

# **CARING FOR OLDER PERSONS WITH INTELLECTUAL DISABILITIES**

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## Overview

- Life expectancy; population size
- Lifestyle and experiences
- Comparison of ID services and old age services; joint work
- High level /different pattern of disease ,and cause of death
- Unmet health needs
- Practical considerations
- Conclusions

## Increasing Life Expectancy

	<b>Date</b>	<b>Men</b>	<b>Women</b>
Stoke Park	1931 - 35	14.9 y	22.0 y
Stoke Park	1951 - 55	29.2 y	36.3 y
St Lawrence	1961 - 65	45.7 y	52.6 y
Stoke Park	1976 - 80	58.3 y	59.8 y
Prudhoe	1983 - 87	62.3 y	66.2 y
Leavesden	1986 - 90	65.6 y	75.4 y

## Deaths and Standardized Mortality Rates - Scotland

	<b>General population (/ 1,000)</b>	<b>Intellectual disabilities (/ 1,000)</b>	<b>SMR (%)</b>
16 – 44 y	1.0	11.6	1160
45 – 59 y	6.6	25.3	383
60 – 74 y	22.1	41.2	186
75 y +	93.4	100.0	107

## Future Predictions

- Changing demographics
  - 53% increase in I D 1960-1995 = 1.2% per annum
  - Projected 11% increase over next 10 years
  - Increase in older persons and with most severe disabilities
- Finance – \$44.1 billion lifetime excess cost (USA 2000 incident cohort)

## Small Numbers - Scotland

	16 – 20 y	21 – 64 y	65 y +
Men	1,475	9,722	1,157
Women	945	7,939	1,131
Total	2,420	17,661	2,288

## Population Size Within the Context of the General Population

- Adult prevalence of ID ~ 4 / 1,000
- Only about 10% of people with ID are older persons
- People with Down syndrome ~ 20% - but most are children and young adults

## Lifestyles and Experiences

- Never married, no children
- Lack of family support, social networks
- Never worked
- Lived in institution for decades
- Resettled to community; individual or shared tenancy with 24 hour support package
- Support packages – accommodating changes can be slow / housing stock
- Nursing home (reinstitutionalization)

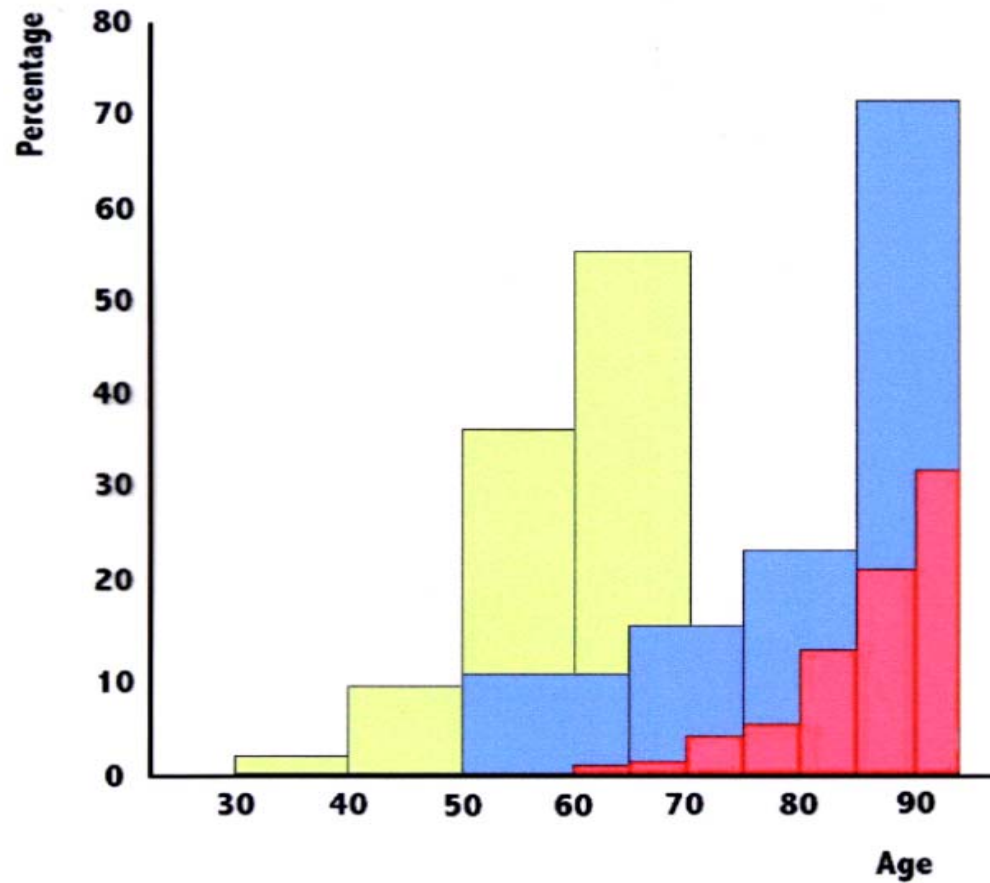
## Intellectual Disabilities Services

- Older persons are a small proportion (10%)
- Geared towards skill development, problem behaviours, and static disabilities (rather than changing needs)
- General health only recently gaining prominence
- Psychiatrists, psychologists, ID nurses, S&LT, OTs, physiotherapists, dieticians, social workers, other therapists

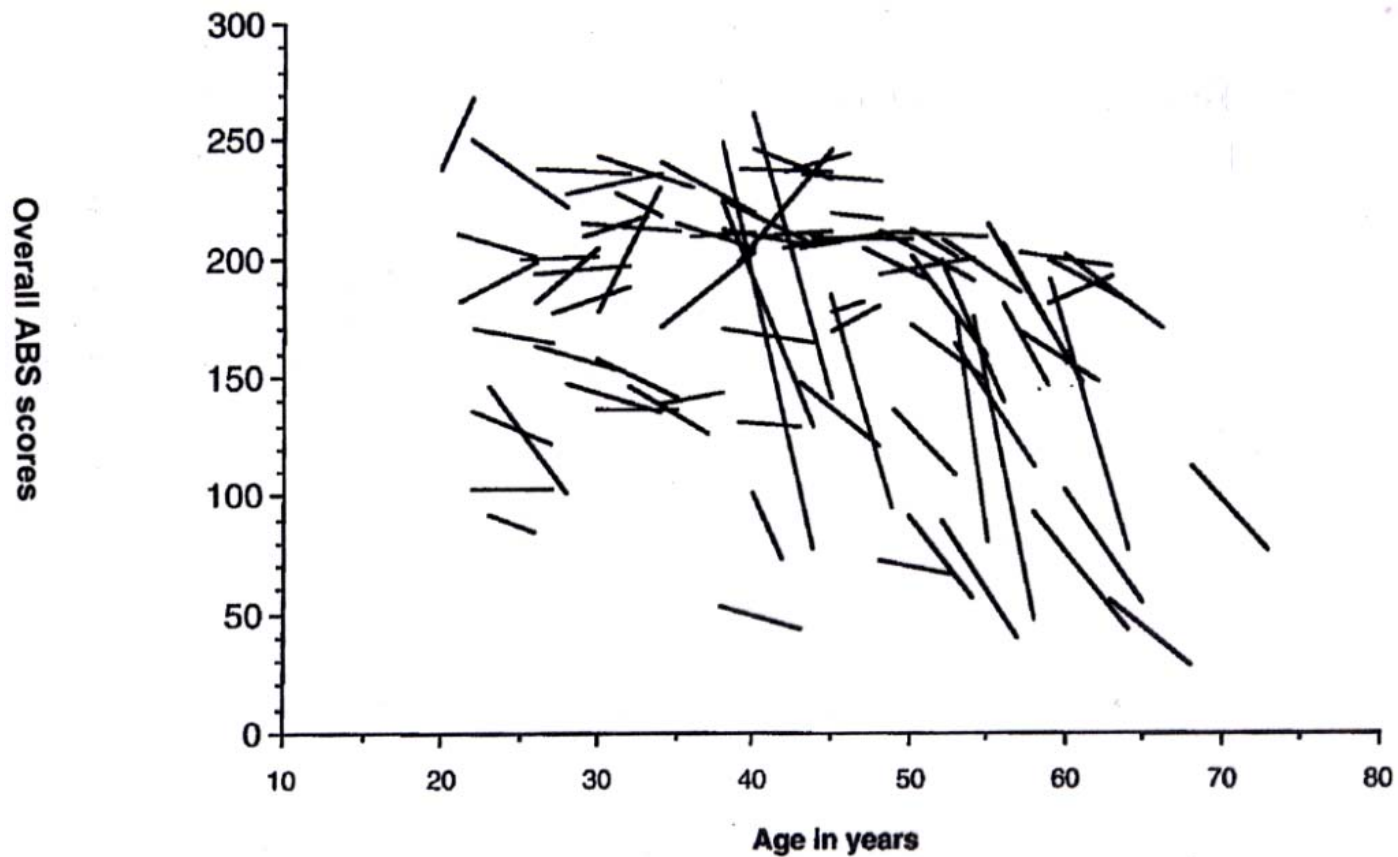
## Services for Older Persons

- Very small proportion of overall work
- Emerging population (life expectancy, hospital closure) with different spectrum of health needs
- When is a person eligible for older persons services
- Premature ageing

## Age Specific Rates of Dementia



## Skill Decline with Age in Adults with Down Syndrome



## Prospective Cohort of Older Persons with Intellectual Disabilities

- Point prevalence of mental ill-health – 53%
- Incidence of mental ill-health – 17%
  - 10% affective
  - 7% dementia
- Deaths within the 2 year period – 19.2%

## Caseload of Older Persons with Intellectual Disabilities

- Old age psychiatrists:
  - 0 - 4 new assessments / year (Mean = 0.9)
  - 0 - 5 on current case-load (Mean = 0.7)
- ID psychiatrists:
  - 0 - 15 new assessments / year (Mean = 5)
  - 0 - 20 on current case-load (Mean = 6)

## Older Persons with Intellectual Disabilities and Dementia

- ID psychiatrists – confident re assessments
- Old age psychiatrists – confident prescribing cognitive enhancers
- Ever used cognitive enhancers with person with ID
  - ID psychiatrists 23%
  - old age psychiatrists – 9%
- Geriatricians?

## High Level of General Health Needs

- Risk factors that affect the whole population
- Risk factors associated with ID
- Risk factors associated with ageing

## Differences from the General Population - Causes of Death

- General population – (1) cancer (2) ischaemic heart disease (3) cerebrovascular disease
- ID (1) Respiratory disease
  - Commonest cause of death
  - Pneumonia and aspiration (swallowing, GORD, PMI, Down's syndrome)
- ID (2) Cardiovascular disease
  - Congenital heart disease
  - Ischaemia less common
- ID (3) Cancer
  - Lower level of lung, prostate and urinary tract cancers, higher oesophageal, stomach and gallbladder
  - Leukaemia and Down's syndrome and ?PWS
  - Lower ranked as cause of mortality

## Some Health Needs are Less Common

- Ischaemic heart disease
- Stroke
- Lung cancer
- Bladder cancer
- Prostate cancer
- Obstructive airways disease
- Alcohol and substance problems
- Suicide and attempted suicide

## Several Health Needs are More Common

- Epilepsy
- Reflux disorder
- Constipation
- Poor nutrition
- Swallowing problems and aspiration pneumonia
- Stomach and oesophagus cancer
- Problem behaviours
- Sleep problems
- Mental ill-health and dementia
- Vision and hearing impairments; ear wax
- Mobility, balance and posture problems
- Accidents, injuries and falls
- Dental problems
- Drug side effects
- Osteoporosis
- Genetic associations

## Top 10 Unmet Health Needs

- Mental ill-health
- Impacted cerumen
- Urine infection / prostatism
- Cataracts / visual impairment
- GORD
- Arthritis
- Eczema
- Hearing impairment (other than impacted cerumen)
- Hypertension
- Drug side effect

## Practical Considerations

- Time
- Change in behaviour = ill-health unless proven otherwise
- Family carers are always right, if there are any
- Paid carers describe problem behaviours voluntarily – other symptoms have to be enquired about
- State versus trait - can't make assumptions. Beware of lack of information
- Sharing of information within and between teams of support workers. Multiple informants
- Coordination of information between services and agencies
- Communication skills; diagnostic instruments

## What to Avoid

- Attribution of additional health needs to ID
- Assuming inappropriate stereotypes and negative assumptions about a persons ability to maintain quality of life
- Inadvertently contributing to institutional discrimination

## Conclusions

- Increasing life expectancy, but small numbers
- High level of physical and mental ill-health
- Co-morbidity and polypharmacy
- High level of unmet health need
- Different pattern of disease and causes of death
- Extrapolation from the general population
- Joint working across professions probably needed
- Time consuming
- Need to improve quantity and quality of research