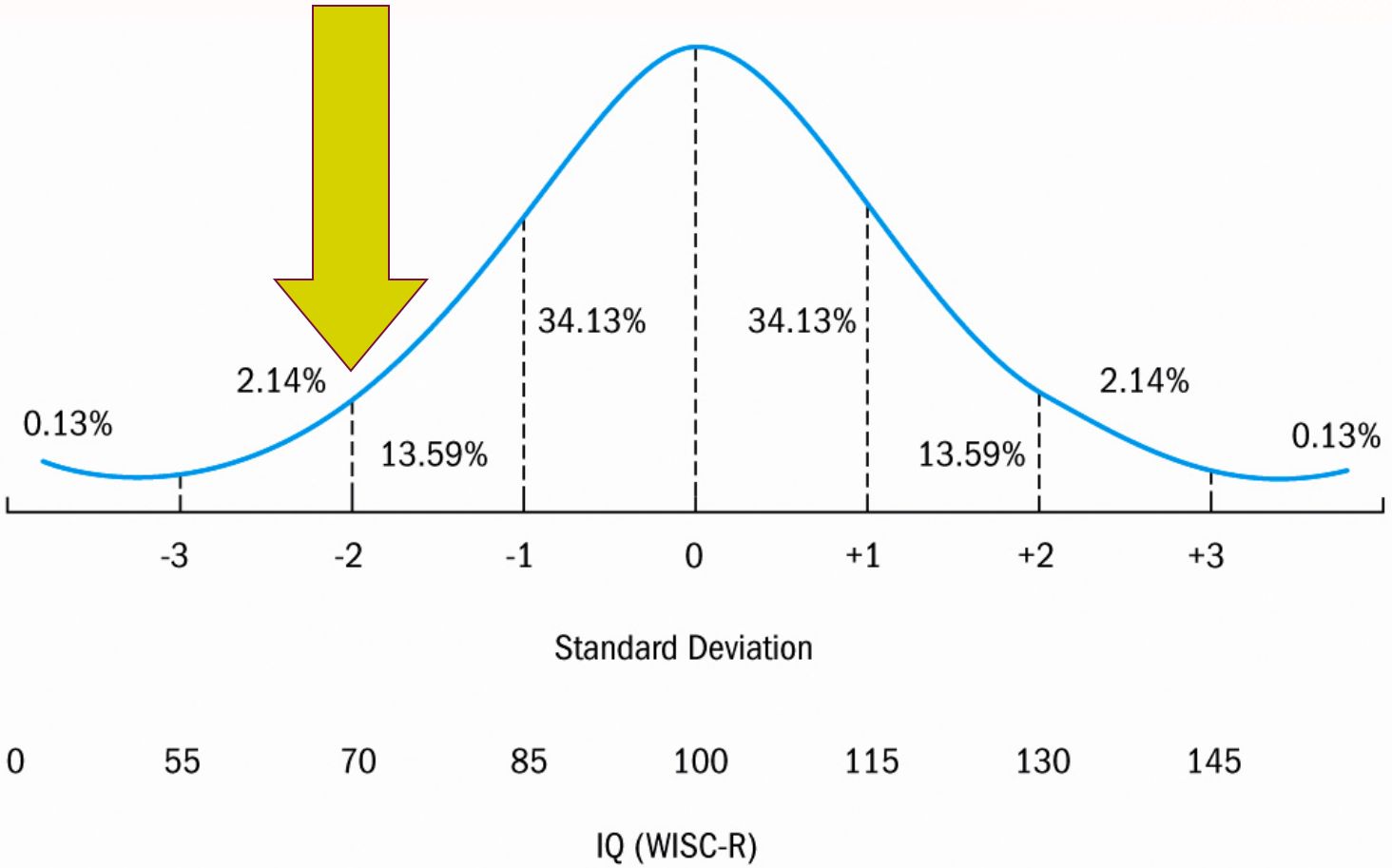
Intellectual Disability

DSM-5 Diagnostic Criteria

- A: Significantly sub-average intellectual functioning (an IQ of approximately 70 or below on an individually administered IQ test).
  - ≤ 2 SD of population mean
- B: Concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/ interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.
- C: Onset is before age 18 years.

Intelligence



Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas which determine how well an individual copes with everyday tasks.

- The **conceptual domain** includes skills in language, reading, writing, math, reasoning, knowledge, and memory.

- The **social domain** refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.

- The **practical domain** centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

- An individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning.

- The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.

- The assessment of intelligence across three domains (conceptual, social, and practical) will ensure that clinicians base their diagnosis on the impact of the deficit in general mental abilities on functioning needed for everyday life. This is especially important in the development of a treatment plan.

The updated criteria will help clinicians develop a fuller, more accurate picture of patients, a critical step in providing them with effective treatment and services.

Levels of Intellectual Disability

Level	IQ Range	% of MR Pop.	Social	Communication	Sensorimotor	Academic Potential	Vocational/Living
Mild	50-55 to 70	85%	Develops in preschool years	Develops normally into preschool years	Minimal deficits	6th grade	Usually achieves adult skills for self-support May need assistance; often successful
Moderate	35-40 to 50-55	10%	Benefits from training	Develops normally in early childhood		2nd grade	Attend to personal care with support Supervised Community Living Perform unskilled/ semi-skilled work
Severe	20-25 to 35-40	3-4%		May learn to talk by school age		Limited benefits of preacademic training	Minimal self-care Simple tasks with supervision as adults Community living with family or group home
Profound	Below 20-25	1-2%	Limited	Improvements with training	Impairments in childhood	Limited	Simple, supervised tasks Requires structure and constant supervision

Epidemiology:

Prevalence

Perhaps 1%-2%

Age:

Most commonly diagnosed in school-age children, perhaps because deficits are most easily observed in academic settings

Gender:

More common in boys (1.3:1)

Organic vs. Cultural-Familial Intellectual Disability

Organic MR:

1. **Children with known causes for their intellectual impairment**
2. **Usually have IQ < 50**
3. **Often have physical anomalies suggesting neurological impairment**
4. **Parents usually have normal intelligence**

Cultural-familial MR:

1. **Children with no known causes for their intellectual impairment**
2. **Usually have IQ 50-70**
3. **Usually appear no different from children without MR**
4. **Parents usually have low intelligence or MR**

Similar-sequence hypothesis:

- Children with mental retardation progress through these same cognitive stages as typically-developing children, albeit at a slower pace
- Supported by research involving children with organic and cultural-familial MR.

Similar-structure hypothesis:

- Two children of the same mental age (one with mental retardation and the other without mental retardation) will show similar abilities
- Supported by research involving children with cultural-familial MR but not organic MR.

Today, many experts prefer to describe youth with MR based on their behavioral phenotype, “the heightened probability or likelihood that people with a given syndrome will exhibit certain behavioral or developmental sequela relative to those without the syndrome.”

Cultural-familial MR:

- **Results from the interaction between the child's genotype and early environmental experiences**
- **Likely reflects the low end of the intelligence continuum**
- **Risk factors**

  Low socioeconomic status and poverty

  Quality of home environment

  Educational opportunities

Implications of Diagnostic Criteria

- Deficits in both intellectual functioning and adaptive behavior must be present.
- MR is not diagnosed when an individual is adequately meeting the demands of his/her environment.
- Assessment must focus on descriptions of present behavior.
- Individually administered intelligence tests are needed.
- The diagnosis is tied to the individual's age level.
- MR diagnosis does not rule out the presence of other disorders.

Adaptive Behavior

- "Adaptive behavior is defined as the effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected for age and cultural group" (Grossman, 1983, p.1).
- Assessment of adaptive behavior stresses an individual's typical performance.
  - Actual behavior, and not abilities or constructs believed to underlie behavior, is important.
- Adaptive behavior varies as a function of age.
  - Increasing demand for meeting the demands of the environment.
- Cultural expectations will also be important, especially when evaluating social functioning.

Mental Retardation: AAIDD

The AAIDD claims that the DSM-IV-TR classification ignores the heterogeneity of people with MR and is not useful in treatment planning

In the AAIDD system, individuals with MR are classified based on "needed supports" in multiple areas of adaptive functioning

- **"intermittent" (i.e., occasional, in time of crisis)**
- **"limited" (i.e., short-term)**
- **"extensive" (i.e., long-term)**
- **"pervasive" (i.e., constant)**

Associated Characteristics

Stereotypies

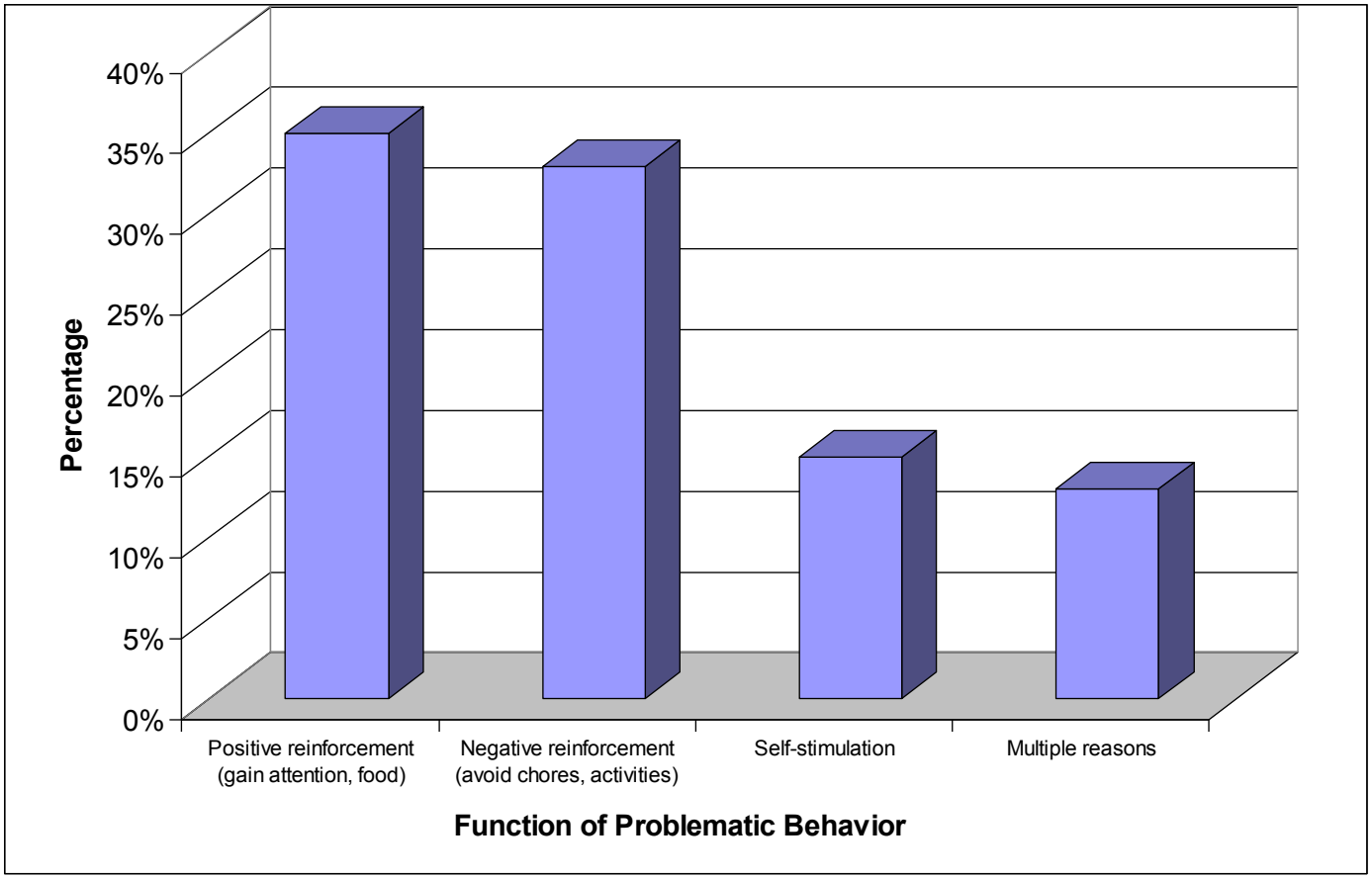
Behaviors that are performed in a consistent, rigid, and repetitive manner and that have no immediate, practical significance

Self-injurious behaviors (SIBs)

Repetitive movements of the hands, limbs, or head in a manner that can, or does, cause physical harm or damage to the person

Why SIBs?

1. **Communication**
2. **Hypersensitivity to dopamine**
3. **High levels of endogenous opioids**


40%
35%
30%
25%
20%
15%
10%
5%
0%
Percentage
Positive reinforcement (gain attention, food)
Negative reinforcement (avoid chores, activities)
Self-stimulation
Multiple reasons
Function of Problematic Behavior

Epidemiology:

Prevalence

Perhaps 1%-3%

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Most commonly diagnosed in school-age children, perhaps because deficits are most easily observed in academic settings

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Today, many experts prefer to describe youth with MR based on their behavioral phenotype, "the heightened probability or likelihood that people with a given syndrome will exhibit certain behavioral or developmental sequela relative to those without the syndrome" (Dykens, 1995, p. 523).

Organic vs. Cultural-Familial MR (Zigler, 1969):

Organic MR:

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Known causes of MR:

1. **Chromosomal abnormalities**
2. **Genetic metabolic disorders**
3. **Embryonic teratogen exposure**

   Maternal illnesses

   Maternal substance use
4. **Complications during pregnancy and delivery**
5. **Childhood illness or injury**

Factors Associated with MR

- Fetal Alcohol Syndrome.
- Phenylketonuria (PKU).
- Chromosomal Anomalies.
  - Down's Syndrome.
  - Klinefelter's Syndrome (XXY).
  - Fragile X.
- Birth factors and growth factors (e.g., inadequate prenatal care).
- Social-environmental factors (e.g., psychosocial disadvantage).

Known causes of MR:

1. Chromosomal abnormalities

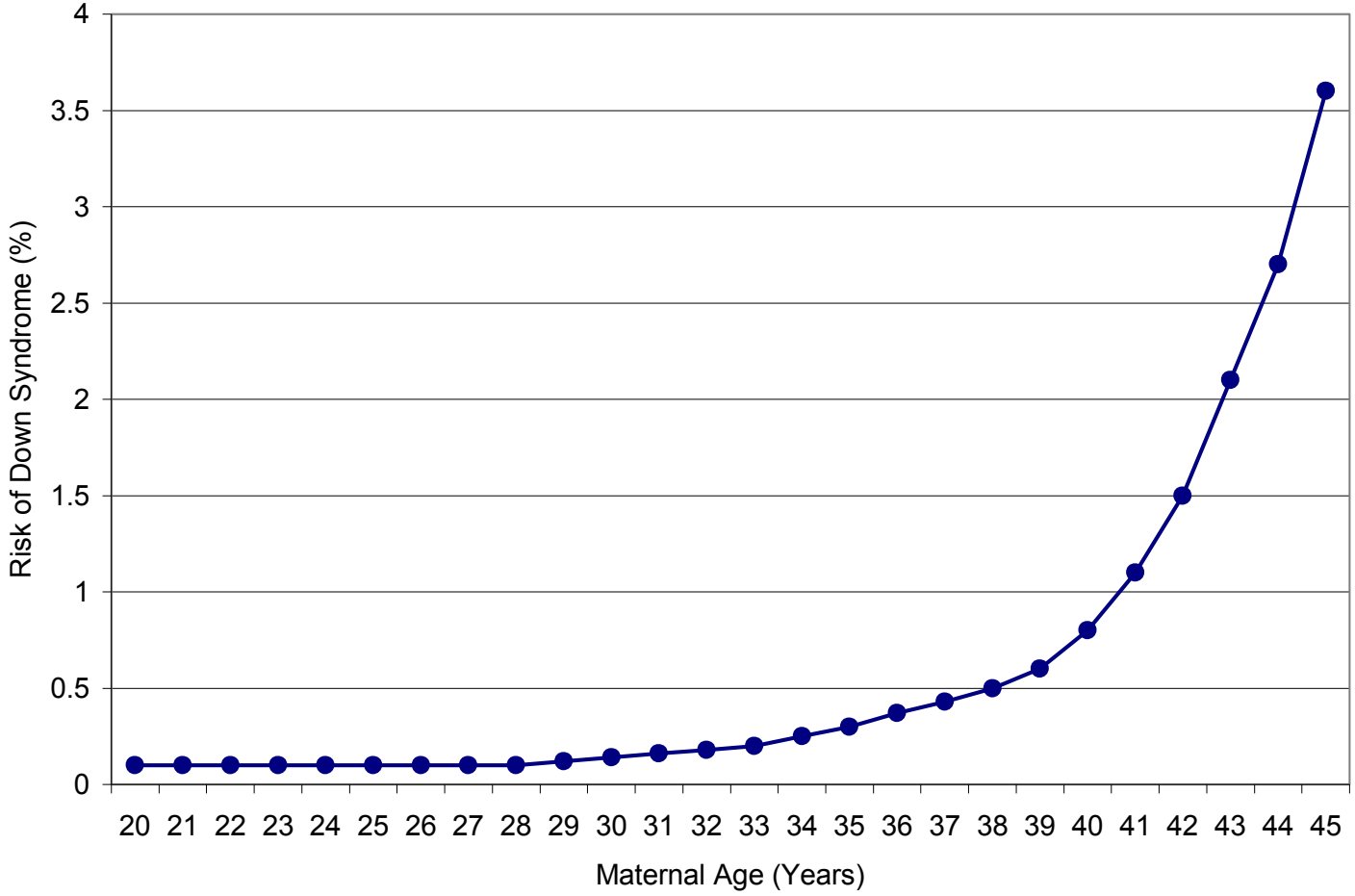
Down syndrome

Fragile X syndrome

Prader-Willi syndrome

Angelman's syndrome

William's syndrome



Risk of Down syndrome increases as a function of maternal age. After age 35, most physicians recommend prenatal screening due to increased risk. Based on Cuckle, Wald, & Thompson (1987).

Etiology of MR

- Etiological factors may be primarily biological, primarily psychosocial, or some combination of both.
- For 30-40 percent of individuals with MR seen in clinical settings, no clear etiology can be determined.
- Major predisposing factors:
  - Heredity (5%).
  - Early alterations of embryonic development (30%).
  - Pregnancy and perinatal problems (10%).
  - General medical conditions acquired in childhood (5%).
  - Environmental influences and other mental disorders (15-20%).

Helpfulness of Determining Etiology

- Family members often have a desire to understand why a child has cognitive and adaptive deficits.
- If a genetic basis is identified, there may be a need for other family members to pursue genetic counseling.
- With a clear etiology, clinicians may be able to provide information on long-term course and type of supports individual will need.
- There may be a clear treatment implication for certain etiologies.
- Determining the etiological basis allows individuals to be placed in more homogeneous groupings.

Etiology of MR

- Familial Group: This group is composed of individuals who fall in the mild range of MR.
  - Primarily in the lower portion of the normal distribution.
  - Likely the result of normal polygenic variation, but can also result from pathological factors interfering with brain functioning or the combined effect of below average heredity and below-average environment.
  - Generally don't come to the attention of the professional community as adults.

Etiology of MR
(Continued)

- Organic Group (25-50%): This group is primarily composed of individuals in the more severely retarded range.
  - May be associated with a genetic component linked to single gene effects, chromosomal abnormalities, or brain damage.
  - Demonstrate a severe lag in behavioral development.
  - Fail to reach normal motor and language developmental milestones.

Epidemiology

1-3% of the general population

More severe cases noticed earlier

Childhood peak time for identification

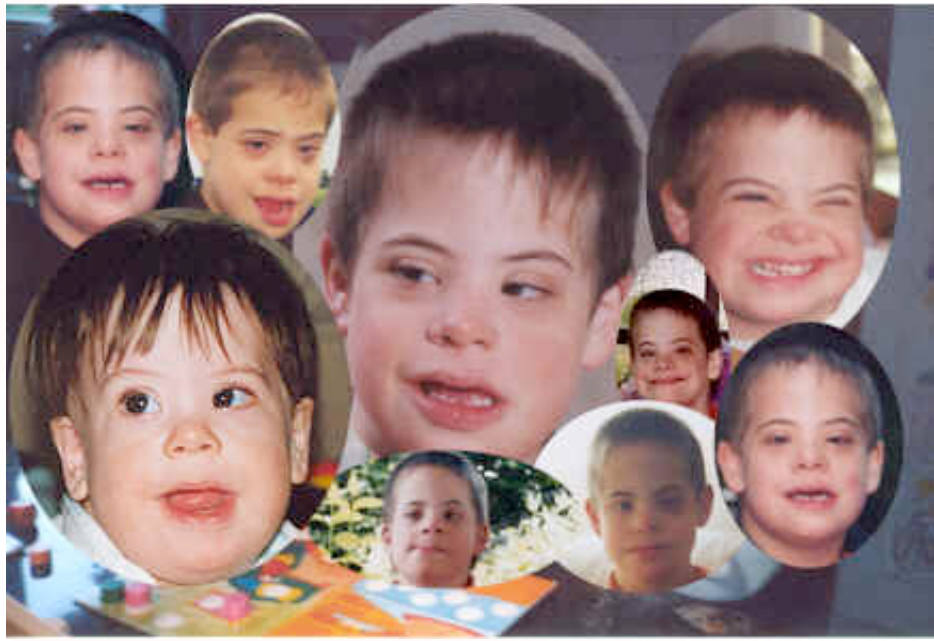
More prevalent in males

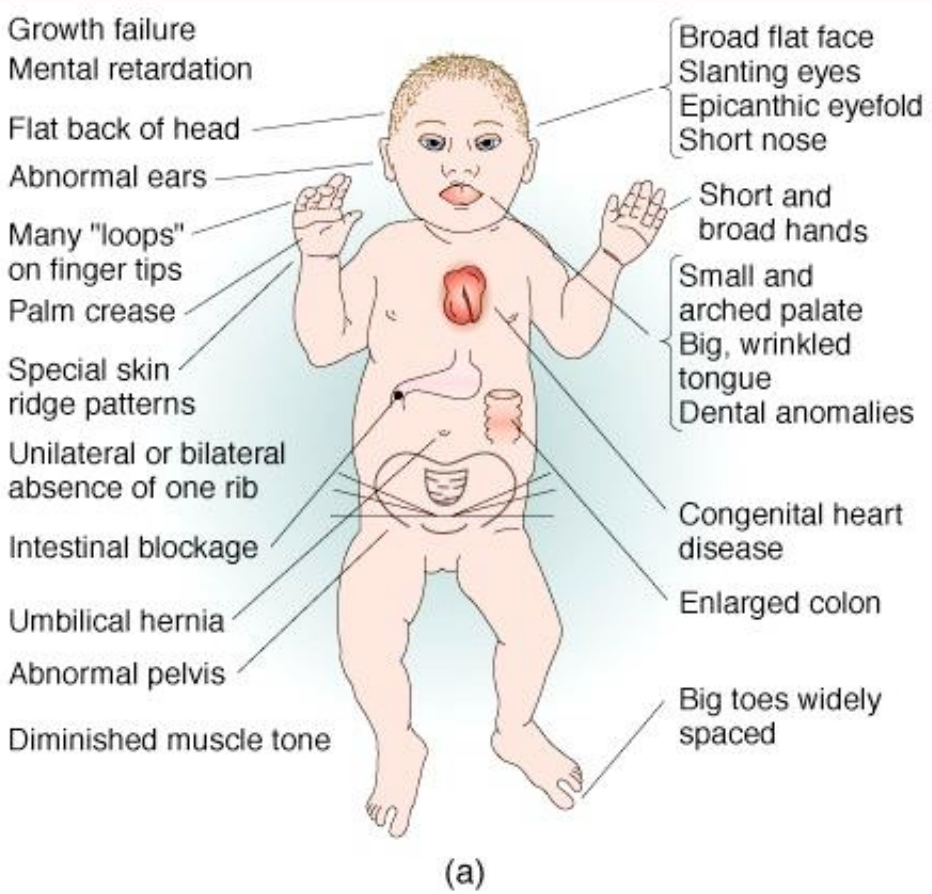
Mild cases more prevalent in low SES group

For mild MR, early intervention and training can result in a child no longer meeting the criteria for diagnosis

Syndrome	Prev.	Cause	Cognitive	Physical	Behavioral
Down	1:1,000	Trisomy 21 (95% of cases)	Moderate to severe MR Delayed speech Expressive language mot affected Deficits in verbal STM & auditory processing Intact VS abilities Dementia in adulthood	Upward slant and folds at corners of eyes Flat facial features Fissured tongue Broad hands and feet Poor muscle tone Heart defects	Relatively good social skills and mild manner Noncompliance, stubbornness, inattention, overactivity Depression developing in adol.
Fragile X	1:4,000 (M) 1:8,000 (F)	200+ DNA nucleotide repeats (CGG) → FMR-1 gene not expressed	Moderate MR Lang. skills plateau @ age 4 Cog. & adaptive behavior slow by age 5 and plateau by late childhood Weaknesses: VS, sequential processing, motor coord., math, and executive funct. Strengths: Verbal STM & LTM	Boys: Velvetlike skin, double-jointed thumbs Adol: Long faces, large ears, oversized testicles	Inattention, hyperactivity, stereotyped movements, anxiety, social avoidance, poor peer interactions Co-occurring autism assoc. w/ > dev. delay
Williams	1:20,000	Small deletions of several genes on Chromosome 7	Deficient depth perception Deficient VS STM & perf. IQ Inability to perceive gross diff. in spatial orientation and copy simple stick figures Strengths: facial expression recognition, verbal STM, verbal IQ, grammar, sophisticated vocab.	"Elfinlike" features (small lower jaw, prominent cheeks) Growth deficiency Often an "aged" appearance in late adol./early adulthood Cardiac & kidney problems Sound hypersensitivity	Anxiety, fears and phobias, inattention, hyperactivity, indiscriminate and overly friendly social interaction, poor social judgment
Prader-Willi	1:15,000	Deletion of genes in certain area of paternal chrom. 15 (70%) or both from mother (30%)	Borderline to moderate MR Deficient verbal IQ, high VS abilities (paternal deletion) Poor VS abilities, fewer facial characteristics, severe depres. & soc. impairments (maternal)	Hypotonia Flat face w/ almond-shaped eyes and prominent forehead Small hands and feet Short, underdeveloped gonads Obesity	Hyperphagia (excessive eating) & food hoarding Obsessions and compulsions Aggression, anxiety, impulsivity, & tantrums

Down Syndrome (Trisomy 21)





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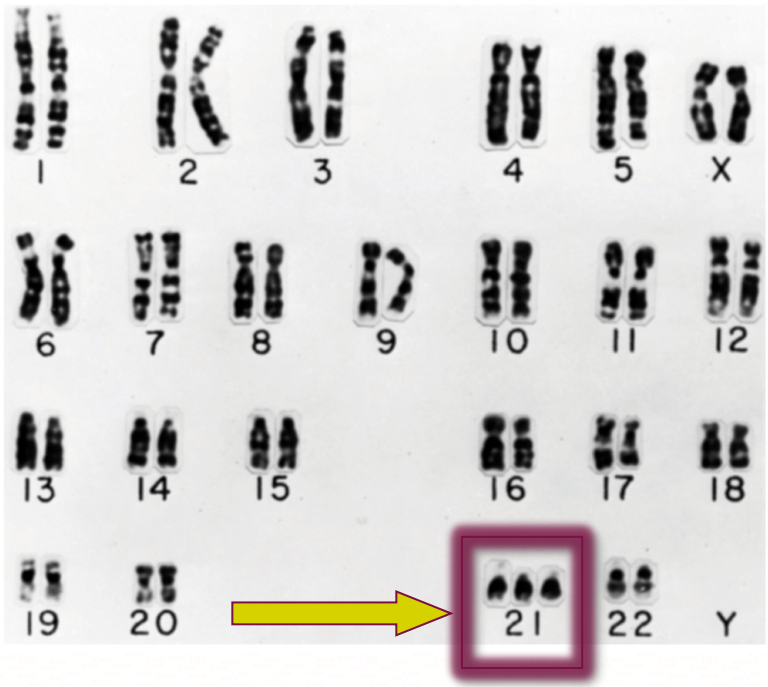

Genetic Syndromes

Table 11-8

Down Syndrome

- Most common single disorder
- Caused by Trisomy 21
- Higher risk with maternal age
- Alzheimer's
- Moderate to severe MR
- Delayed speech, verbal short-term memory and auditory processing deficits

Fragile X

- Most common inherited form
- Fractured X chromosome
- More common in boys - they have more severe forms
- Long faces, prominent jaws, large ears (males)
- Visual-spatial, sequential processing, motor coordination and executive function deficits
- Social impairments

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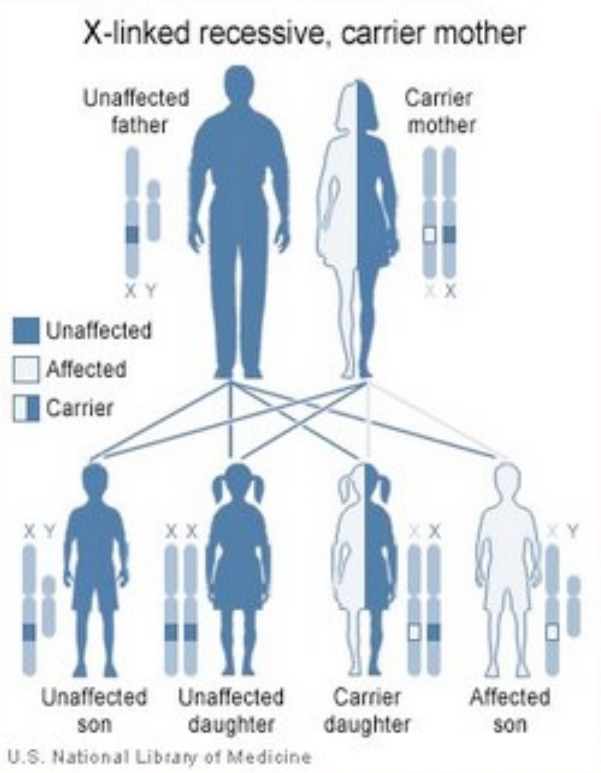
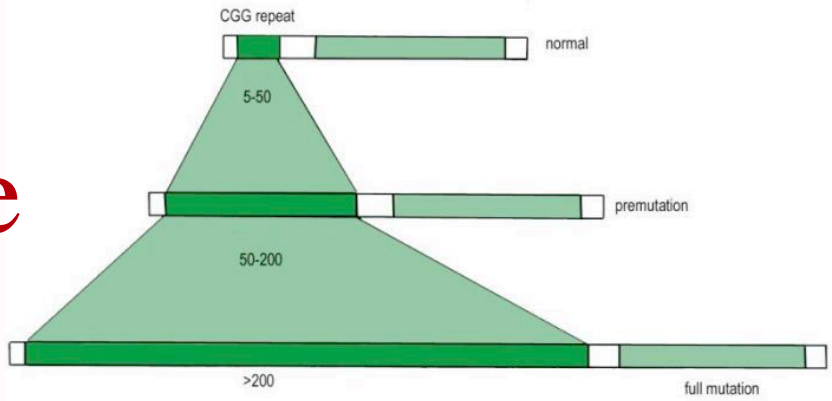
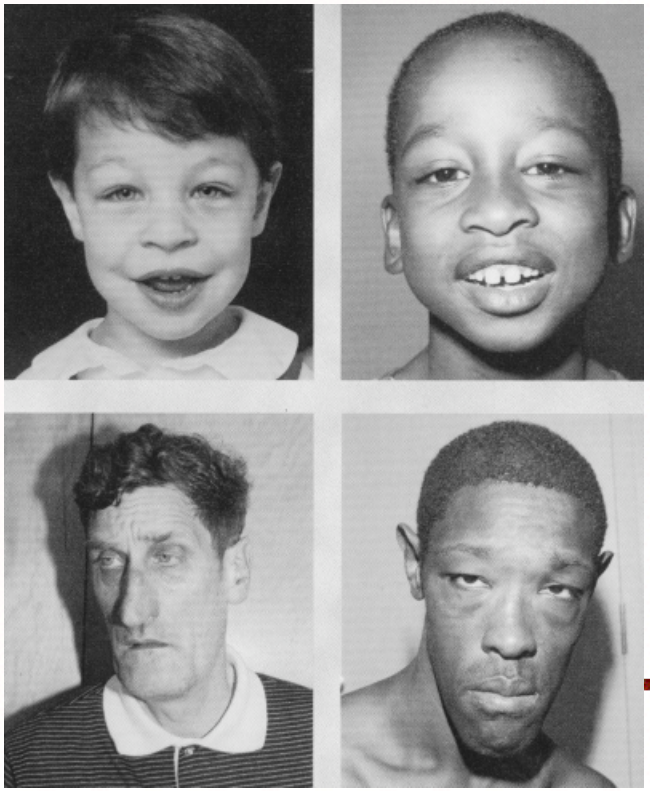
Fragile X Syndrome







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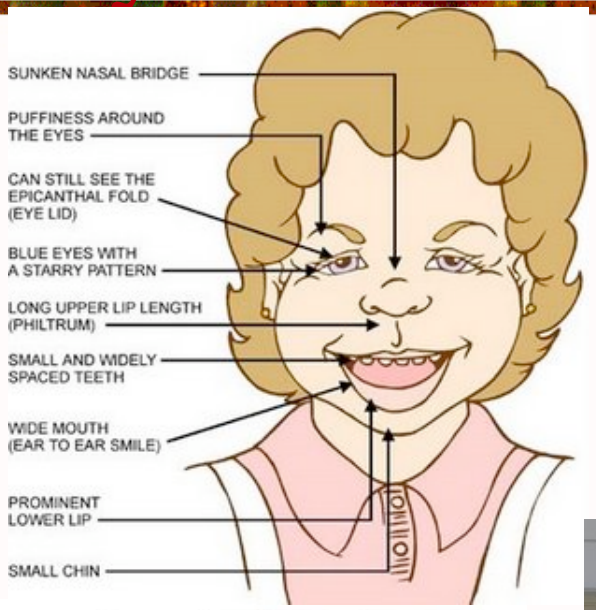
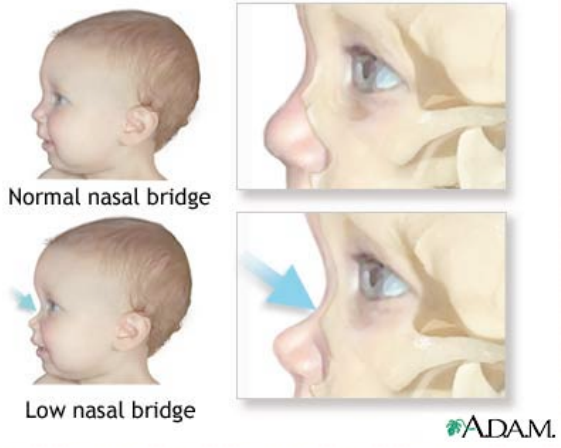
Genetic Syndromes

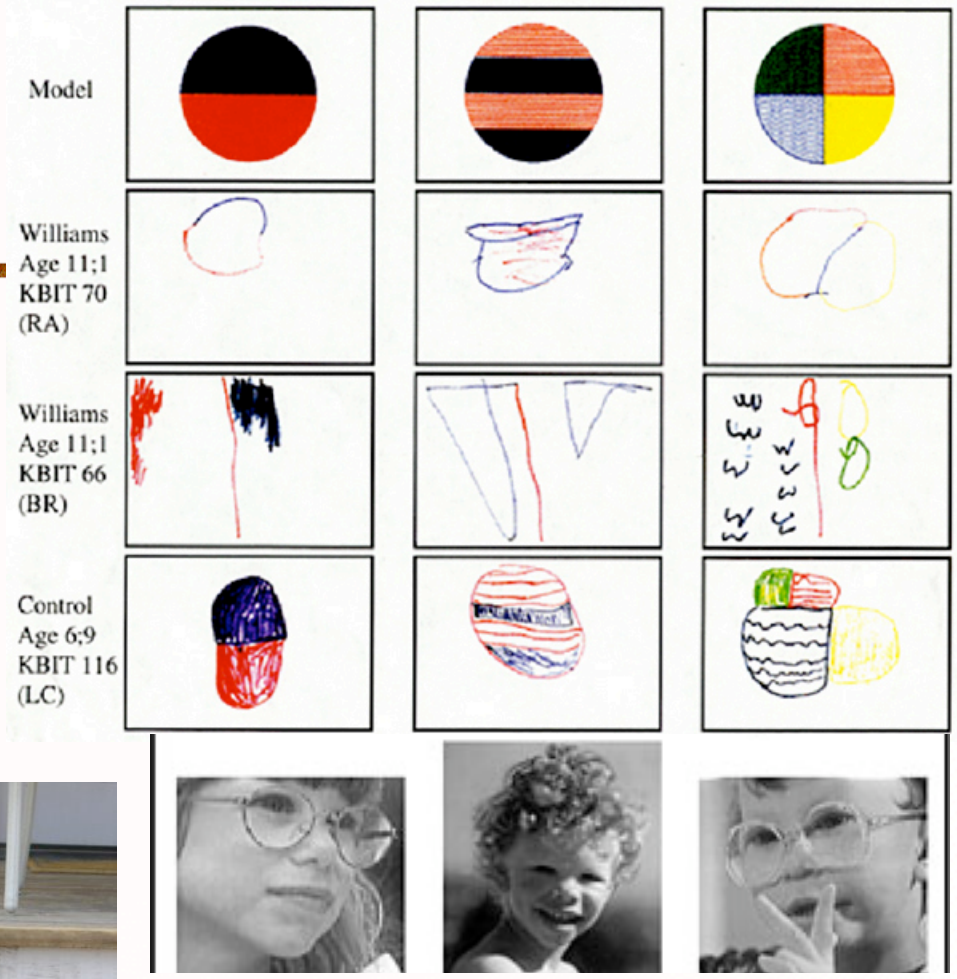
Williams Syndrome

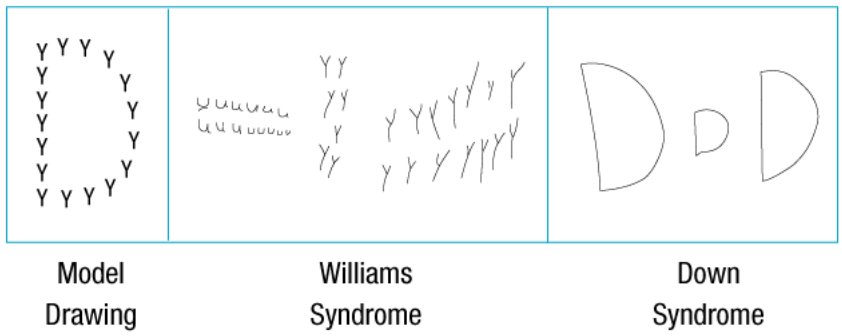
- Rare
- Deletions on Chromosome 7
- Cardiac and kidney problems, sound sensitivity, depth perception weaknesses
- Mild to moderate MR
- General knowledge & visual spatial deficits
- Relative strengths in language
- Elfin appearance

Williams Syndrome









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Prader-Willi Syndrome

70% of cases result from paternal deletion chromosome 15

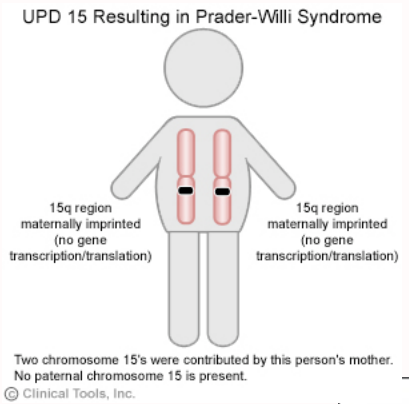
IQ ranges from borderline to moderate impairment

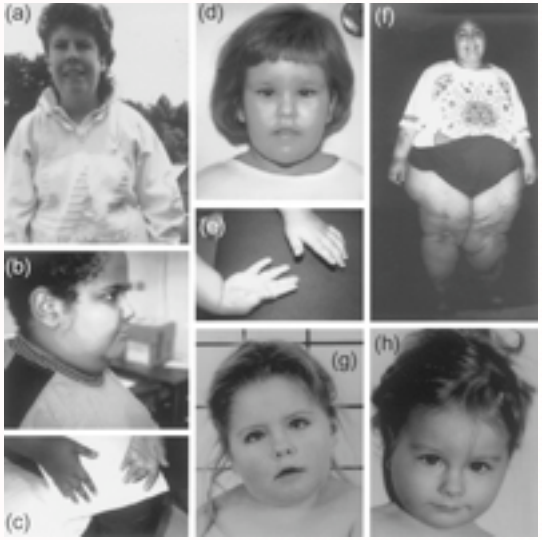
Hyperphagia and food hoarding

Other compulsions, skin picking

Strengths and weakness may vary depending on cause

Prader-Willi Syndrome





Narrow temple distance
and nasal bridge

Almond-shaped eyes
Mild strabismus

Thin upper lip
Downturned mouth

Overweight

Family

- Adjustment is a lifelong process
- May be related to the severity of the impairment
- Stressors
  - Diagnostic
  - Medical
  - Financial/employment
  - Social
  - Marital
  - Parental distress
- Coping
  - Ethnic differences
  - Beliefs/parenting style
  - Skills
  - Support
  - Parental IQ
  - Siblings
    - Stressors
    - Rewards
- Access to resources is key

Treatment of MR

Prevention

The enzyme phenylalanine hydroxylase (located on chromosome 12) is needed to metabolize the amino acid phenylalanine to the amino acid tyrosine—untreated, it results in severe intellectual disability, seizure, & death

- Prenatal care and diet
  - e.g., Phenylketonuria (PKU)
- Education on the impact of toxins
- Early intervention programs
- Educational services

Functional Analysis

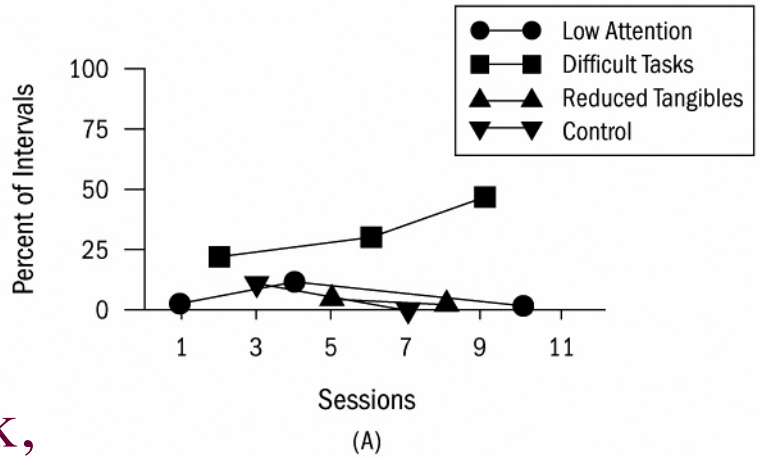
Matt, 5 y.o. boy w/ moderate MR

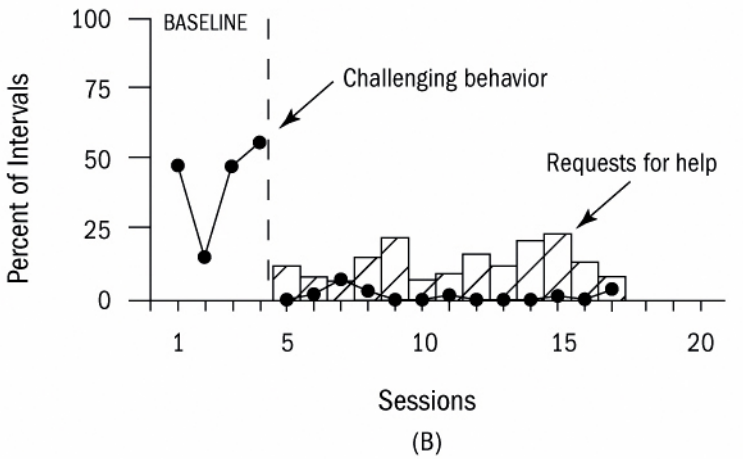
Observations during 4 conditions:

- low teacher attention during a task, low access to a preferred object during a task, a more difficult task, and a control condition

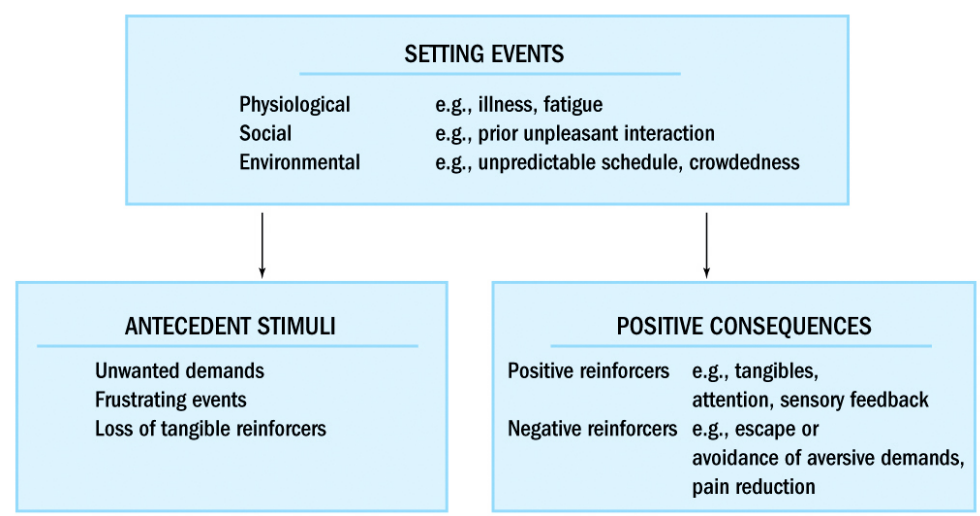
Observations determined Matt engaged in SIB most during difficult tasks

Matt trained to ask for help with difficult tasks





Behavioral Intervention



- Discrete trial learning
- Naturalistic or incidental learning
- Operant conditioning to build adaptive skills
- Positive behavioral support
  - Functional assessment vs. functional analysis
- Research supports use of behavioral interventions for increasing prosocial and adaptive behaviors, and reducing maladaptive behaviors, e.g., self-injurious behavior (SIB)

Educational interventions

Education of All Handicapped Children Act (PL 94-142)

- **Mandated a free, appropriate public education to youth with disabilities**

Individuals with Disabilities Education Act (IDEA; PL 105-17)

- **Required that children with disabilities by identifies by local school districts and educated in regular classroom environments to the maximum extent possible (initiated the practices of mainstreaming and academic inclusion)**

Individuals with Disabilities Education Improvement Act

(IDEA reauthorization; PL 108-446)

- **Most recent reauthorization of IDEA**

Guidelines on Using Punishment to Control Self-Injurious Behaviors

Highly restrictive procedures are not used unless:

1. **There is an immediate physical danger to the individual or to others**
2. **The scientific literature suggests the restrictive procedure would be effective**
3. **A less restrictive intervention would be ineffective or harmful**
4. **The restrictive treatment is combined with positive reinforcement (e.g., DRI, DRO)**
5. **The restrictive treatment is discontinued when its benefits can be maintained through a less restrictive means**
6. **The treatment is reviewed and approved by a peer and human rights committee, and the individual's guardian provides consent**

Based on APA (1996).

Other Interventions

- Pharmacological
  - Frequently prescribed
  - Usage increases when child exhibits behavioral problems
  - Stimulant medications
  - Antipsychotic medications
    - Overused
    - Lack of research
- Psychotherapy
  - Talk therapies not widely employed or researched
  - Modifications necessary

Comorbid Diagnoses

- Between 20% and 35% of non-institutionalized individuals with MR have a comorbid psychiatric diagnosis or behavioral disorder.
- The rates of psychiatric and behavioral diagnoses are four to five times those of individuals without MR.
- Rates increase with age and cognitive impairment.

Relevant Legislation

Individuals with Disabilities Education Act (IDEA)

- In 1975, Congress passed Public Law 94-142 (the Education for All Handicapped Children Act).
- This law was updated in 1990, and its name was changed to IDEA.
- IDEA was reauthorized and amended in 1997, becoming IDEA ‘97.

IDEA '97 Principles of Interest

- Children with disabilities must receive a ***F*ree *A*ppropriate *P*ublic *E*ducation** that provides special education and related services.
- Children with disabilities should be placed in the **Least Restrictive Environment** to the maximum extent possible.
  - "Mainstreaming".
  - This decision is made by the IEP team after evaluation.
  - School systems must maintain a full continuum of alternative placements to meet the needs of children with disabilities.

IDEA '97 Principles of Interest
Continued

- Each child being considered for special education must receive a **full, individualized, and appropriate evaluation**.
  - *Schools are responsible* for finding, identifying, and evaluating these children.
  - Assessment measures must be *nondiscriminatory*.
  - *No single procedure* must be used as the sole criteria for making determinations of eligibility.
  - Standardized tests must be *validated* for the specific purpose in which they are used and must be administered by *trained* personnel.

IDEA '97 Principles of Interest
Continued

- Procedural safeguards are provided so that:
  - The rights of children with disabilities are protected.
  - Children and their parents are provided with the information they need to make informed decisions about the educational opportunities available.
  - Procedures are in place to resolve disagreements between the parents and the school district.

IDEA '97 Principles of Interest
Continued

- State- or district-wide group tests administered to children without disabilities should also be administered to children with disabilities.
  - Accommodations can be made.
  - Alternative assessments can be provided.

IDEA '97 Principles of Interest
Continued

- The Individualized Education Plan (IEP) and the IEP team.
  - It is determined that children are eligible for services when they have a disability and that disability affects their educational performance adversely.
  - The IEP spells out the needs of the child and how the agency will meet these needs.
  - The IEP must be reviewed at least once per year, and the child must be reevaluated at least once every three years.

IDEA Part C: Infants and Toddlers with Disabilities

- In 1986, P.L. 99-457 amended P.L. 94-142 and authorized early intervention programs for infants and toddlers with disabilities and *extended the rights of P.L. 94-142 to children with disabilities from ages 3 through 5 years*.
  - These rights can be extended to 2-year olds.
- In identified cases, an Individualized Family Service Plan is developed with parental consent.

Section 504 of the Rehabilitation Act of 1973

- It was designed to protect individuals with disabilities from discrimination in any setting receiving funds from the federal government.
- Reasonable accommodations must be made for children and adults with disabilities.

Americans with Disabilities Act (ADA)

- Also known as P.L. 101-336.
- It provides protection from discrimination for individuals with disabilities in all settings, regardless of whether federal funding is involved.