

# Summary on TCD School of Nursing and Midwifery Paper

Supporting Persons with Intellectual  
Disability and Advanced Dementia  
( Fusing the Horizons of Intellectual Disability, Palliative and  
Person Centred Care)

# Backdrop

- Ageing general population
- Ageing population of people with disability
- NIDD : Over 50's proportional increase
- Survival into age of risk of dementia
- People with Down Syndrome unique risk
- 15/40% present with symptoms

# Research

- TCD / ID Service Providers / Palliative Care provider
- 57 participants = focus groups
- 50 from ID sector Greater Dublin
- 7 from PC sector Greater Dublin

# Aims

- Explore experiences of staff in IDS
- Explore experiences of staff in PCS
- Identify education and training needs
- Develop deliver and evaluate responsive educational intervention

# Findings

- Building on Service's History
- Values based / person centred : lack of preparedness
- Small community based settings / keeping people in usual home / advanced dementia ?
- Family, peer, staff inclusion - impact
- Co-ordination of service systems
- Advanced dementia / care needs / environments

RESIDENTIAL CIRCUMSTANCE	2003	04	05	06	07
HOME	756	752	796	817	838
INDEPENDENT/SEMI INDEPENDENT	212	234	268	295	331
COMMUNITY GROUP	948	1010	1036	1138	1253
RESIDENTIAL	1275	1302	1307	1344	1354
OTHER	66	70	124	135	149
PSYCHIATRIC HOSPITAL	283	274	238	218	197
NURSING HOME	55	80	97	110	126
INSUFFICIENT INFORMATION	274	271	64	51	31
TOTAL	3869	3993	3930	4108	4279

# Findings (contd)

- Supporting comfort and optimal death
- Recognising central tenets of care
- Training and awareness needs – pain and symptom management / communications / systems and structures / dementia
- Cultural diversity and end of life care
- Collaboration

# Design and Delivery of Training

- Introduction to history and philosophy of IDS
- Alzheimer's Dementia in Persons with ID
- Health Co-morbidities in persons with ID/AD
- Understanding Persons centred care in persons who are deeply forgetful
- Introduction , history and philosophy of palliative care
- Fusing the horizons of care
- Ethics, decision making and the person with ID/AD
- Influences of culture in approaching illness, dementia and healthcare
- Death and dying : exploring personal beliefs
- Loss grief and bereavement
- Breaking bad news
- Communication about loss, dementia, death and dying with persons with ID/AD
- End of life care – the last 24/48 hours
- Teamwork and collaboration
- Syringe drivers

# Conclusions

- Training and fusing service systems perspectives
- Resource issues and emotional cost
- Need for sustainable services
- Integrated packages of care and service collaboration
- Memory clinics in IDS
- Preparing for end of life care
- Understanding the terminal stage of dementia
- Cultural understanding
- Relationship with acute settings
- Ethics committees
- Nurse practitioner posts
- Further research