

Transition To Adulthood

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Review of the Literature

- Research has examined the intellectual ability of individuals with FXS and recent data maintains that males with FXS typically have a moderate-to-severe intellectual ability (Hall, Burns, Lightbody & Reiss, 2008)
- Females are less severely affected and one third to one demonstrate average intellectual functioning (Loesch et al., 2002)

Review of the Literature

- Subsequent research focused on more specific patterns of cognitive functioning such as attention, memory and executive functioning (Cornish, 2004; Hooper et al., 2008)
- From these studies, we know that FXS affects multiple aspects of functioning and is associated with a number of co-occurring conditions such as attention, anxiety, hyperactivity and autistic-like behaviors (Bailey, Raspa, Olmstead, & Holiday, 2008)

The Transition To Adulthood

- Little is known about the extent to which individuals with FXS develop functional skills to enable them to become independent.
- Little is known about the life course or timing of acquisition of specific skills
- Parents are usually more interested in knowing the likelihood of their child attaining specific skills such as speaking, reading and independence in personal hygiene

The Transition To Adulthood

- This information could be especially helpful to parents and clinicians as they attempt to gather baselines in order to provide services and ultimately affect functional independence

- Functional Assessments focus on acquisition of tasks and not cognitive processes such as memory and attention
- Functional Assessments provide more specific information about the supports need to gain independence

How Do We Sort This Out?

- International Collaborative sponsored by the World Health Organization (2001) developed the International Classification of Functioning, Disability and Health (ICF)
- The intent of this collaboration was to shift the focus from diagnostics and cognitive functioning to that of overall functioning
- This tool (ICF) is used to describe the extent the disorder or disease impacts the ability to participate in daily routines.

New Research

Bailey, Raspa, Olmstead, & Holiday, 2008 surveyed parents of 1,105 males and 283 females to define functional skill development in a variety of domains. Significant differences were found between males and females. Their findings highlighted major skill attainments, identified skills that should be the target of specific intervention programs, suggest variable trajectories to be tested through direct assessments and look at longitudinal benefits from treatment.

New Research

Summary of Findings

1. The majority of adults 20 yrs and older had many daily living skills (Eating, dressing, bathing and toileting).
2. 90% of the males were verbal (single words and signs)
3. Skills attained by less than 65% of the males even by adulthood included eating at a normal pace, tying shoes independently, wiping independently, brushing hair and teeth, using complex sentences and engaging in conversation and speaking clearly at a typical rate.

New Research

Summary of Findings

4. Only 20% of the males could read books containing new words or concepts
5. 2/3 of the males could recognize words by sight
6. The development of functional skills occurred relatively early in some skill areas and showed continuous increases across ages in other areas

The Bottom Line

- Behavioral and developmental characteristics including overall thinking, reasoning and learning ability, adaptability, ability to pay attention and total number of co-concurring conditions were predictive of functional skills in both males and females
- Respondent education level was not associated with any functional skill attainment in males.

The Not So Scientific Study

Taken from National FX Foundation's Adolescent and Adult Project

Several parents and professionals came together to interview and survey parents with children with Fragile X Syndrome over a year's time

They provided the information to the foundation who then produced a book with DVD to transmit the information

Predictors of Independence

- Encourage a variety of experiences within the home community
- Develop interests and “common denominators” that make them more viable social partners
- Encourage social engagement in small groups such as church activities, scouting or clubs
- Encourage age appropriate dress, interests and activities
- Encourage grooming and personal hygiene

Behavioral Issues In Adolescents and Adults

- Mood Disorders
 - Unable to sit for long
 - Paces aimlessly
 - Sleeplessness
 - Irritability
- Depression
 - Loss of interest in favorite activities
 - Lack of appetite
 - Increased rigidity in routines
 - Nervousness
- Panic Episode
 - Become flushed
 - Look frightened
 - Try to flee
 - Breathe rapidly
 - Sweat heavily
 - Rapid pulse rate
 - React with self-injury

Taken from National FX Foundation's Adolescent and Adult Project

Socialization

Social venues that have brought positive experiences to those with FXS

- Church
- Sports/Special Olympics
- Theatre/Movies
- Karate
- Choir
- Boy/Girl Scouts

Socialization

Sports Activities That Have been Most Successful

- Swimming
- Basketball
- Watching sports on TV
- Baseball
- Horseback riding
- Music
- Bowling
- Library
- Karate
- Fitness center

Living Options and Settings

- Completely independent
- Shared living environment
- Solo living environment with intermittent case manager/care provider
- Communal living
- Group home- numbers can vary- with a responsible adult always onsite
- Residential or assisted living with larger number of residents and opportunities to explore various types of employment
- State institutions or developmental centers-only considered for people who are a danger out self or others

Taken from the National FX Foundation's Adolescent and Adult Project

The World of Work

Potential Job List

- Working at a college bookstore or food court
- Serving lunch or juice at a senior center or skilled nursing facility
- Cooking/prep chef
- Working at a grocery store
- Working at a day care center
- Working at a library
- Working at the Humane Society

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RESOURCES

- Fitting In and Having Fun, Vol. 2: Moving on to Middle School – www.difflearn.com
- The National Fragile X Foundation's Adolescent and Adult Project: Smoothing the Transition to Successful Adulthood
- Community Success CD
- Conversation Skills On the Job and in the Community
- Social Skills at Work CD
- Social Skills on the Job CD set

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