“A Life Well Lived”

Mental Health and Well Being of Older Adults with Intellectual Disabilities

Dr Jennifer Torr
ELDERS WITH INTELLECTUAL DISABILITIES CHARACTERISTICS OF A COHORT
Defining Older Age for People with Intellectual Disability

General Population
- 60-65 years
- 70 years

Intellectual Disability
- 40-55 years in ID studies
- >65 years in recent ID studies
- >50 years World Health Organisation
Life Expectancy of People with Intellectual Disabilities in the 20th Century

Premature Mortality

Mortality

- Excess of disease mortality before age 40 years $^1$
- 58 times more likely to die by 50 years $^2$
- SMR >4 $^3$

Major Causes of Death

- Pneumonia
- Seizures
- Congenital Heart Disease

Some people with mild ID are living as long, if not longer than the general population

Women in the majority from age 60 cf 35 in general population

Oldest woman 97 years

Oldest man 95 years

High adaptive functioning

Few physical problems

Selective Mortality

Factors Associated with Premature Death
- Youngest age
- Severe ID
- Minimal or no mobility
- Limited or no feeding ability
- No toileting skills/incontinence
- Sensory impairment
- Epilepsy
- Serious medical conditions
- Down Syndrome
- Cerebral Palsy
- Prader Willi Syndrome

Healthy Survivors
- Less people with Down Syndrome, Prader Willi Syndrome
- More females
- More mild ID
- Less physical health problems
- Higher adaptive functioning
  - population studies - increase in adaptive functioning with age
- Adaptive functioning declines after age 74
  - toileting, dressing, grooming, eating, language, reading, writing
Residential Circumstances Of Older (55+) Australians with Intellectual Disability

(Ashman et al 1996 JIDR 40:120-129)
Changing Profile of Accommodation Arrangements

Group Home <7, 37%
Group Home >7, 15%
Residential >20, 9%
Aged Care, 8%
Independent, 8%
Family, 9%
With Peer, 9%
Other, 5%

Thompson, D. *Well, we've all got to get old haven't we? Reflections of older people with intellectual disabilities on aging and change*. Journal of Gerontological Social Work. Vol.37(3-4), 2002, pp. 7-23.
Institutionalisation
- Early separation from family
- Disruption of family and community relationships
- Life long family relationships

Deinstitutionalisation
- Aged care facility
- Community group home
- Separation from life long friends
- Re-established family relationships
The Well Being of Elders with Intellectual Disabilities:

“Life, if well lived, is long enough”

Seneca, De Ira
Well Being

Physical Needs
- Shelter

Health

Security
- Predictability
- Control

Social
- Interconnectedness

Growth
- Challenge
- Independence
- Agency

Service
- Giving

Spiritual

Play
- Fun
- Humour
- Laughter
Physical Well Being
Physical Health = Brain Health = Mental Health

Look after our own planet

Eat well

Wash your hands before every meal

Eat plenty of fruit

Healthy living

Quit smoking

Well groomed
# Delaying Cognitive Decline and Dementia

## 3 City Studies: Bordeaux, Dijon and Montpellier

<table>
<thead>
<tr>
<th>Life Style</th>
<th>Nutrition</th>
<th>Health Care/Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Crystallised intelligence / What you have learnt</td>
<td>• Fruit and vegetables</td>
<td>• High cholesterol</td>
</tr>
<tr>
<td>• Mentally stimulating activities</td>
<td>• Dietary fibre</td>
<td>• Diabetes</td>
</tr>
<tr>
<td>• *Social engagement</td>
<td>• B vitamins</td>
<td>• Hypertension</td>
</tr>
<tr>
<td>• *Physical exercise</td>
<td>• Olive oil</td>
<td>• Depression</td>
</tr>
<tr>
<td>• *Not Smoking</td>
<td>• Omega-3 fatty acids</td>
<td></td>
</tr>
<tr>
<td>• *Limited Alcohol</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Other Studies
Vitamin D Deficiency

Endemic
Associated with Brain Disorders and Mental Ill Health
Identify and correct, but don’t overcorrect

Cherniack, E.P., et al.,
Some new food for thought: The role of vitamin D in the mental health of older adults.
Time for a Positive Psychology of Intellectual Disability

Marybeth Solinski 59 years
mediagallery.usatoday.com
Maslow’s Hierarchy of Needs

- Basics – Air, Water, Food, Shelter
- Safety
- Love and Belonging
- Esteem
- Self Actualisation/
  Self Fulfilment
“Life, if well lived, is long enough”
Seneca, De Ira
“The Getting of Wisdom”

Personality Development
Ageing as Life Transition and Development

- Childhood
- Adulthood
- Elderhood
George Vaillant
Adaptation to Life

Social / Interpersonal maturation

- Self to Other to Community
- Development of social skills
- Fostered by social engagement and participation in life
- Fostered by quality of relationships with families, peers, carers, community

Emotional / Intrapersonal maturation

- Development of increasingly adaptive coping mechanisms
- Can be taught and learnt
- Related to decline in challenging behaviours
- Fostered by quality of relationships with families, peers, carers, community

Vaillant, G. Ageing Well. Scribe 2002
### Resilience: Having the Time of My Life

**13 women with mild ID, independent, good verbal skills**

- Positive view of ageing, felt ageing well, optimistic, felt good about themselves

- Resilience – ability to cope with adversity, able to recover from and gain positive effects from adverse event

- Related to self rated health, social supports, absence of depressive symptoms, confidence in performing basic activities

---

Relationships

Gloria
John Hopkins University
Family Relationships
Elders with Intellectual Disabilities

Less likely to live with family

In family setting, usually live with elderly parents

Less likely / unlikely to have a spouse or children

Relationships with Siblings, Nieces/Nephews
Eco Maps: Visualising Social Relationships

Anne Eco-map

Karen: worker, self-appointed advocate
DHS

Key worker
Ed: HS DHS house

Housemates: No longer recognised
CDDHV

Father
Siblings

Previous contact with friends from previous CRU. No contact any more. Does not recognise

minor relationship
moderate relationship
strong relationship
tenous/uncertain
stressful/conflictual

Participant
Family
Peers
Direct support/Carers
Medical/Health Care systems

Carling- Jenkings CDDHV
Concerns of Elders with Intellectual Disabilities

Main concerns were about loss and changes

- Family
- Friends
- Services

Less concerned about physical health

Wanting more control over issues affecting their lives

Meaningful roles incl. employment

Mental stimulation

Companionship

Reliable support

Safety

Listening to Elders

- Empowerment
- Active involvement, meaningful roles
- Sense of security
- Maintaining skills and learning
- Congenial living arrangements
- Optimal health and fitness
- Being safe and feeling safe and having
- Satisfying relationships and support

Fun, Humour and Laughter

Max Lewis in Notes on a Scandal
The Importance of Pets, Gardens, Hobbies, Collections
What is Ageing?

- Natural physiological process of decline in cell repair and renewal
- Results in loss of cellular structure and organ function over time

General ageing processes

Individual variation

Interaction of lifelong disability and ageing

Health in earlier stages of life impacts health at later stages

Age related conditions

- Premature ageing
- Patterns of ageing
- Pathological mechanisms
- Targeted interventions
- Practice guidelines

Syndrome Specific Ageing
5-Ds of Ageing

- (Physical) Decline
- Depression
- Dementia
- Delirium
- Dying and Death
Physical Decline

- Bones, Joints, Mobility
- Pain
- Senses
- Organs
- Metabolism
- Energy
PHYSICAL HEALTH

- Incontinence
- Immobility
- Falls and fractures
- Sensory
- Arthritis
- Pain

- Hypertension
- Cerebrovascular
- Cardiorespiratory
- Hypothyroidism
- Parkinson’s Disease

- Health Status rather than age is guide to functional ability

Earlier onset of age related disorders in DS

<table>
<thead>
<tr>
<th>Sensory impairments</th>
<th>Musculoskeletal</th>
</tr>
</thead>
</table>
| • High risk of hearing impairment, increases with age  
  38% <50 yrs  
  62% >50 yrs  
  (Meuwese-Jongejeugd et al. 2006) | • Osteoporosis  
  (Centre et al 1998, Angelopolou et al 1999) |
| • Increasing vision impairment and blindness with age  
  1/3 vision impairment > 50 yrs  
  2/3 vision impairment > 50 yrs and severe ID | • Osteoarthritis  
  • Spine  
  • Hips  
  • Knees.  
  (Hresko et al. 1993) |
| • Blindness  
  • ~2.6% <50  
  • 7% >50 years  
  (van Splunder et al 2006) | |
Sensory Impairments Impact Upon

General functioning  Communication  Social relating  Well being
<table>
<thead>
<tr>
<th>Non-degenerative mild cognitive impairment in elderly people and use of anticholinergic drugs</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Medications for</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Mental illness</td>
</tr>
<tr>
<td>• Antipsychotic side effects</td>
</tr>
<tr>
<td>• Incontinence</td>
</tr>
<tr>
<td>• Cardiac conditions</td>
</tr>
<tr>
<td>• Other</td>
</tr>
</tbody>
</table>
Depression and Other Mental Ill Health in Elders with Intellectual Disabilities

Image from Feeling Blue. Books Beyond Words. Gaskell
Psychopathology
Adults vs Elders

Data from Cooper 1998 JIDR
Psychotropic Drug Use
Adults vs Elders

- All Psychotropics
  - 20-39 years: 50%
  - 55+ years: 66%
- Neuroleptics
  - 20-39 years: 26%
  - 55+ years: 50%
- Antiparkinsonians
  - 20-39 years: 8%
  - 55+ years: 42%
- Lithium
  - 20-39 years: 18%
  - 55+ years: 7%
- Antidepressants
  - 20-39 years: 5%
  - 55+ years: 10%
- Anticonvulsants
  - 20-39 years: 7%
  - 55+ years: 23%
- Anxiolytics
  - 20-39 years: 13%
  - 55+ years: 8%

Pary 1993 AJMR
Pary 1995
Archeological Psycho-Pharmacology

Why is this person on these medications?

Does this person have a documented psychiatric diagnosis? Is there documented evidence for this diagnosis? Is the diagnosis correct?

Has a psychiatric diagnosis been missed? Is this person on chemical restraint for aggressive behavior rather than specific treatment for bipolar disorder?

Is the person “old fashioned” Antipsychotics? Antidepressants? Anticonvulsants?


Is this person on depot antipsychotics? Do they take other medications by mouth?
Depression in Older Age

- Older population, higher life time rate of depression
- Strong relationship between depression, self esteem, social engagement, disruptive life events in adults with intellectual disabilities
- No depression or treatment of depression associated with better cognition
- Relationship to brain disorder
  - Vascular changes
  - Association with dementia
- Depression and dementia results in higher levels of disability than dementia alone
CDDHV Depression Checklist for Adults with Intellectual Disabilities

- Depressed mood
- Depressed thinking
- Loss of interest in or enjoyment of usual activities
- Irritability
- Anxiety
- Social interaction + communication
- General functioning,
- Other behaviours,
- Appetite/ weight, sleep

http://www.cddh.monash.org/research/depression/
Factor Analysis of CDDHV Depression Checklist

Core Features of Depression

- Depressed Mood
- Social withdrawal
- Loss of interest/loss of enjoyment

Torr, Iacono, Graham, Galea
Psychosocial Interventions

- Address psychosocial stressors
- Social Support
- Re-engagement in work, day program, social activities
- CBT Social Skills
  - Self Esteem
  - Problem Solving, Goal Setting
Books Beyond Words: Feeling Blue
Available Online RCP website
# Treatment with Antidepressants

<table>
<thead>
<tr>
<th>No Randomised Control Trials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case reports and case series</td>
</tr>
<tr>
<td>Beware of undiagnosed bipolar disorder</td>
</tr>
</tbody>
</table>

## Side effects
- Gastrointestinal
- Sleep disturbance
- Agitation
- Manic switch/elevated mood

## Importance of Monitoring
Mr L: 60 yo man with Fragile X Syndrome
Rx Depression with Sertraline 50mg

At Diagnosis 6 Months
Treatment of Depression with ECT

- 57 year old woman with past history of major depressive disorder
- Loss of 20kg over 6 months
- Repeat A+E attendances
- Agitated
- Tearful
- Fearful
- Nihilistic Delusions

- Involuntary Admission
- Misdiagnosis of autism
- Discharge with no follow up
- Life threatening complications
- Carer advocacy
- Readmission and ECT
- Recovery, cheerful, socially engaged
Behavourial and Observable Features of Mania in ID

**Non Specific Behaviours**
- Agitation
- Physical and verbal aggression
- Property destruction

**Mood**
- Elevated Mood
  - Inappropriate laughing, singing, whistling,
- Irritability

**Behavioural Equivalents**
- Hyperactivity
- Increased intensity, frequency of usual activities/traits
- Increased communication
- Disinhibited behaviour

**Biological features**
- Lack of sleep
- Weight loss
- Increased appetite
BEHAVIOUR CHART

- Behaviour: giggling, hyperactive, aggressive, absconding, property destruction
- Weight: kg
- Melleril/Chlorpromazine x 10mg

Graph showing data from June 1966 to April 1988 with various markers and data points.
Diagnostic Overshadowing
Manic Episode

- 51 year old man, mild ID, meningitis and hydrocephalus
- At age 45 years, 10 day psychiatric admission with 2/52
  - Decreased functioning
  - Mood lability and irritability
  - Verbal abuse, physical aggression
  - Sexual disinhibition
  - Rapid, loud, incoherent speech peppered with sexual references and expletives

- Episodes of low mood, frequent crying, ruminations about death of his mother, low self esteem, social isolation, self neglect, loa, low

- At age 51 years
  - 2001 hyperactive, physically violent, smashing windows and throwing furniture, sleeping periodically for about an hour, pacing, smoking, drinking coffee, joking, laughing, speech loud repaid incoherent jumping from one topic to another, teasing tone, rhyming, swearing, obscene gestures, exposing himself
  - 6 police required to get him to hospital
  - DX of behaviour disorder. Rx Risperdal And sent home in this condition. Carers told it was not appropriate for them to send him to AMHS, as his behaviour was disturbed, he did not have a psychiatric disorder
  - Advice from CDDHV to GP to commence valproate 400mg bd
  - Marked improvement and mood stability
<table>
<thead>
<tr>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Down Syndrome</strong> 50-75% by 65 years</td>
</tr>
<tr>
<td><strong>Non Down Syndrome</strong> ~ 10 years earlier than general population</td>
</tr>
<tr>
<td>Early distress “what is wrong with me?”</td>
</tr>
<tr>
<td><strong>What do you tell the person with dementia?</strong></td>
</tr>
<tr>
<td>Loss of mental abilities</td>
</tr>
<tr>
<td>Eventual loss of self</td>
</tr>
</tbody>
</table>
Dementia
Disruption to Social Relationships

Anne Eco-map

Karen: worker, self-appointed advocate

Key worker

Ed: HS DHS house

Housmates: No longer recognised

Father

Siblings

CDDHV

DHS

Previous contact with friends from previous CRU. No contact anymore. Does not recognise

minor relationship

strong relationship
tenuous/uncertain
stressful/conflictual

Participant

Family

Peers

Direct support/Carers

Medical/Health Care systems

Carling- Jenkings CDDHV
Transitions in Care
Life Events: Older People with DS

In 6th decade people with DS experience significantly more life events than people without DS

- Death of parents,
- Relocations, home to group home, change group home, nursing home
- Change of day program,
- Medical events

Life events associated with behaviour problems and depressive symptoms

Older Parents

Positive adaptation

- Less dependent on services
- At risk of increasing frailty, chronic and acute illness, and death
- Residential planning most emotionally laden
- Less than 1/3 of older carers have engaged in permanency planning
Intergenerational Transfer of Care

Half of actively involved siblings were willing to take on future care responsibilities

- 36% planned to coreside
- 64% planned to live apart but were involved in future planning and planned to be legal guardian.

Predictors of Intergenerational Care

- Family communication and parental approval
- Female, Older Sibling
- Married with children,
- Middle age, Middle class, Post secondary education, Employed
- Level of ID
- Mothers health

Krauss et al. 1996 Mental Retardation 34:83-93
Social Connections: Eco Maps

Carling-Jenkins CDDHV
Failure to Plan

Precipitous removal from home

Permanent and fundamental change in lifestyle

Inappropriate placements
  • Nursing Homes
  • Emergency/Respite Care

Grief and Adjustment Reactions

Precipitate medical, psychiatric and behavioural disorders
The art of living well and dying well are one.

- Epicurus
Am I going to die?

Books Beyond Words
Social Story
Royal College of Psychiatrists
Bereavement and Grief

Books Beyond Words
Social Story
Royal College of Psychiatrists
End of Life Decisions

Who makes end of life decisions?

When to make end of life decisions?
Thankyou