Learning Disability and associated diagnoses

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Introduction

- Long stay institutional population:
  - 1970: 70,000
  - 1999: 3,000
  - 2008: 11,000
Introduction

- Extent of need:
  - 2-3% population LD
  - 0.4% moderate, severe, profound LD
  - Heterogeneous population
  - Wide range of support
  - Greater burden mental and physical ill health
  - Associated with reduced quality of life and community adaptation
Psychometric Testing – WAIS III

- Measures current intellectual functioning
- IQ test
Defining Learning Disability

1. Significant impairment of intellectual functioning:
   - IQ 50-69       Mild/Moderate
   - IQ <50         Severe

2. Significant impairment adaptive/social functioning:
   - Communication
   - Self care/home living
   - Social/interpersonal skills
   - Use of community resources
   - Self direction
   - Functional academic skills
   - Work/leisure
   - Health and safety

3. Onset before adulthood (age 18)
Mild Learning Disability

- 2-3% population (98% pwld)
- IQ 50-70
  - Develop social and communication skills
  - May not be diagnosed until teens
  - Gain some academic skills
  - Capable of employment
  - Can live independently or with supervision
  - Vulnerable to social and economic stress
Mild Learning Disability

- **Diagnosis**
  - Significant impairment of IQ **and** adaptive/social functioning.
  - Can diagnose LD in IQ 70-75 if significant deficit in adaptive behaviour.
  - Conversely, can have IQ lower than 70, but no LDIS if no significant deficits or impairments in adaptive functioning.
  - Adaptive impairments are usual presenting symptoms in PWLD.
Additional disabilities

- **Epilepsy** (in 15-30% pwld)
  - Often severe, complex
  - Associated with polypharmacy
  - Reduced community access

- **Physical disabilities** (occur in up to 30% pwld)
  - e.g. cerebral palsy
  - Increased survival of children with complex disabilities
  - Occasional need for palliative care
Additional disabilities

- Sensory disabilities
  - 30% Significant visual impairment
  - 40% Hearing impairment
General Health Needs

- Higher range and intensity of health problems
- Evidence of under-recognition
- Syndromes associated with health risks e.g. thyroid disorder, Down’s etc.
- Pwld living longer – age related problems
ICD 10

- F 70 – F 79  MR
  - F 70  Mild MR  IQ 50-69
  - F 71  Moderate MR  IQ 35-49
  - F 72  Severe MR  IQ 20-34
  - F 73  Profound MR  IQ <20
  - F 78  Other MR  Impossible
  - F 79  Unspecified MR
Rates of psychiatric disorder

- **Pooled Studies:**

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Mild LD</th>
<th>Mod/Severe LD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>2-6%</td>
<td>2%</td>
</tr>
<tr>
<td>Affective Disorder</td>
<td>3-8%</td>
<td>8%</td>
</tr>
<tr>
<td>Neuroses/Anxiety</td>
<td>25%</td>
<td>50%</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>1-3%</td>
<td>10-30%</td>
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</table>

Dementia 20% > age 65

In Down’s syndrome 60% > age 60
Schizophrenia and LD:

- On average earlier age onset (22.5yrs of 26.8)
- Difficulties in diagnosis
  - Impaired communication
  - Chronic abnormalities of speech
  - Simple delusions and hallucinations
  - Non-specific symptoms:
    - Social withdrawal
    - Fearfulness
    - Sleep disturbance
- Rare symptoms
- Passivity
- Thought echo
- Commenting voices
- Negative symptoms may be difficult to differentiate from LD
Schizophrenia and LD: Treatment

- Other therapeutic interventions:
  - CBT for delusions – no studies, occasional use
  - Family/carer education/support
  - Outcome studies very few
  - Suggest high support needs
Depression and LD

- Symptoms
  - Low mood/anhedonia
  - Irritability/aggression
  - Sleep disturbance
  - Withdrawal
  - Loss of skills, social and adaptive
  - Disturbance of memory
  - Loss of concentration
  - Obsessions/compulsions
  - Self injury
Depression and LD

- Rare
  - Suicidal ideation
  - Hallucinations
  - Delusions

- May be masked by
  - High dose neuroleptic medication
  - Autism
  - Severe and profound LD
  - Long standing behavioural disorder
  - Additional medical problems
  - Dementia
Depression and LD

- **Treatment**
  - Anti-depressant medication
  - Others
  - Psychological support/counselling therapy
  - Social support/educate carers

- **Prognosis**
  - Uncertain – few studies
AUTISM SPECTRUM DISORDERS

- Pervasive developmental disorders
  - Autism
  - Asperger's Syndrome

- Complex developmental disabilities
  - Affects 1 in 110
  - M:F 10:1
  - 75% PWA IQ<70
  - Only 25% live independently
Others

Additional health needs

- Epilepsy 30%
- Mental Health Problems 30-50%

Prevalence

<table>
<thead>
<tr>
<th>IQ</th>
<th>Value</th>
<th>Rate</th>
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<tbody>
<tr>
<td>&lt;70</td>
<td>20</td>
<td>20/10,000</td>
</tr>
<tr>
<td>&gt;70</td>
<td>71</td>
<td>71/10,000</td>
</tr>
</tbody>
</table>

- Asperger’s 36/10,000
Wings Triad of Impairments

1. Impairment of social relationships
   - Aloof and indifferent to others
   - Passive acceptance of social approaches
   - One sided social approaches
   - Lack of understanding of social rules

2. Impairment of communication
   - Absence of ability or desire to communicate
   - Communication only to express needs
   - Irrelevant or factual comments
   - Talking at people – no reciprocal conversation
Wings Triad of Impairments

3. Impairment of Social Understanding and Imagination

- Absence of pretend play
- May copy actions, no understanding of meaning
- Repetitive and stereotyped behaviour
- No empathy or “Theory of Mind”
## Prevalence

<table>
<thead>
<tr>
<th>IQ under 70</th>
<th>Approx rate/10,000</th>
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<tbody>
<tr>
<td>Autism</td>
<td>5</td>
</tr>
<tr>
<td>Other Spectrum Disorders</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
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<th>IQ over 70</th>
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<td><strong>Total</strong></td>
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**Total Estimated Prevalence** 91

Overall prevalence increasing 20-25% P/A from birth to birth cohort
Theory of Mind

- The cluster of abilities needed:
  1. To understand the mental process of others
  2. To attribute mental states of others
  3. To predict the behaviour of others based on 1 and 2

  - Develops from age 3 onwards
Down’s Syndrome

- In early life, most common △ depression, then dementia.

- Age specific prevalence rates:
  - 35-49: 8%
  - 50-59: 55%
  - >60: 75%

- Average length of illness 4.5 years
Down’s syndrome

- Clinical presentation – withdrawal:
  - Depression/Irritability/Confusion
  - Memory loss
  - Visuospatial skills ↓
  - Disorientation +/- personality change
  - Dysphasia
  - Dyspraxia
  - Motor Impairments
  - Epilepsy

- Clinical deterioration marked over age 50 with changes obvious every 6 months
Depression in Down’s Syndrome

- 10% have 1-2 episodes (lifetime) – risk 2-3 greater than other pwld
- Low mood may be observed/reported – often present with pseudo dementia

  - 50% lose self care skills
  - 65% apathy/withdrawal
  - 35% personality change, aggression
  - thought retardation
  - impaired concentration
  - 80% single depressive episode
  - 50% 2 year duration

- At follow up do poorly on measures of adaptive skills compared to non-depressed peers
Challenging Behaviour

- Social construct
- Culturally abnormal behaviour
- Physical safety of person or others likely to be placed in jeopardy
- Seriously limits use or access to ordinary community facilities
- Males > Females
- Prevalence ↑ through childhood
- Peaks age 15-34
- Impaired vision, hearing or communication increases risk
- Prevalence correlated with ↓ IQ
- Current estimates 24/100,000
Psychopharmacology for pwld

- pwld most highly medicated in society
  - 20-45% take antipsychotics
  - 15-30% prescribed for CB

- Discharge from institutions no ↓
  - may even be ↑

- Evidence base
  - in adult populations:
    - Depression 70% respond to meds
    - Schizophrenia 70-80% respond to meds (200 RCT’s)
Psychopharmacology for pwld

- But in LD:
  - no RCT’s for the treatment of CB
  - 1 RCT antipsychotics in schizophrenia
  - few studies on the treatment of depression

- In LD, extrapolate from adult populations
  - “off licence” prescribing
Hierarchy of validated evidence

1. Systemic review including at least one RCT
2. RCT
3. Other experimental study
4. Observational study
5. Expert opinion

- In LDIS, most evidence still comes from 4 and 5 which may be valid and relevant
Good practice in psychopharmacology

- Proper psychiatric evaluation and diagnosis, baseline mental state
- Multi disciplinary assessment
- Behavioural analysis
- Rationale for drug treatment clear and explicit
Good practice in psychopharmacology

- Regular monitoring of targeted symptoms
- Inform carers of side effects
- Consider exit strategies from drugs
- Consider drug reduction programmes (successful in up to 30% when given for CB)
Consent

- To be valid must be competent

- Need to:
  1. Understand the relevant info (risks benefits and alternatives)
  2. Appreciate the nature of the situation and consequences for self
  3. Manipulate the information rationally (weigh risks and benefits of treatment)
  4. Communicate a choice

- Without this, no capacity to give informed consent

- In LDIS, specialist teams may be able to improve capacity to consent or assent.
Decision making capacity

- Outcome (“Wrong” decision assumes incapacity)
- Status (Diagnosis)

Capacity is time and decision specific not enough to give a diagnosis.
Decision making capacity

- 4 key requirements of capacity:
  1. Ability to communicate a choice
  2. To understand
  3. To retain the relevant info
  4. To balance the info and arrive at a choice
Assessment of Capacity in pwld

- **4 key requirements**

  1. Ability to communicate a choice
     - May not be possible
     - Can use sign language
     - Electronic aids
     - Writing
     - A speech and language therapist may help

  2. Understanding the relevant info
     - Key issues are:
     - The nature of the treatment
     - The purpose of the treatment
     - The risks of having treatment
     - The risks of not having treatment
     - Alternative treatments

     An information sheet shown to be helpful
Assessment of Capacity in pwld

3. Can the person understand and balance the information? Best predictor of overall capacity is person accepting that they might be unwell. Failure to appreciate purpose of treatment is a good predictor of overall incapacity.

4. Can they balance the info so as to inform their decision e.g. not having treatment might lead to death? No clarity as to threshold for deciding that an individual is incapacitated – balance has to be struck between autonomy and neglect.
Assessment of Capacity in pwld

- Best interests
  - Identify discernible wishes of individual
  - Views of family or significant others
  - Act in least invasive/restrictive manner possible

- May be able to achieve informed consent

- For situations such as sterilisation etc. have to go to court
Valuing People

- A new strategy for learning disability for the 21\textsuperscript{st} century
Mental Health of pwld

- People to receive maximum support to stay in homes
- Specialist teams to enable access to generic services
- Pwld to have access to counselling and psychological services to address emotional and behavioural problems