizophrenia, 4x dementia)
- 20x epilepsy
- 3x respiratory deaths than the generic population

# Frailty: An new and emerging syndrome in the field of Geriatrics

## A Definition

- Frailty is identified by slowly decreasing reserves in multiple organ systems. There is loss of muscle mass (called sarcopenia), abnormal function in inflammatory and hormonal systems, and poor energy regulation. This may all be covered by the description "excess demand imposed on reduced capacity". Once frailty is established, there is often a rapid downward spiral towards death (Ahmed et al 2007)

# Frailty and Ageing

Not all elderly are frail.

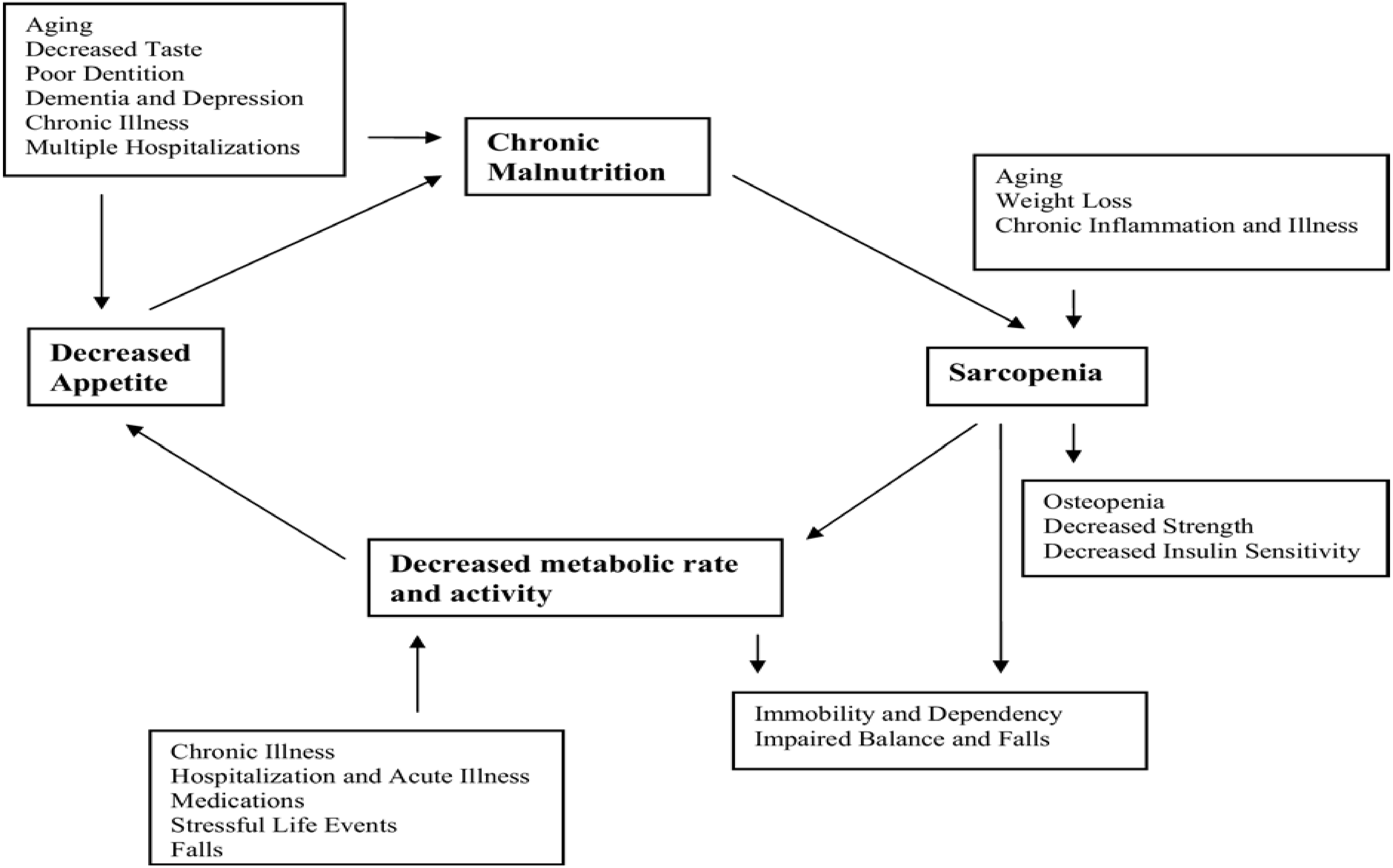
- Only 3% to 7% of elderly persons between the ages of 65 to 75 years are frail.
- The incidence of frailty increases with age, reaching more than 32% in those aged more than 90 years.
- 7% of the frail elderly have no illness, and 25% have only1 comorbid diagnosis.
- Once a person is pre-frail, he or she is more likely to progress to frailty, thus emphasizing the downward spiral affect of this syndrome (Fried et al 2003)

# Differentiating Frailty from Disability

- Disability, defined as the inability to perform activities of daily living (ADL), instrumental activities of daily living (IADL), or difficulty with mobility, does not affect the body across multiple organ systems.
- Among frail elderly persons, only 60% have difficulty completing IADL, and 27% cannot complete ADL; furthermore, only 28% of disabled elderly persons are frail.

(Fried et al 2004)

# The frailty cycle (Ahmed et al 2007)



Aging
Decreased Taste
Poor Dentition
Dementia and Depression
Chronic Illness
Multiple Hospitalizations

**Chronic Malnutrition**

Aging
Weight Loss
Chronic Inflammation and Illness

**Decreased Appetite**

**Sarcopenia**

Osteopenia
Decreased Strength
Decreased Insulin Sensitivity

**Decreased metabolic rate and activity**

Immobility and Dependency
Impaired Balance and Falls

Chronic Illness
Hospitalization and Acute Illness
Medications
Stressful Life Events
Falls

# Physical Activity

**U.S. Surgeon General recommendation for Older Adults**: Moderate physical activity, 30 minutes a day on most days.

IDS-TILDA Preliminary findings (N=230)

- Vigorous physical activity **very low across all levels** of intellectual disability (ID) with **81-100% never participating**
- **69.4% hardly ever or never participated** in moderate physical activity (range from 45 – 100% across ID levels, with participants with mild levels of ID participating the most in moderate activity)
- **All levels engaged** in mild activities more than once a week (ranges from 50 -82% across ID levels)

(McCarron et al 2010)

# Clinical significance and relevance to persons with ID

- When compared with non-frail elderly, pre-frail elderly have an increased risk of falls, institutionalization, and mortality but not as high as the frail elderly.
- During the pre-frail stage, the frailty syndrome may be reversed
- Frailty markers have been shown to improve after 30 to 60 minutes of exercise, done 3 times a week.
- By recognizing the frailty syndrome in people with ID and suggesting lifestyle changes, physicians and carers may help people with ID prevent co-morbidities later in life.

# The Challenge of Dementia

- Increased prevalence of dementia in persons with Intellectual Disability
- Dementia care is a challenge for family caregivers and for Service providers
- Symptoms of dementia challenge the emphasis on skills acquisition prevalent in programming philosophies in services
- Providers have responded in a number of ways, seeking to provide services that will support ageing in place, creating specialized units or encouraging transfer to more restrictive settings with greater medical supports

# Challenges

- Those involved in planning and service provision for persons with intellectual disabilities have come under criticism for being overly concerned with cost issues and giving insufficient consideration to quality of life outcomes
- Effectively documenting quality of life for persons with ID and AD is not an inconsequential undertaking given that many are not able to speak for themselves

# Critical Questions for Service providers supporting persons with ID and AD

- What specific care settings are most useful in addressing and responding to dementia care needs in terms of both cost effectiveness and quality of life outcomes?

# An exploratory analysis of cost and quality of life in various residential settings for persons with Down syndrome and dementia

- Funded by the Health Research Board
- Gathered cost and quality of life data for 92 persons with ID and dementia served by 22 ID service providers throughout Ireland

(McCarron et al 2008)

# Study Objectives

- To assess the physical and mental health characteristics of people with AD supported within a range of out of home care placements: dispersed housing in the community; specialist dementia units, campus group homes and residential/ institutional ageing settings.
- To measure the comparative costs of supporting people with AD and DS associated with each type of care provision.
- To measure the quality of life (QoL) outcomes for persons with AD and DS associated with each type of care provision
- To measure staff subjective appraisal of the impact of care associated with each type of care provision

# Measuring QoL: Operationalization

- Severity of Dementia: ***Adaptive Behavior and Dementia Questionnaire* (ABDQ)** (Prasher 2004)
- Physical Health: **Health of the Nation Scale (HoNOS-LD)** (Ashok et al 2002)
- Functioning**: Bristol Activities of Daily Living Scale (BADLS)** (Bucks et al, 1996).
- Staff Functioning: **Maslach Burnout Inventory (MBI)** (Maslach and Jackson 1981)
- Quality of Living Environment: **Adaptation of Kane Scale** (Kane & Kane, 2000)
- Physical Environment Assessment**: the HOME Scale** (McCallion & McCarron, 2006)
- Leisure and Community Participation. **Leisure Activities Scale** (Mc Carron, 2004)
- Psychosocial Functioning: **Assessment for Adults with Developmental Disabilities (AADS)** (Kalsy et al, 2004),
- Caregiver Burden. **The Caregiving Difficulty Scale-ID (CDS-ID)** (McCallion et al, 2005).

# Cost Methodology

A total cost of care (not just health costs) was calculated for each participant for a 3 month period

- Direct staff costs (actual that may be attributed to individual including additional staffing)
- Individual’s share of related overheads, heat, light, food, clothing, and supplies.
- Health and Social services, hospital, pharmacy, medical supply use were assigned costs based upon Department of Health reported national averages.
- Donated services and services/activities paid for by the individual themselves or their families were assigned costs based upon Department of Health reported national averages

# Participants (*n=92*) with ID and AD

- Mean age: 55.86 years (7.64)
- Majority female 71.2%
- Community based group home 26%
- Campus based unit 20.7%
- Specialist dementia facility 7.6%
- Institutional unit 45.7%
- 41.9% had been moved to their current facility because they had symptoms of dementia.

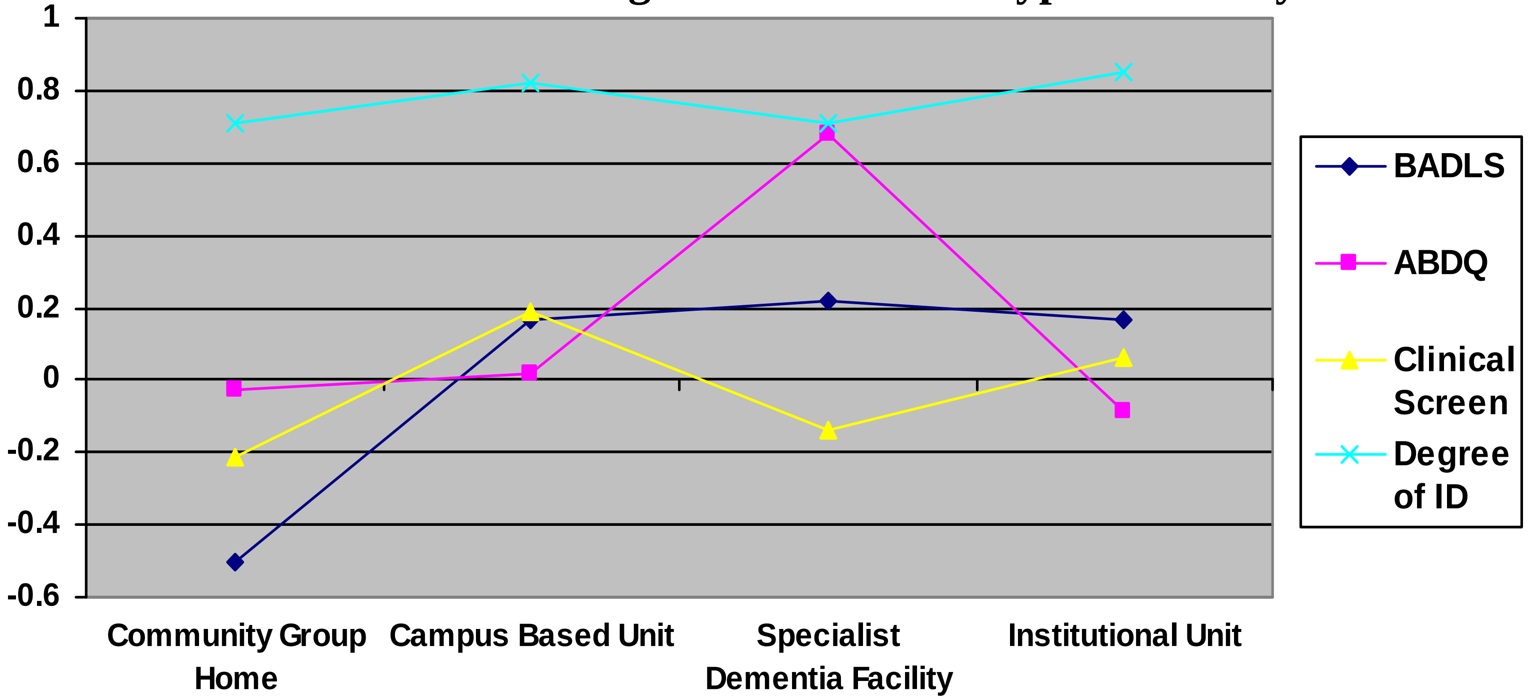
# Service Use by the Consumers

| **Name** | **Community Group Home** | **Campus Based Unit** | **Specialist Dementia Facility** | **Institutional Ageing Unit** |
|---|---|---|---|---|
| **Person moved to facility because of dementia** | 41.7% yes<br>58.3% no | 27.8% yes<br>72.2% no | 100% yes<br>0% no | 35.1% yes<br>64.9% no |
| **Previous home type** | 50% community<br>10% campus<br>40% family home | 33.3% community<br>50% campus<br>16.7% family home | 42.9% community<br>14.3% institutional<br>42.9% family home | 30.8% community<br>38.5% campus<br>15.4% institutional<br>15.4% family home |

# Service Use by the Consumers

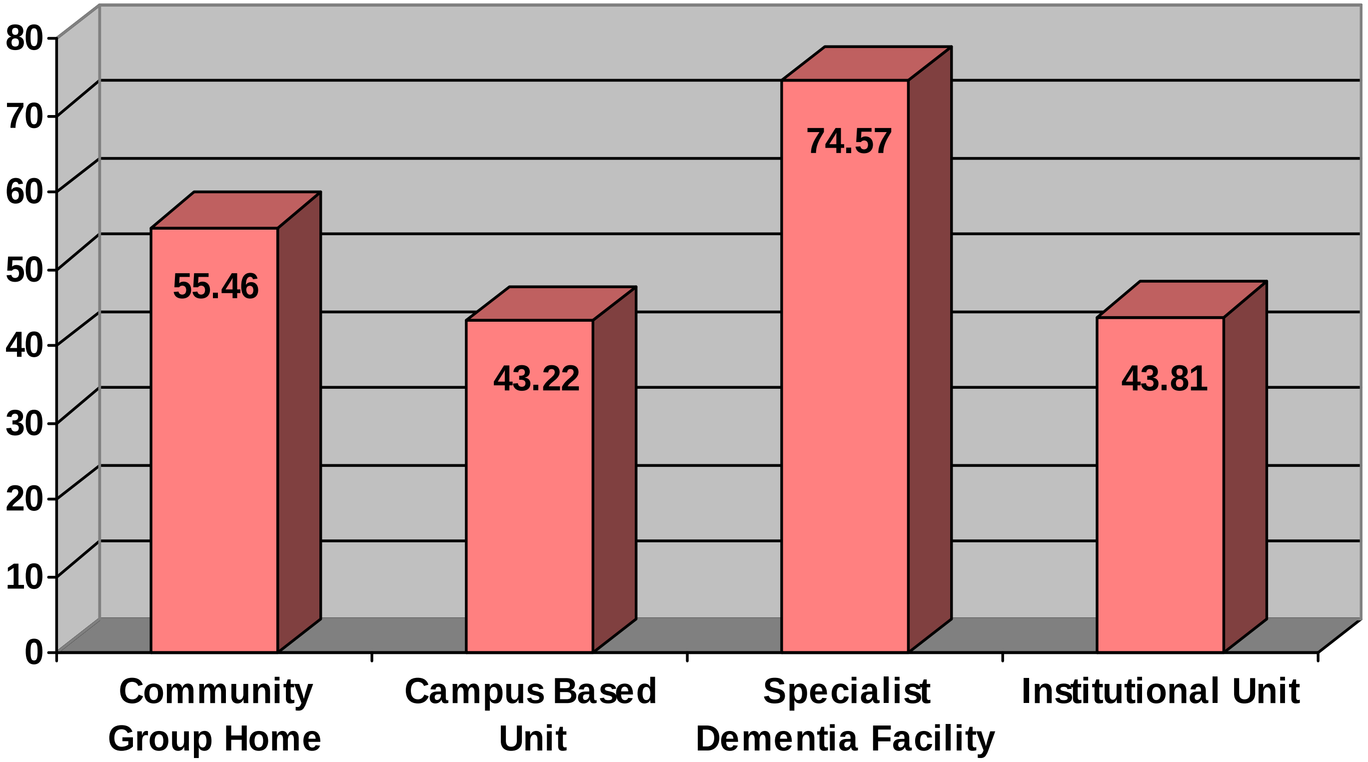
| **Name** | **Community Group Home** | **Campus Based Unit** | **Specialist Dementia Facility** | **Institutional Ageing Unit** |
|---|---|---|---|---|
| **Person participates daily activities** | 62.5% yes<br>37.5% no | 47.4% yes<br>52.6% no | 14.3% yes<br>85.7% no | 46.3% yes<br>53.7% no |
| **Activity involved leaving the residential setting** | 86.7% yes<br>13.3% no | 44.4% yes<br>55.6% no | 100% yes | 20% yes<br>80% no |

# A Comparison of Daily Functioning, Co-morbidity, Severity of Dementia and Degree of ID Across Type of Facility

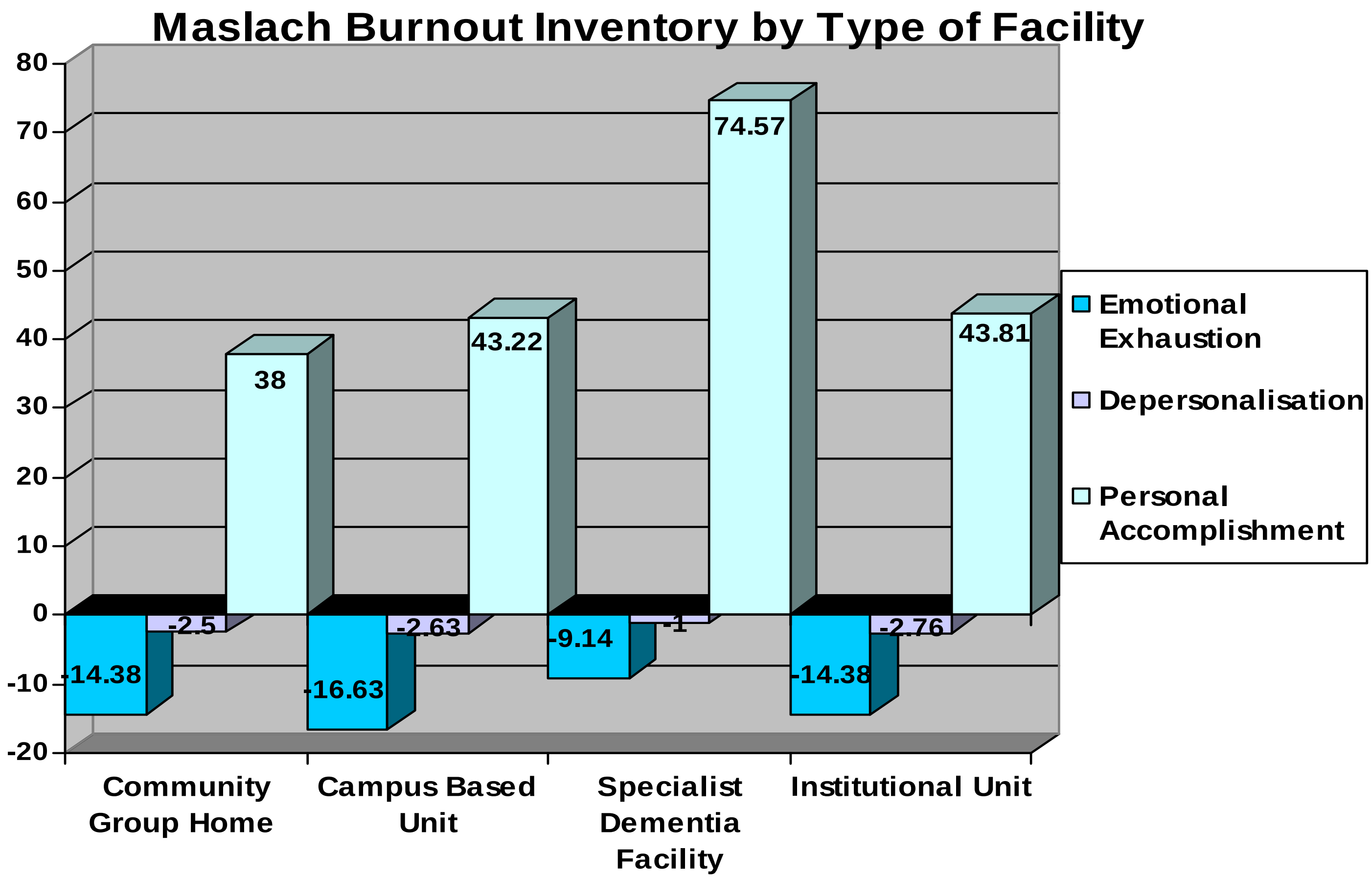


- Service users in community group homes had lowest levels of co-morbidity and highest levels of daily functioning.
- Campus based service users have the highest rates of co-morbidity.
- Specialist dementia facility service users have the most severe dementia and the lowest levels of daily functioning.
- Institutional unit service users had the most severe degree of ID and lowest levels of dementia

# HOME Scale by Type of Facility



Community and specialist dementia facilities appeared to have better environmental conditions than campus based or institutional facilities while specialist dementia facilities appeared  to be superior to community based facilities on this measure, (*F*(3, 83)=17.66, p<0.01).



Staff at specialist dementia facilities: significantly higher sense of personal accomplishment *F*(3, 84)=3.09, p<0.05).

No significant between group differences emerged on the emotional exhaustion (*F*(3, 86)= 1.95, p>0.05) or depersonalisation (*F*(3, 85)=1.14, p>0.05) subscales – trend for less emotional exhaustion for specialist dementia facility staff.

# Constructing an Overall Quality of life Measure

- Scales were recoded: Larger numbers indicative of more positive findings.
- Scale totals calculated: AADS and MBI scales.
- Principal components factor analysis: 9 recoded scales.
- First Factor (Service User Functioning): BADLS, HoNOS, ABDQ and LEISURE
- Second Factor (Quality of Setting): KANE and HOME
- Third Factor (Staff functioning/coping): AADS, CDS-ID and MBI

# QoL Findings

**No significant differences emerged between**

- Type of facility and service user functioning (*F*(3, 84)=0.66, p>0.05)
- Type of facility and staff functioning (*F*(3, 86)=1.69, p>0.05).

**Quality of setting did produce between group differences**

- specialist dementia units (M=351.39, SD=5.38) had significantly higher quality of setting scores than all other facilities,
- Community group homes (M=317.44, SD=20.34) quality of setting scores was significantly higher than for both campus (M=287.42, SD=26.00) and institutional units (M=276.97, SD=34.79),

  (*F*(3, 87)=20.07, p<0.01).

# Three Month Costs by Setting

| HOMETYPE | | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|---|
| community based group home | | 24 | 12810.83 | 90107.92 | 30346.22 | 20268.61 |
| | | | | | | |
| campus based unit | | 18 | 9546.32 | 32505.31 | 21353.03 | 6917.47 |
| | | | | | | |
| specialist dementia facility | | 7 | 26700.51 | 28205.00 | 27435.19 | 589.52 |
| | | | | | | |
| institutional unit | | 38 | 8778.85 | 29451.65 | 18526.08 | 4282.36 |
| | | | | | | |

# Cost Issues

- Based upon mean scores, the institutional and campus based units were the least costly
- The greatest range of costs were for community residences and included the most expensive situations as well as community homes that were almost as low cost as institutional and campus based units
- The narrowest range of costs were for specialist dementia units and each of the other settings had instances of care that cost more than specialist units

# Conclusions

- Cost alone does not justify moving people from community group homes or even campus settings
- Much of the cost difference was driven by the needs of particular individuals whereas the QoL across settings appeared more stable
- Community group homes and Specialist Dementia Units preferable from a QoL perspective
- When individual needs exceed the ability of the setting cost will be driven higher and there maybe circumstances where alternative settings need to be considered
- The higher QoL ratings and predictable cost picture suggests this setting should be Specialist Dementia Unit