



Transition to Adulthood:
Supporting Adults with
Fragile X Syndrome and Their Families

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Transition to Adulthood

- Diagnostic confusion
- The "culture" of ID professionals
- Adult day and work programs
- Residential options
- Legal issues
- Revisiting the grief cycle



Age 21: The Big Shift

- Child → Adult
- Mandated Education → Local Availability
- School District → Adult Services Agency
- School → Work / Day program
- Home → Residential
- Parent control → Individual choice



Etiological Diagnoses

In the adult services setting:

- Etiological diagnoses often considered irrelevant
- Behavioral / psychiatric diagnoses determine services and treatment approaches

Psychiatric Diagnoses


OCD

ADD ANXIETY DISORDER OPPOSITIONAL DEFIANT DISORDER

ADHD BIPOLAR DISORDER

AUTISTIC DISORDER MR (ID) IMPULSE CONTROL DISORDER

INTERMITTENT EXPLOSIVE DISORDER



Demystifying Diagnoses

- Diagnostic confusion abounds!
- Psychiatric / behavioral symptoms: found in association with many genetic ID syndromes
- Causes vs. symptoms: Important for families and professionals to understand distinction

The Adult ID Culture

- Person-centered approach
- Focus on individual rights, protections
- Non-mandated services subject to funding and local availability
- Eligibility for services based on DSM and behavioral criteria
- Primarily non-medical professionals (social workers, psychologists)

The Adult ID Culture

- Potential for adversarial relationships with families over philosophical differences
- Little exposure to recent advances in genetic diagnostics, treatment approaches
- Sometimes negative, suspicious attitudes about medicine, particularly psychiatry and genetics

ID Nomenclature

- “Consumers” not “patients”
- “ID” not “MR”
- People-first language
- Services are “supports”

Adult Day Programs

- Traditional workshop setting
- Supported employment
- Non-work day programs
- Recreation and social groups

Adult Day Programs - Pitfalls

- Programs but no funding
- Funding but no programs
- Waiting lists
- Transportation issues
- Squeaky wheel phenomenon
- Not mandated – no legal recourse

Transition to Adult Services

- Pre-vocational training starts early (middle school)
- Graduation with HS class at age 18, then 3+ years in vocational training
- Ages 18 – 21: transition plan, ideally involving adult services

Residential Options

- Living at home
- Congregate care
- Community living
- Family living programs
- Waiver programs

Legal Guardianship

- Assigned by the courts
- Situation-specific (financial, medical)
- Does not cover issues of privacy, including sexual consent, sterilization, reproductive decision-making, prenatal testing
- Guardian must petition court for specific situation; precedent cases have denied involuntary sterilization

Presumption of Competency

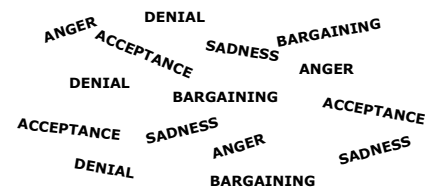
- Adults with ID presumed competent unless proven otherwise

Elements of Competency

- Knowledge: able to identify the important aspects of a decision
- Understanding: evidence that the knowledge is comprehended, including moral, physical consequences
- Voluntariness: lack of coercion

Chronic Sorrow

A stage-wise model for parents of people with long-term disability



Revisiting the Grief Cycle

Triggering events:

- Missed milestones
- Comparison with chronological peers
- Entry into school
- Graduation from school
- Parental aging / illness
- Residential placement

Revisiting the Grief Cycle

Stressors:

- funding concerns
- waiting lists
- relinquishing control; trusting providers
- feelings of abandonment by genetic support organizations, school community
- ambivalence about sexuality issues
- philosophical differences with ID culture