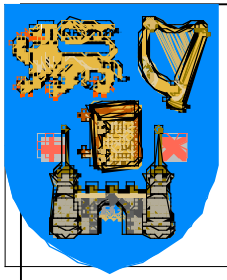
DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE

promoting excellence in dementia care

Professor Mary McCarron



TRINITY COLLEGE DUBLIN
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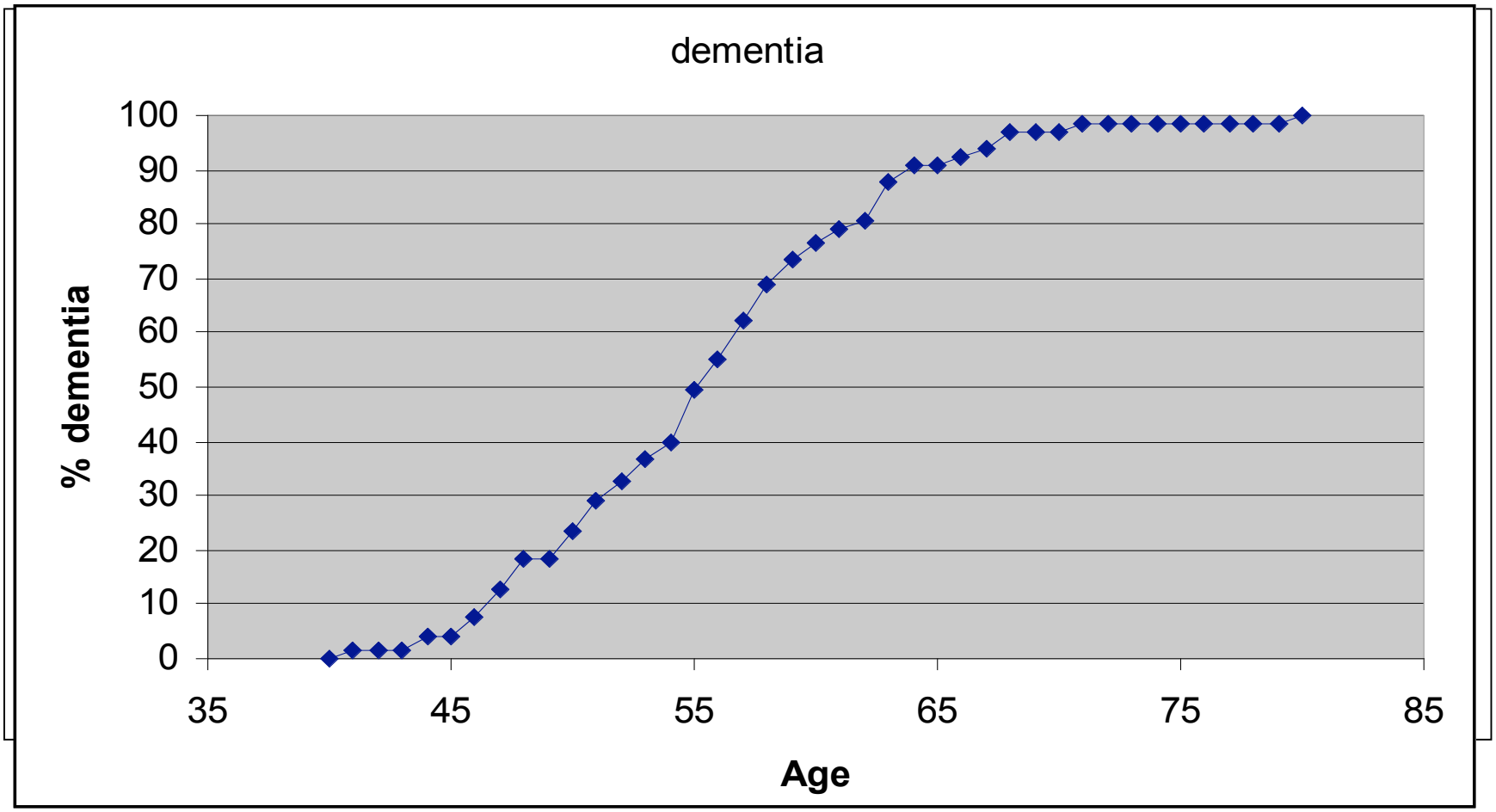
Cost and Quality of Life in Service Delivery for Persons with the Dual Disability of Down Syndrome and Alzheimer's Dementia

Professor Mary McCarron.

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

Risk of developing dementia by age



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?

The Study

- 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

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

Components of QoL in ID and Dementia

- Absence of pain
- Maintenance of health
- Psychosocial well-being
- Skills maintenance and support
- Absence of and supportive responses to problem behaviors
- Leisure and community participation
- Family and friends
- Dementia -focused programming
- Supportive environments
- Alleviation of caregiver burden

(McCallion & McCarron, 2003 & 2007)

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

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

Staff Informants

Majority Female (89%)

Role

- 29.7% direct care workers,
- 40.7% staff nurses,
- 26.4% unit heads
- 3.3% 'other'

Qualifications

- RNID 26.2%,
- Social care worker 15.5%
- RGN 13.6%
- No formal / professional

- Full time 90%
- Day shift 70%
- Evening only 1%
- Both shifts 27.5%

Average years

- Working with persons with ID: 5.13(2.08)
- Working with individuals with dementia 2.91(1.83)
- Working in current setting 3.41(1.96)
- Known the service user 6.56 (7.63).

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.

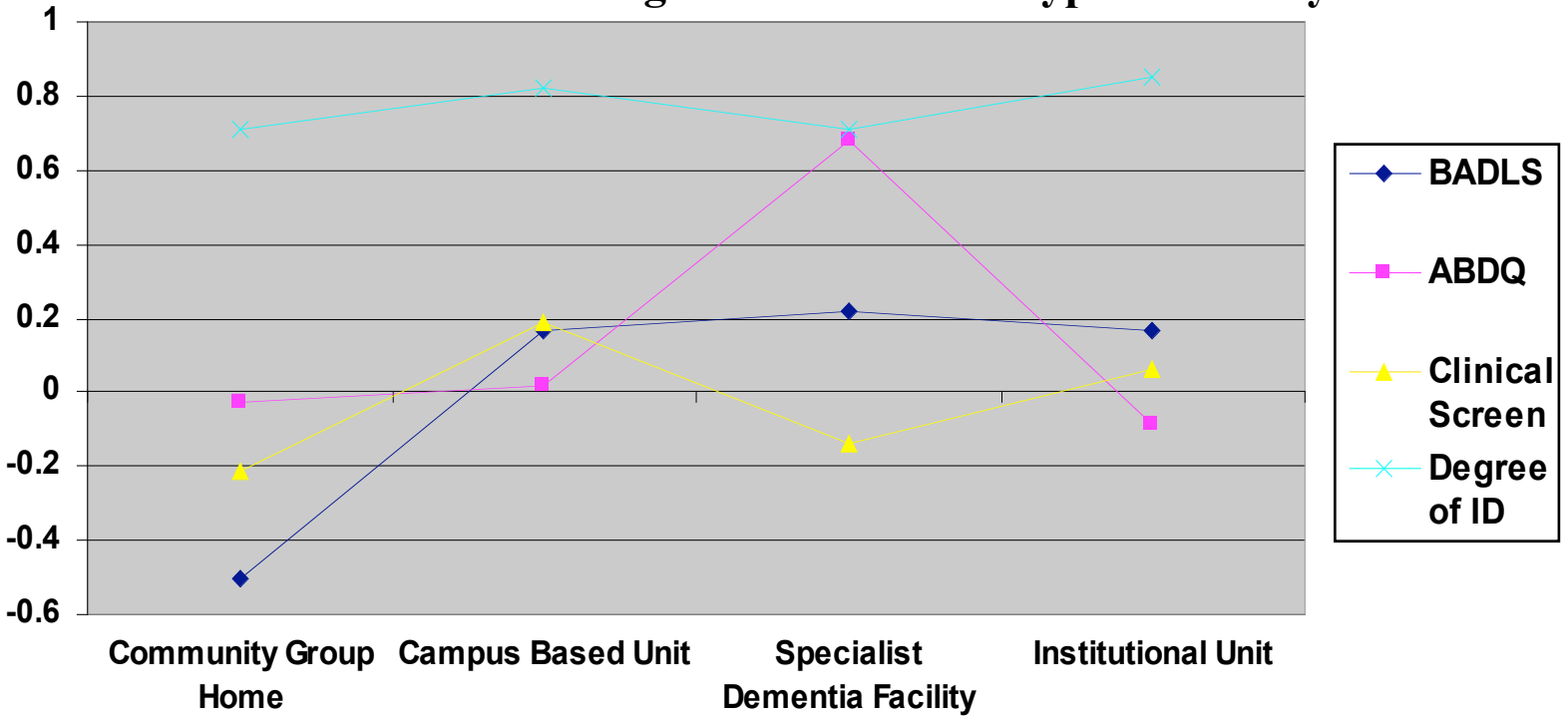
Service Use by the Consumers

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

Service Use by the Consumers

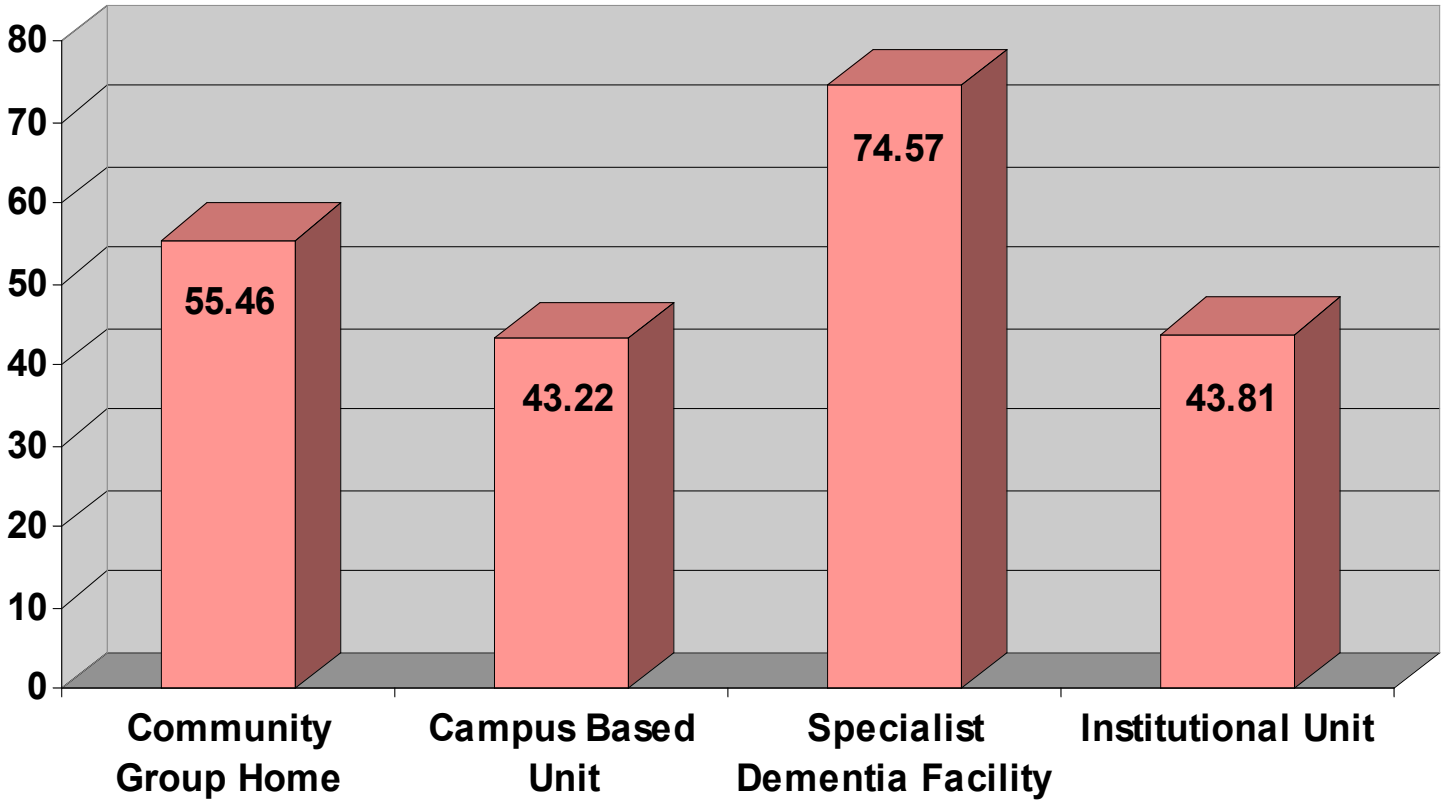
Name	Community Group Home	Campus Based Unit	Specialist Dementia Facility	Institutional Ageing Unit
Person participates daily activities	62.5% yes 37.5% no	47.4% yes 52.6% no	14.3% yes 85.7% no	46.3% yes 53.7% no
Activity involved leaving the residential setting	86.7% yes 13.3% no	44.4% yes 55.6% no	100%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

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

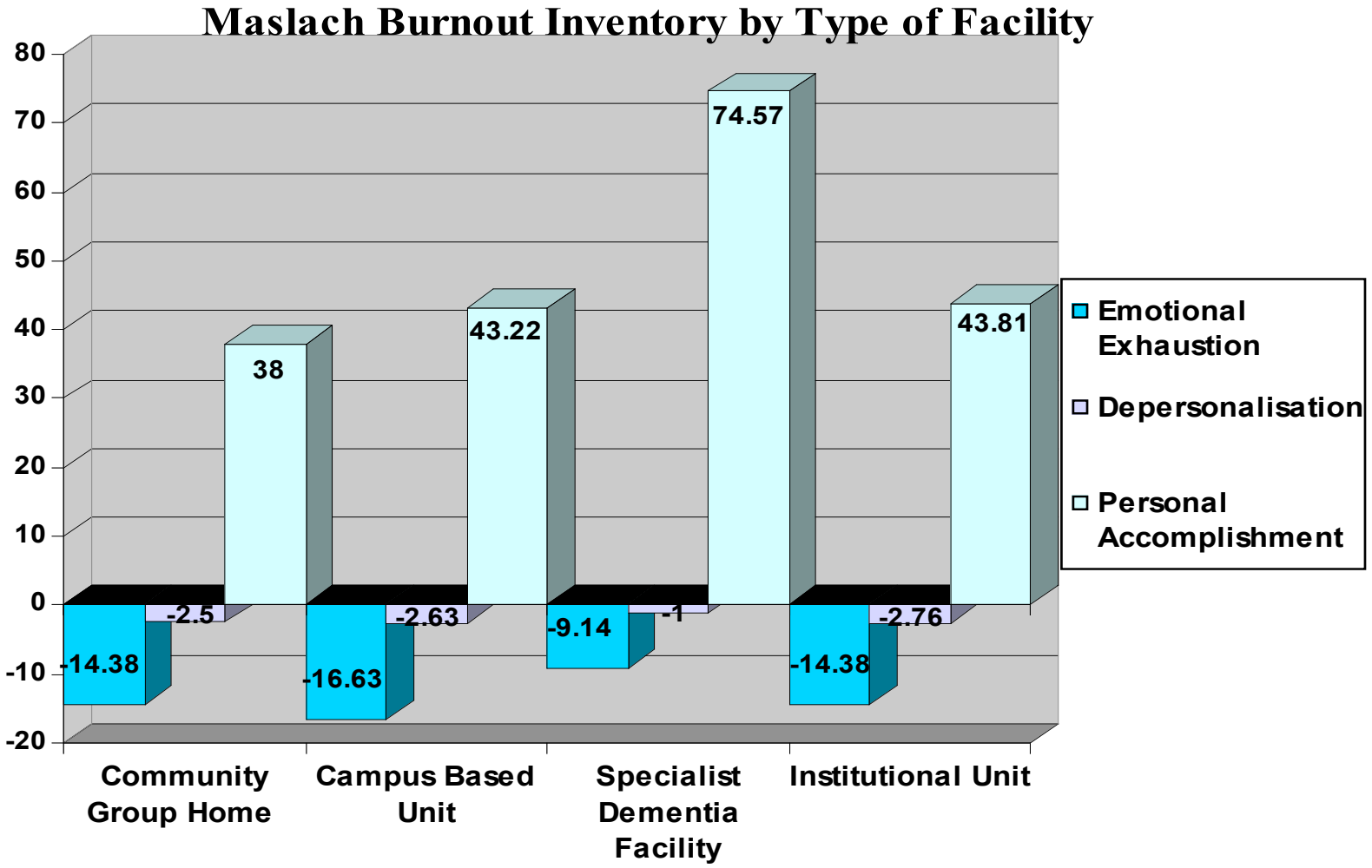


- Service users in community group homes had lowest levels of co-morbidity and highest levels of daily functioning.
- Campus based service users have the highest rates of co-morbidity.
- Specialist dementia facility service users have the most severe dementia and the lowest levels of daily functioning.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

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

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