

Adaptive Living Skills in Fragile X Syndrome

Self-Help Skills

Males with fragile X syndrome show strengths in daily living skills, especially regarding personal and domestic skills such as dressing and household skills. This relative strength is mainly seen in older males. Individuals with fragile X syndrome also have relative strengths in motor skills.

Communication

Communication skills in fragile X syndrome can vary widely. Some males with fragile X syndrome may only experience mild difficulties with language and communication, but others may not develop any spoken language at all.

On average, research suggests that most boys with fragile X syndrome develop language at about half the rate of typically developing children in early childhood.

Language development in fragile X syndrome can be complicated by hearing and oral problems. For example, recurrent ear infections (otitis media) can lead to conductive hearing loss. Hypotonia (low muscle tone), which affects the oral-facial muscles, can impact speech development.

Individuals with fragile X syndrome often have greater delays in their expressive language compared to their receptive language, meaning that they may be able to understand more than they can say.

Individuals with fragile X syndrome often have particular speech characteristics, such as frequent perseveration (excessive self-repetition of a word, phrase, sentence, or topic). Some individuals experience difficulties in turn-taking and staying on a topic of conversation, and many individuals have an unusual variability in speaking rate with unpredictable shifts from slower to faster speaking.

It is important to ensure that children with fragile X syndrome start Speech and Language Therapy early on and have regular assessments of their language abilities to profile their strengths and weaknesses.

Development of Skills Over Time

Cognitive and behavioural development seems to plateau during childhood and early adolescence, which means that the gap between individuals with fragile X and their typically developing peers on measures of communication, socialisation and adaptive behaviour begins to widen. Also, some research indicates that there may be a regression in skills at around ten years for the majority of boys with fragile X syndrome. This regression occurs most often in socialisation skills and may be associated with increased social anxiety in adolescence. Research suggests that a subset of boys may also show regression in motor skills and adaptive communication. Individuals who are more able and who have fewer characteristics of autism tend to show better skill development overall.