Better Lives and Better Mental Health
Children and Adults with Intellectual Disabilities and their Families

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May 2010
WHO Definition of Health (1946)

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
Relevant UN instruments

• the Convention on the *Rights of People with Disabilities*

• the Convention on the *Rights of the Child*

• the Standard Rules on the *Equalization of Opportunities for Persons with Disabilities*
### In childhood

<table>
<thead>
<tr>
<th>Rank</th>
<th>Category</th>
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<tr>
<td>1</td>
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<td>Migraine</td>
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<td>Bipolar affective disorder</td>
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<td>Obsessive-compulsive disorder</td>
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Recent Developments in the UK

• MENCAP Report 2007:
  • ‘Death by Indifference’
  • 6 avoidable deaths described
  • Institutional discrimination claimed
Independent Inquiry into Access to Healthcare for People with Intellectual Disabilities 2008

The ‘Michael Inquiry’

Who set it up?
Secretary of State for Health

Why?
To see if the problems raised in Mencap’s report were widespread in the NHS
What did the Michael Inquiry find?

- People with intellectual disabilities have worse health and get worse care
- Staff knowledge and attitudes are poor
- Staff have too little training
- ‘Reasonable adjustments’ are not made to services despite the law
- Good practice exists but it’s patchy
  - *(no surprises!)*
What do we want for intellectually disabled people?

To promote and support their health and wellbeing by:

- reducing their health inequalities
- ensuring a successful transition to adulthood
- enabling them to live stimulating and fulfilling lives with their families and peers
So how are we doing?

Many experience:

- Discrimination, neglect and abuse in both institutions and communities
- Poverty, inequality and little formal support for their families
- Negative attitudes and stereotypes
- Barriers in gaining access to physical and mental health care
Many experience an Earlier Death

- Early death not accounted for simply by social deprivation
- Factors include:
  - Differential access to health promotion, checks and treatment
  - Failure to make ‘reasonable adjustments’
  - Low expectations by staff
  - Diagnostic overshadowing
Ten Priorities identified by WHO EURO:
-in consultation with experts, family members, self advocates, and NGOs

-in partnership with UNICEF, the Council of Europe and the European Commission

Hope for a Better Life for Children and Young people with ID
1. Protect children and adults with intellectual disabilities from neglect, harm and abuse
2. Enable children to grow up in families

- Make sure all children have a loving family
- Some families are loving but need much more support
- Some children will need a foster or adoptive family
- Don’t set up children’s homes for abandoned/orphaned disabled children
3. Transfer care from institutions to the community

- *End all admissions to institutional care*
- Develop local services first
4. Identify the needs of each person

- Identify intellectual disability in infancy
- Intervene early for better long term outcomes
- Assess and plan for a young person’s needs in adulthood
- Continue to assess health and mental health needs in adulthood
5. Ensure that good quality health care is available, coordinated and sustained

- Disabled people have some of the *same* health needs
- Sometimes have *complex* mental and physical health problems that affect their quality of life
Epilepsy

- Prevalence of epilepsy amongst people with intellectual disabilities: 22%
- Prevalence rate for general population: 0.4%-1%
- Guidelines available on management of epilepsy in people with intellectual disabilities published by IASSID
• Specialist treatment for epilepsy supports school attendance and community participation
6. Safeguard the health and wellbeing of their family carers

- The wellbeing of the whole family affects the disabled child or adult
- Parents/carers need information, skills and support
- Psychosocial interventions improve outcomes
7. Enable children to speak up for themselves, be listened to, and make a contribution within their communities

- Create opportunities for their voices to be heard

- Give them information they can understand
Books Beyond Words
www.rcpsych.ac.uk/publications/

• Stories told in pictures
• For information
• To check for understanding
• For counselling
Information for carers

- How to recognise health problems
- Tips for carers on working with the health care team
- Questions to ask the doctor
- What to do if the doctor won’t see you
8. Build the capacity and reinforce the commitment of the workforce

- Positive attitudes- help to prevent burnout

- Therapeutic optimism

- Provide all health care staff with information and skills
Education and training for staff
Michael Inquiry Recommendation:

Training on intellectual disabilities should be mandatory at undergraduate and postgraduate levels and should involve service users and carers
9. Collect essential information and assure quality

- Identify all children and adults who have Intellectual Disabilities

- Evaluate whether services work

- Share information across education, health, social care, justice agencies
10. Invest Preferentially to ensure the best possible health outcomes

In order for children to be *included in the same* services as their brothers and sisters:

- *extra support must be funded* so that they can make full use of those services

- Reasonable adjustments must be made
For example through an identified Health Facilitator who will:

- Make sure people get what they need to be healthy

- Help primary care and other health professionals to get things right for their patients
Conclusions

• The impairment can’t be cured but *co-morbid conditions can be treated*

• Co-morbid conditions include mental illness which has a *higher prevalence* in this group

• Key advocacy role for psychiatrists
• Diagnostic overshadowing is common

• Doctors are unskilled or uncomfortable in assessing and treating patients with intellectual disabilities

• There will never be enough specialists—its everyone’s responsibility
Whatever the question, and whatever your chosen field of medicine, if it's about learning disability then www.intellectualdisability.info probably has the answer.

We can all benefit from health screening programmes but would you know what additional checks a patient with Down's syndrome should have at different stages in their life?

What do you need to know before you try to examine a patient with learning disabilities and poor verbal communication?

How do you tell a new mother that her baby may have a learning disability, knowing that the way she hears the news will have a lasting effect on her relationship with her child?

A patient with Down's syndrome presents with depression and weight gain. Thyroid deficiency or just a consequence of the Down's syndrome?

www.intellectualdisability.info
It's all you need to know

www.intellectualdisability.info is a Health Alert initiative, jointly managed by the Down's Syndrome Association and St Georges Medical School, funded by the Department of Health and Gulf Charitable Trust.