INTELLECTUAL DISABILITY

William Walker, MD
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UW / SCH
ICF MODEL

- **DISABILITY**
  - a significant problem in functioning

- **IMPAIRMENT**
  - capacity to perform

- **ACTIVITY LIMITATIONS**
  - ability to perform

- **PARTICIPATION RESTRICTIONS**
  - opportunity to perform
ICF in an Educational Context

Health Condition

Body Functions and Structures → Activities ← Participation → Educational and Developmental Goals

Environmental Factors ← Personal Factors

Methods, Provision and Services

Vision of Responsible, Happy and Healthy Citizen with Capabilities, Competence and the Ability to Adjust to the Challenges of Society
Over time “Disability” has changed – now a more “person centered” trait

Limitations in individual functioning within a social context that represents a substantial disadvantage to the individual.

Results from a health condition that gives rise to impairments in body function and structures, activity limitation and participatory restrictions.
"MENTAL RETARDATION"

- "Retardation is not a disease, it is not a brain defect, nor is it necessarily the result of a brain defect … It is a mental status, a stage of mental development."
  (Witmer 1900)

- A stigmatizing label with universally negative connotations. (Smith 2007)

- We need to change minds as well as terms!
THE QUESTIONS

1. What kind of diagnosis is intellectual disability: medical, educational, social, political?
2. Why does the "label" selected to describe individuals with intellectual disabilities make a difference?
3. Should anyone really care about "why" these individuals are affected?
4. How will this information change your clinical practice / interactions?
THE DIAGNOSIS

1. What kind of diagnosis is intellectual disability:

Medical
Educational
Social
Political
2. Why does the "label" selected to describe individuals with intellectual disabilities make a difference?
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<tbody>
<tr>
<td>55-69</td>
<td>Moron</td>
<td>Educable</td>
<td>Mild</td>
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<tr>
<td>40-54</td>
<td>Imbecile</td>
<td>Trainable</td>
<td>Moderate</td>
<td>Severe</td>
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<tr>
<td>25-39</td>
<td>Idiot</td>
<td>Custodial</td>
<td>Severe</td>
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<tr>
<td>&lt;24</td>
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<td>Profound</td>
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Early 20\textsuperscript{th} Century to Now!

- **Then:**
  - There was an emphasis on \textit{Incurability}.
  - Individuals with "MR" were predetermined by their limitations and \textit{prevented from participating} in everyday environments because of their low IQs.

- **Now:**
  - Increased compassion for the rights and opportunities for persons with ID
  - Increased efforts to mainstream individuals with ID into society to improve their quality of life;
  - Decreased tolerance for stigmatizing labels.
QUICK POLL
QUESTION
TIME
Rosa's Law

- Rosa Marcellino
- 2010 (PL 111-256)
- Replaced the term MR with ID in all federal laws
- Applied to SSA in August 2013
- "People first" language
The term “MR” has been eliminated in DSM-5.

It is characterized as a “Neurodevelopmental Disorder” rather than a "Neurocognitive Disorder".

An impairment of general mental abilities that impacts adaptive functioning in 3 areas:

- **Conceptual Domain**
- **Social Domain**
- **Practical Domain**

Must begin during the developmental period.

Chronic, can co-occur with other mental conditions.
Defining ID in DSM-5

- **Deficits in general mental abilities** (intellectual functioning) - reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience.
  - Confirmed by both clinical assessment and individualized standardized intelligence testing.

- **Deficits in adaptive functioning**, such that the individual fails to meet developmental and socio-cultural standards of personal independence and social responsibility.
  - Without ongoing support, the adaptive deficits limit function in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments, such as home, school, work and community.
The Domains

• **The Conceptual Domain**
  Skills in language, reading, writing, math, reasoning, knowledge, and memory.

• **The Social Domain**
  Empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.

• **The Practical Domain**
  Self-management in areas such as personal care, job responsibilities, money management, recreation Organizing school and work tasks.
IQ Scores

- Should still be included in an individual’s assessment.
- Approximately 2 SD or more below the population (~ 70)
- Greater emphasis on linking intellectual deficits to adaptive deficits
- Critical components to be assessed: verbal comprehension, working memory, perceptual reasoning, cognitive efficacy
“Show Me The Numbers”

- **Cognitive***- many choices*
  - Infant developmental testing (Bayley)
  - Tools for the pre-school child (WPPSI)
  - Tools for the school-aged child (WISC)

- **Adaptive** *
  - Vineland Adaptive Behavior Scales II
  - Adaptive Behavior Assessment Scale II
  - Scales of Independent Behavior - Revised
  - Support Intensities Scales

* Validity can be affected by cultural and other factors
Emphasis on Functional Ability

- **Severity** is now based primarily on adaptive functioning in the 3 domains rather than IQ test scores
  - What is a person’s **ability** in each domain?
  - What is the **impact** of these deficits on everyday life?
Subtypes vs. Specifiers

- **Traditionally**
  - Severity characterized by subtypes (Mild, Moderate, Severe, Profound)
  - Subtypes based on extent of intellectual impairment (IQ)
  - IQ measures are less valid in the lower end of the IQ range.

- **DSM-5**
  - Severity characterized by specifiers (Mild, Moderate, Severe, Profound)
  - Specifiers describe the extent of adaptive dysfunction in 3 domains (Academic, Social, Practical)
  - Adaptive functioning determines level of support required
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| Preschoolers: *May be no obvious conceptual differences*  
For School-Age children and Adults:  
**Difficulties learning academic skills** involving reading, writing, arithmetic, time or money.  
**Support may be needed to meet age related expectations.**  
For Adults:  
Abstract thinking, executive function (planning, strategizing, priority setting, cognitive flexibility) as well as functional use of academic skills (reading, money management) are impaired.  
**There is a somewhat concrete approach to problems and solutions compared with age-mates.** | Compared with typically developing age-mates, the individual is **immature in social interactions.**  
Examples: Difficulty in accurately perceiving peers’ social cues.  
Communication, **conversation and language are more concrete or immature than expected for age.**  
Difficulties regulating emotion and behavior in age appropriate fashion.  
**Differences are noticed by peers in social situations.**  
Limited understanding of risk in social situations.  
**Social judgment is immature for age.**  
The person is at risk of being manipulated by others (gullibility) | **May function age-appropriately in personal care.**  
Need some **support with complex daily living tasks compared to peers.**  
In adulthood, supports typically involve grocery shopping, transportation, home and child-care organization, nutritious food preparation and banking and money management.  
Recreational skills resemble those of age-mates, although judgment related to well-being and organization around recreation requires support.  
**In adulthood, competitive employment is often seen in jobs that do not emphasize conceptual skills.**  
Individuals generally need support to make health care decisions and to learn to perform a skilled vocation competently.  
**Support is typically needed to raise a family.** |
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<td><strong>All through development, their conceptual skills lag markedly behind those of peers.</strong>&lt;br&gt;For Preschoolers: Language and pre-academic skills develop slowly.&lt;br&gt;For School Age children: Progress in reading, writing, mathematics and understanding of time and money occurs slowly across the school years and is markedly limited compared with that of peers.&lt;br&gt;For Adults: <strong>Academic skill development is typically at an elementary level and support is required for all use of academic skills in work and personal life.</strong>&lt;br&gt;Ongoing assistance on a daily basis is needed to complete conceptual tasks of day-to-day life, and others may take over these responsibilities fully for the individual.</td>
<td><strong>Shows marked differences from peers in social and communicative behavior across development.</strong>&lt;br&gt;Spoken language is typically a primary tool for social communication but is much less complex that that of peers. <strong>Capacity for relationships is evident</strong> in ties to family and friends and the individual may have successful friendships across life and sometimes romantic relations in adulthood. Individuals may not perceive or interpret social cues accurately. <strong>Social judgment and decision-making abilities are limited and caretakers must assist the person with life decisions.</strong>&lt;br&gt;Friendships with typically developing peers are often affected by communication or social limitations. <strong>Significant social and communicative support is needed in work settings for success.</strong></td>
<td><strong>Can care for personal needs</strong> involving eating, dressing, elimination and hygiene as an adult although an <strong>extended period of teaching and time is needed for the individual to become independent in these areas and reminders may be needed.</strong>&lt;br&gt;Participation in all household tasks can be achieved by adulthood although an extended period of teaching is needed and ongoing supports will typically occur for adult-level performance. <strong>Independent employment in jobs that require limited conceptual and communication skills can be achieved but considerable support</strong> from co-workers, supervisors, and others is needed to manage social expectations, job complexities, and ancillary responsibilities such as scheduling, transportation, health benefits and money management. A variety of recreational skills can be developed. These typically require additional supports and learning opportunities over an extended period of time. <strong>Maladaptive behavior is present in a significant minority and causes social problems.</strong></td>
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**Moderate**
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<td>Attainment of conceptual skills is limited. <strong>The individual generally has little understanding of written language or of concepts involving numbers, quantity, time and money.</strong> Caretakers provide extensive supports for problem solving throughout life.</td>
<td><strong>Spoken language is quite limited in terms of vocabulary and grammar.</strong> Speech may be single words or phrases and may be supplemented through augmentative means. <strong>Speech and language are focused on the here and now within everyday events.</strong> Language is used for social communication more than for explication. <strong>Individuals understand simple speech and gestural communication.</strong> <strong>Relationships with family member and familiar others are a source of pleasure and help.</strong></td>
<td><strong>Requires support for all activities of daily living,</strong> including meals, dressing, bathing and elimination. <strong>Requires supervision at all times.</strong> Cannot make responsible decisions regarding well-being of self or others. In adulthood, participation in tasks at home, recreation and work requires ongoing support and assistance. <strong>Skill acquisition in all domains involves long-term teaching and ongoing support.</strong> <strong>Maladaptive behavior, including self-injury, is present in a significant minority.</strong></td>
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<td>Conceptual skills generally involve the physical world rather than symbolic processes. May use objects in goal-directed fashion for self-care, work and recreation. Certain visuospatial skills, such as matching and sorting based on characteristics, may be acquired. <strong>Co-occurring motor and sensory impairments may prevent functional use of objects.</strong></td>
<td>Limited understanding of symbolic communication in speech or gesture. May understand some simple instructions or gestures. <strong>Expressions his or her own desires and emotions largely through nonverbal, nonsymbolic communication.</strong> Enjoys relationships with well-known family members, caretakers, and familiar others and initiates and responds to social interactions through gestural and emotional cues. <strong>Co-occurring sensory and physical impairments may prevent many social activities.</strong></td>
<td>Dependent on others for all aspects of daily physical care, health and safety, although he or she may be able to participate in some of these activities as well. Individuals without severe physical impairments may assist with some daily work tasks at home. <strong>Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support.</strong> Recreational activities may involve enjoyment in listening to music, watching movies, going out for walks, or participating in water activities, all with the support of others. <strong>Co-occurring physical and sensory impairments are frequent barriers to participation</strong> (beyond watching) in home, recreational and vocational activities. <strong>Maladaptive behavior is present in a significant minority.</strong></td>
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# Expectations for Outcome by Level

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<tr>
<th>Level</th>
<th>Expected Outcomes</th>
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| Mild ID    | Good self-help skills  
Some academic skills (early to late elementary level)  
May achieve independent living and employability, but most will need some support in these domains as adults |
| Moderate ID | Can perform basic self-help skills  
Possible limited academic skills (early reading and math)  
Will need supportive living and structured/supervised employment and recreation |
| Severe ID  | Self-help and daily living skills typically require supervision and support  
Will not live independently  
May succeed in sheltered work setting |
| Profound ID | Limited communication  
Will require support for self-help and daily living skills  
Will remain dependent for all or most activities |
Global Developmental Delay (GDD)

- Diagnosed when an individual fails to meet expected developmental milestones in several areas of intellectual functioning.

- Used for individuals who are unable to undergo systematic assessments of intellectual functioning, including children who are too young to participate in standardized testing.
Life Span Issues
Inclusion of children with ID - a best educational practice
Nationally, defined as % of students with ID in regular education classrooms (>79% of the time)
States have been successful in moving them out of separate schools. Not so successful for classrooms
    Vermont (60.3%) to Utah (2.22%)
1/3 of states lost ground in the previous 10 years
Change/Persistence of ID with Age

Three possible explanations for changes in the prevalence of ID from childhood into adulthood:
(1) changes in IQ scores from childhood to adulthood (unlikely)
(2) changes in adaptive functioning from childhood to adulthood (likely)
(3) failure to identify many adults with ID (likely)
Functional Status in Adults with ID

Multidimensional

- Living arrangements
- Education
- Employment
- Social relationships
- Health
- Recreation
- Self esteem
Living Arrangements of Adults with ID

- Since 1967, the number of individuals living in large state institutions (US) has decreased by nearly 80%.
- 60-75% live with family caregivers
- 14-25% live on their own or with a spouse
- 8-13% live in supervised out-of-home residential services; 75% is small group homes (6 individuals or less)
Definition of Employment Related Terms

- **Competitive Employment**
  Employment in the regular workforce at competitive wages and benefits without ongoing supports

- **Supported Employment**
  Paid employment, in the regular workforce, with supports

- **Sheltered Workshop**
  Employment at a worksite specifically designed for individuals with disabilities
Employment

- With **appropriate support**, employment is a realistic goal for most individuals with ID.
- Current support systems do not lead to employment for most adults with ID.
- For employed adults with ID, having a “job” does not fully describe employment outcomes.
- Individuals with ID in competitive or SE are most likely to find jobs in food service, custodial work, manufacturing, clerical work and, in rural settings, agriculture.
- On average, they work 20 to 28 hours per week.
Aging

- Higher rates of morbidity and mortality in adults with ID
- Conditions unrecognized and poorly managed
- Various syndrome specific aging issues (Downs, etc.)
- Health care is affected by challenges of physical, communication and behavioral limitations
an alternate definition ...

“Mental retardation refers to a level of functioning which requires from society significantly above average training procedures and superior assets in adaptive behavior on the part of society, manifested throughout the life of both society and the individual”

Marc Gold, (1980)
Tolteca Culture
Mexico, 500 CE
THE REASON

3. Should anyone really care about "why" these individuals are affected?
DEFINING ETIOLOGY

“A specific diagnosis [is] that [which] can be translated into useful clinical information for the family, including providing information about prognosis, recurrence risks, and preferred modes of available therapy.”

Schaefer, Bodensteiner PCNA 1992
EPIDEMIOLOGY

- Statistical prediction: 2.5%
- Actual measurement lower: 0.8-1.2%
- Excess people with severe: 0.4-0.5%
- Recurrence risk (if 1st child has severe MR without a specific diagnosis): 3-9%
- More common in boys: 1.5:1-2:1
What's on the "X"?

- Oral-facial-digital I (OFD1)
- Coffin-Lowry (RSK2)
- Nance-Horan (NHS)
- Pyruvate dehydrogenase deficiency (PDHA1)

- Glycerol kinase deficiency (GKD)
- Duchenne muscular dystrophy (DMD)
- Ornithine transcarbamylase deficiency (OTC)
- XLMR-epilepsy (Renin receptor: ATP6AP2)
- Stocco dos Santos (KIAA1202)
- XLMR-cleft lip/palate (PHF8)
- Epilepsy/macrocencephy (SYN1)

- Repenning
- Sutherland-Haan
- Cerebropalatocardiac (Hamel)
- Golabi-Ito-Hall

- Menkes disease (ATP7A)
- Phosphoglycerate kinase deficiency (PGK1)
- Allan-Herndon

- Pelizaeus-Merzbacher (PLP)
- Mohr-Tranebjaerg (DDP)
- X-linked lissencephaly (DCX)

- Lowe (OCRL1)
- Simpson-Golabi-Behmel (GPC3)

- Lesch-Nyhan (HPRT)
- Fragile X (FMR1)
- Mucopolysaccharidosis IIIA (IDS)
- Myotubular myopathy (MTM1)
- Adrenoleukodystrophy (ABCD1)

- Rett, PPM-X (MECP2)
- Incontinentia pigimenti (NEMO)
- Dyskeratosis congenita (DKC1)

- Autism (NLGN4)
- Telecanthus-hypospadias (MID1)
- XLMR-infantile seizures, Rett like (STK9)
- Spermine synthase deficiency (SMS)

- Partington
- West
- Proud
- XLAG
- MRX (IL1RAPL1)
- MRX (TM4SF2)
- Monoamine oxidase-A deficiency (MAOA)
- MRX (ZNF41)

- Norrie (NDP)
- MRX (ZNF81)
- OFCD, Lenz microphthalmia (BCOR)
- MRX (FTSJ1)

- Aarskog (FGD1)
- MRX (JARID1C)

- XLMR-cerebellar dysgenesis (OPHN-1)
- MRX (DLG3)

- XLMR-Hypotonic Facies
  - α-Thalassemia mental retardation
  - Carpenter-Waziri
  - Holmes-Gang
  - Chudley-Lowry
  - Jüberg-Marsidi (?)
  - Smith-Fineman-Myers (?)

- (XNP, XH2)

- MRX (FAACL4)
- MRX (PAK3)

- XLMR-optic atrophy (AGTR2)

- Börjeson-Forssman-Lehmann (PHF6)
- XLMR/growth hormone deficiency (SOX3)
- MRX (ARHGEF6)

- X-linked hydrocephaly-MASA spectrum (L1CAM)
- Periventricular nodular heterotopia,
  Otopalatodigital 1, Otopalatodigital 2, (FL1, FLNA)

- Melnick-Needles
- MRX (FMR2)
- MRX (GDI1)
- Creatine transporter deficiency (SLC6A8)
# Causes of ID - Literature (Varies)

- **Chromosome abnormalities**: 4-28%
- **Recognizable syndromes**: 3-7%
- **Known monogenic conditions**: 3-9%
- **Structural CNS abnormalities**: 7-17%
- **Complications of prematurity**: 2-10%
- **Environmental / teratogenic causes**: 5-13%
- **“Culture-familial” MR**: 3-12%
- **Unique, monogenic syndromes**: 1-5%
- **Metabolic / endocrine causes**: 1-5%
- **Unknown**: 30-50%
MR (all levels) with dysmorphic features often diagnosed at birth.

Birth defects = 27X more likely “MR”

Severe MR (<40) often diagnosed by 1 year of age

Moderate MR often diagnosed by 3 to 4 years of age

Mild MR often diagnosed at school age
QUICK POLL
QUESTION
TIME
WHY ASK WHY?

For the Patient
- Appropriate medical and nonmedical therapies
- Indicated medical interventions / referrals
- Presymptomatic screening for complications
- Educational planning
- Eliminate unnecessary testing and evaluations

For the Parents
- Anticipatory guidance
- Education and advocacy
- Referrals
- Reproductive counseling
- Family networking

AJMG 133A: 170-175, 2005
THE SEARCH!

- No standard work-up (4 PP!)
- Stepwise vs. “Shotgun”
- Search will depend upon:
  - Clinical features
  - Family history
  - Degree and profile of developmental delays, or
  - Severity and pattern of IQ deficits

- Intensity of the search depends on:
  - Patient /Family/Physician desire
  - Financial Limitations- Managed Care
  - Tests / Technology
  - Sedation
WHAT DO THE EXPERTS SAY?

NEUROLOGY
Practice parameter: Evaluation of the child with global developmental delay
   *Neurology* 60: 367-380, 2003

GENETICS
Diagnostic Evaluation of Developmental Delay / Mental Retardation: An Overview
   *American Journal of Medical Genetics* 117C: 3-14, 2003

PEDIATRICS
Clinical Genetic Evaluation of the Child with Mental Retardation.
   *Pediatrics* 117 (6): 2304-16, 2006

PSYCHIATRY
Practice Parameters for the Assessment and Treatment of Children, Adolescents and Adults with Mental Retardation and Comorbid Mental Disorders.
   *Journal of the American Academy of Child and Adolescent Psychiatry* 38: 5S-31S, 1999
Comorbidity

- Mental disorders can co-occur with ID
  - 3-4 x higher in this population
  - When criteria are met, make both diagnoses
- Modify assessment procedures to take into account associated disorders
- Examples:
  - MDD, ADHD, Bipolar, Anxiety, ASD
  - Impulse control, Stereotypic movement disorder
  - SIB, Suicide
## Co-Morbid Associations

- **Behavioral / Mental Illness (Dual)** 30-60% (4x)
- **Seizures** 10-40% (5-15x)
- **Sensory Impairments** 7-20%
- **Cerebral Palsy** 10-20%
- **Sleep Disorders** 80% in SMR
- **Recurrent Emesis** 15% in SMR
- **Obesity** 30-50% (2-3x)
- **Autism** 10-30%
- **Etiologic specific complications**
THE IMPACT

4. How will this information change your clinical practice and interactions?
“Persons with intellectual disabilities, as other human beings, are born free and equal in dignity and rights.”

“To recognize that persons with intellectual disabilities are full citizens in society.”
QUESTIONS?