

Daily Living Skills of Individuals with Fragile X Syndrome

Findings from the National Fragile X Survey

October 2009

This report provides information about the daily living skills of individuals with fragile X syndrome, including eating, dressing, toileting, bathing, communicating, articulating, and reading. The results are reported across five age groups: birth to 5 years, 6 to 10 years, 11 to 15 years, 16 to 20 years, and over 20 years. The majority of adults had mastered many skills independently. However, some skills were not as well developed, such as using complex sentences, reading, or speaking at a normal volume. As expected, significant differences were found between males and females.



Overview

This report examines how well children and adults with fragile X syndrome are able to perform a variety of daily living skills, including the following:

- eating
- dressing
- toileting
- bathing
- communicating
- articulating
- reading

Summary of Results

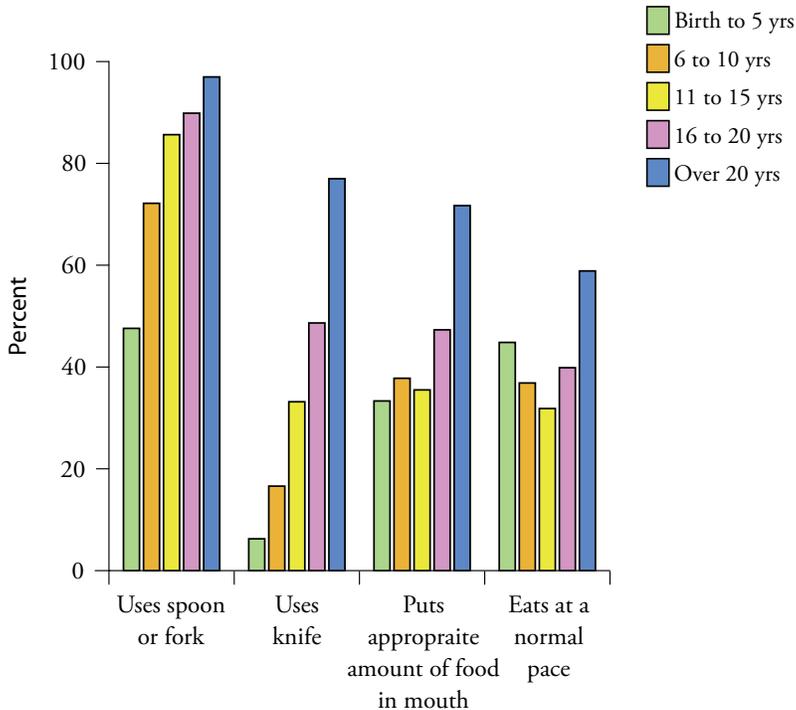
Overall, the majority of adults had mastered many skills independently. Most adults were verbal, used the toilet, dressed, bathed, and ate independently. However, some skills were not as well developed, such as using complex sentences, reading, or speaking at a normal volume. As expected, significant differences were found between males and females.

Figures 1-7 present in greater detail the percentages of males and females who were able to perform these skills either “fairly well” or “very well.” Data are based on 1,105 males and 283 females with the full mutation of fragile X syndrome. Skills are reported in five age categories: birth to 5 years, 6 to 10 years, 11 to 15 years, 16 to 20 years, and over 20 years.

The survey findings are important because they highlight specific daily living skills acquired across five age categories and identify time points at which professionals could target specific interventions. The results also provide general guidelines and expectations for parents who work with children and adults on mastering these skills.

1. Eating Skills

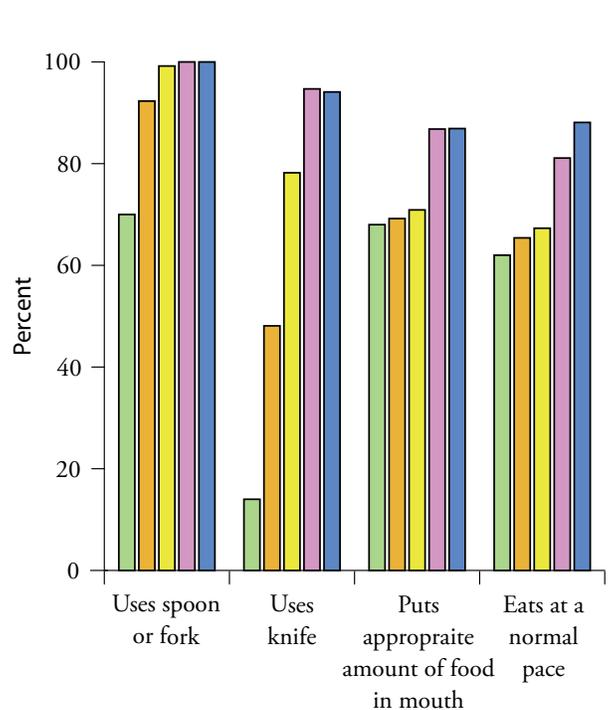
Figure 1a. Males with the Full Mutation



Highlights

- The percentage of males who could use a spoon or fork, or cut with a knife increased across each of the five age categories.
- The skills related to the amount of food taken and the pace of eating remained relatively stable across the first 20 years of life, with increases in the percentages reported in these areas only after age 20.
- Most adult males 20 years or older could use a spoon or fork (97%) and many could use a knife (77%).
- A majority (72%) of adult males put an appropriate amount of food in their mouth, but only 59% ate at a normal pace.

Figure 1b. Females with Full Mutation

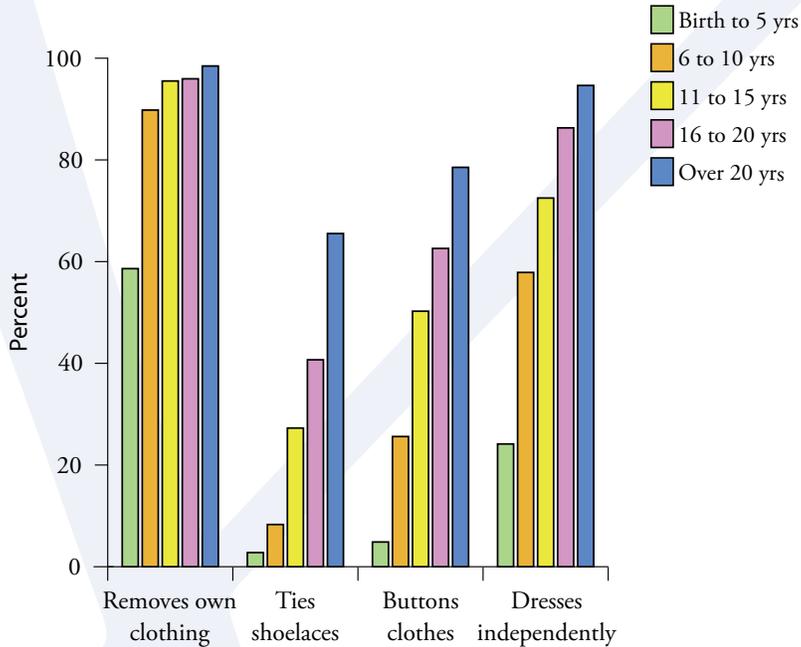


Highlights

- Overall, females tended to develop eating skills earlier than males.
- Percentages for some skills (e.g., using a knife) increased across each of the five age categories.
- Similar to males, skills related to the amount of food taken and the pace of eating remained relatively stable until 16 to 20 years of age.
- The majority of females aged 11 to 15 used a spoon or fork (98%), used a knife (78%), put an appropriate amount of food in their mouth (71%), and ate at a normal pace (67%).

2. Dressing Skills

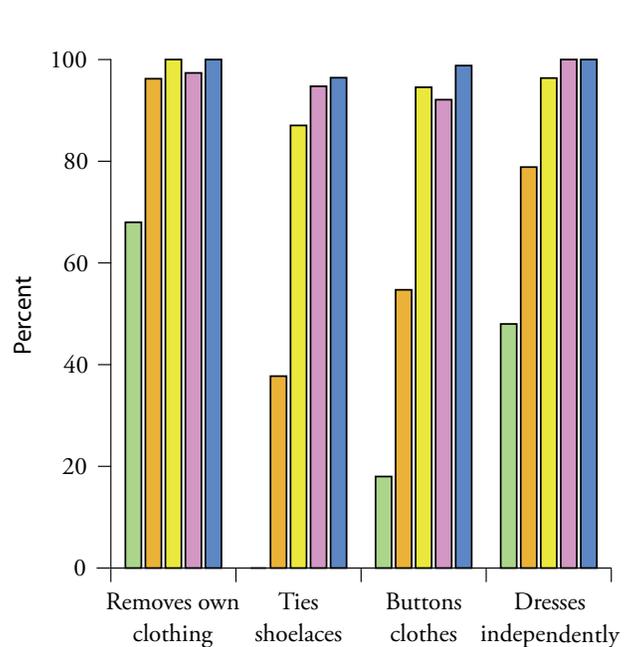
Figure 2a. Males with Full Mutation



Highlights

- Similar to eating skills, there were increases in dressing skills across the age categories for males.
- Most males had an easy time removing their own clothing, but tying shoelaces was the hardest skill to master.
- Most males aged 20 years or older were able to remove their own clothing (98%), tie their shoelaces (66%), button their clothes (79%), and dress independently (95%).

Figure 2b. Females with Full Mutation



Highlights

- Females acquired dressing skills in the same sequence as males; however, their skills developed at earlier ages.
- Almost all females aged 11 to 15 were able to remove their own clothing (100%), tie their own shoelaces (87%), button their clothes (95%), and dress independently (96%).

3. Toileting Skills

Figure 3a. Males with Full Mutation

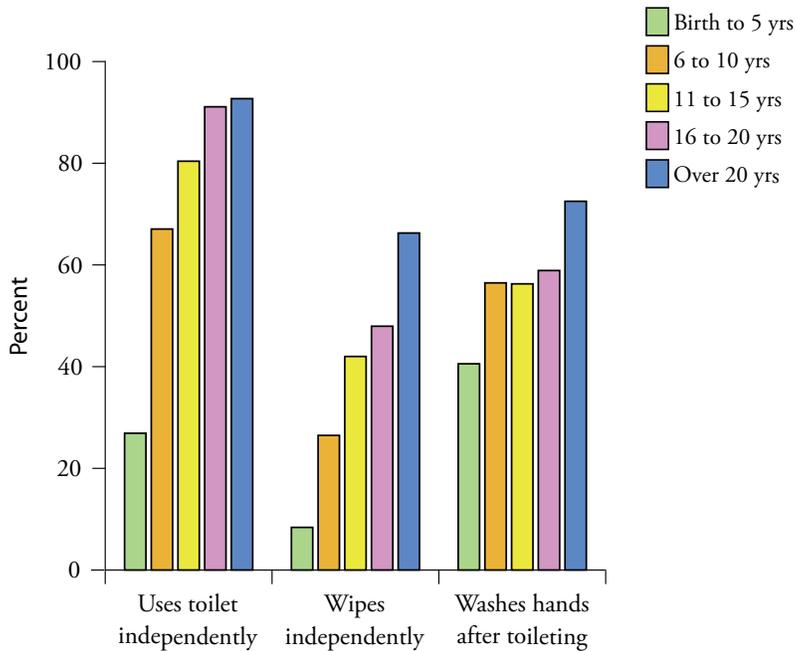
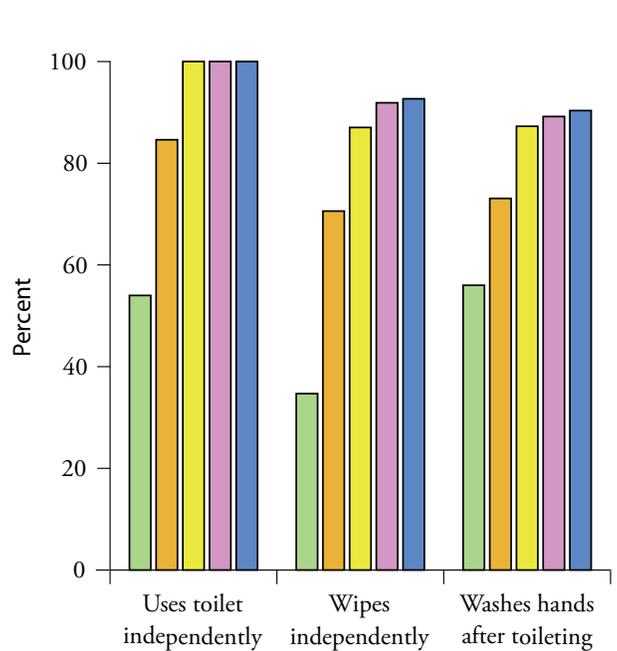


Figure 3b. Females with Full Mutation



Highlights

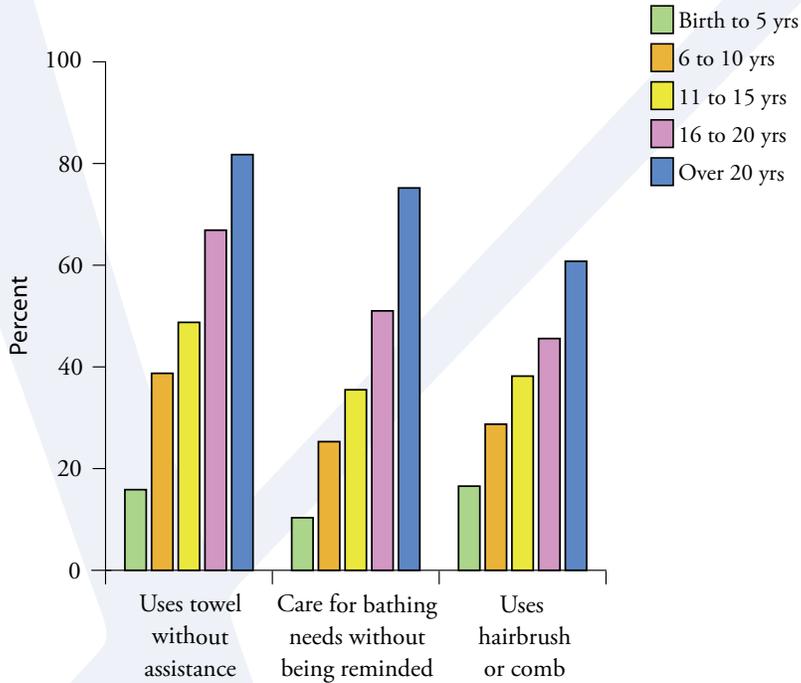
- For each of the toileting skills, a steady increase in the percentage of males caring for their own needs was seen across the age categories.
- Many males aged 6 to 10 years (67%) were able to use the toilet independently, and by age 20 years or older, most males (93%) had mastered this skill.
- Wiping independently and washing hands were harder for males. By age 20 years or older, 66% and 73%, respectively, were able to perform these skills.

Highlights

- Rapid increases in toileting skills were evident for females after the first 5 years of life.
- Females tended to master toileting skills earlier than males.
- The majority of females were able to use the toilet independently (85%), wipe independently (71%), and wash hands after toileting (73%) by the time they reached 6 to 10 years of age.

4. Bathing Skills

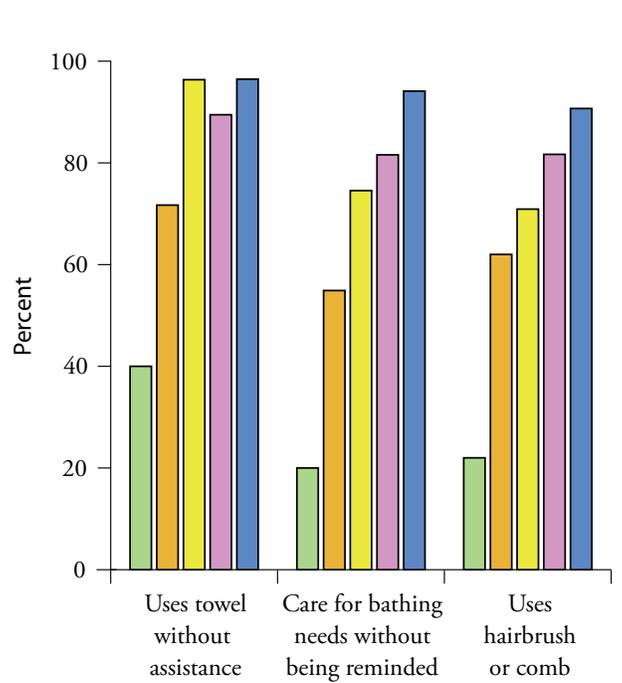
Figure 4a. Males with Full Mutation



Highlights

- Bathing and hygiene skills for males increased steadily into adulthood.
- The majority of adult males aged 20 years or older could use a towel without assistance (82%) and care for their own bathing needs without being reminded (75%).
- Fewer adult males were able to use a hairbrush or comb (61%).

Figure 4b. Females with Full Mutation



Highlights

- Unlike males, the percentage of females demonstrating bathing skills grew rapidly during the first 15 years, with some increase in skill development in late adolescence and adulthood.
- Over 50% of females aged 6 to 10 years and 90% of females aged 20 years or older were able to use a towel without assistance, care for bathing needs without being reminded, and use a hairbrush or comb.

5. Communication Skills

Figure 5a. Males with Full Mutation

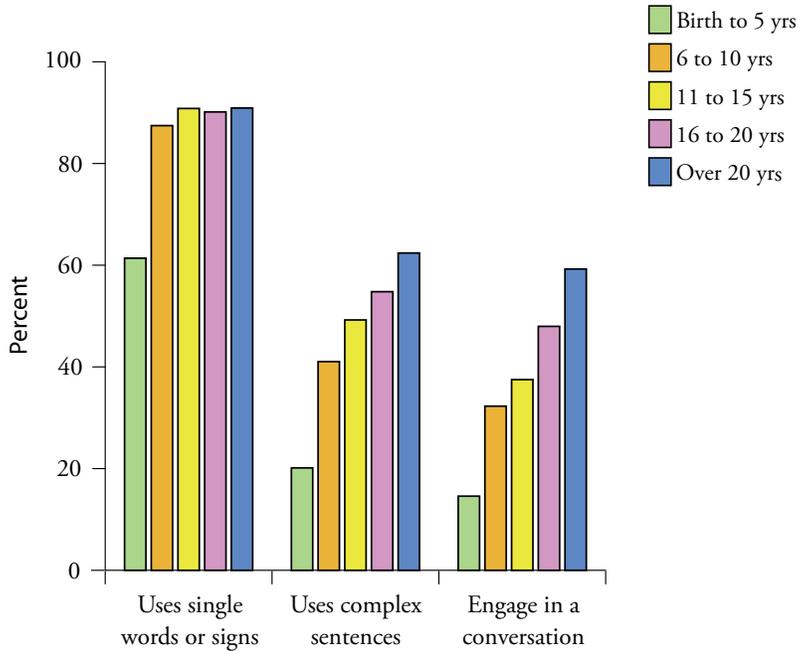
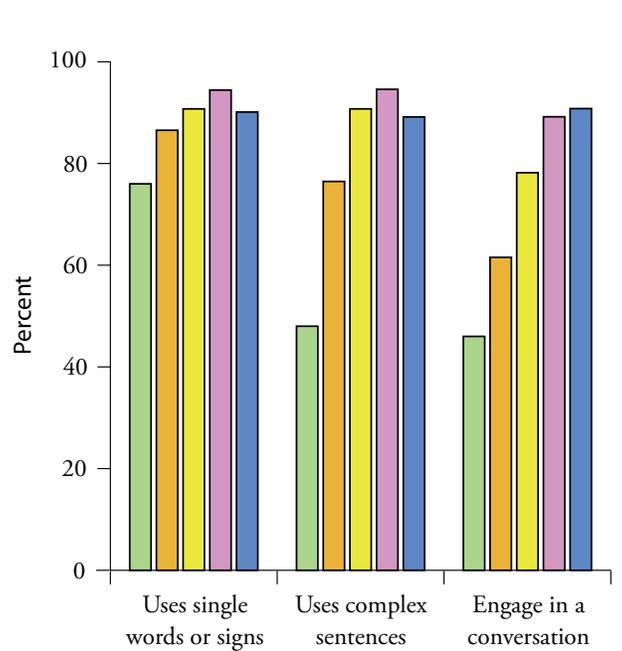


Figure 5b. Females with Full Mutation



Highlights

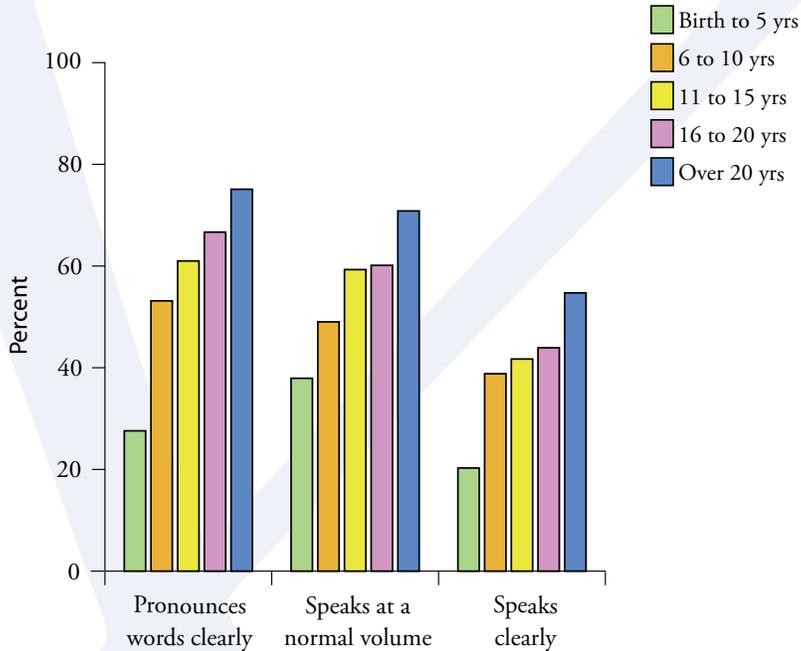
- Males developed basic communication skills early, with more than 80% of males using single words or signs by 6 to 10 years of age.
- More advanced communication skills were slower to show change across the age categories.
- By age 20, the majority of males were able to use complex sentences (62%) and engage in a conversation (59%).

Highlights

- Females acquired communication skills at earlier ages than males.
- Basic communication skills were acquired between birth and 5 years, but more advanced skills emerged in older females.
- By age 20 or older, 90% of females could use single words or signs, 89% used complex sentences, and 91% engaged in a conversation.

6. Articulation Skills

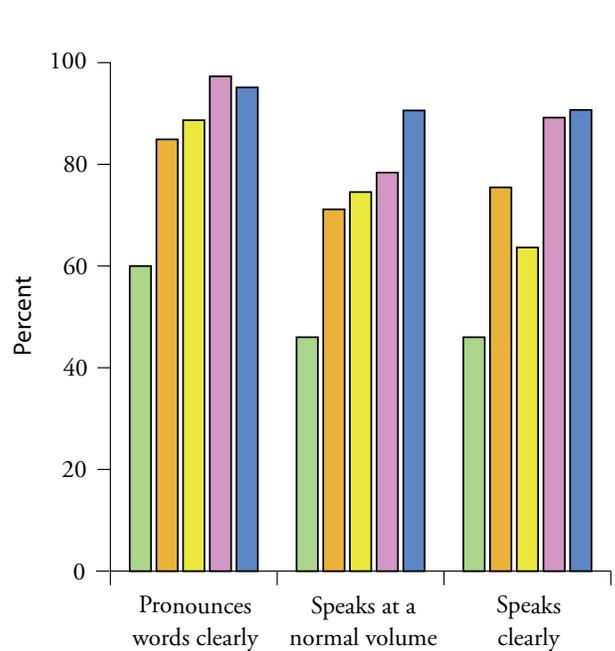
Figure 6a. Males with Full Mutation



Highlights

- Articulation skills were more difficult for males to master than communication skills, with increases in percentages seen across the age categories.
- Between 6 and 10 years of age, about half of males could pronounce words clearly (53%) and speak at a normal volume (49%), but only 39% could speak clearly.
- By age 20, the majority of adult males were still learning articulation skills, with over 70% able to pronounce words clearly and speak at a normal volume, and 55% able to speak clearly.

Figure 6b. Females with Full Mutation

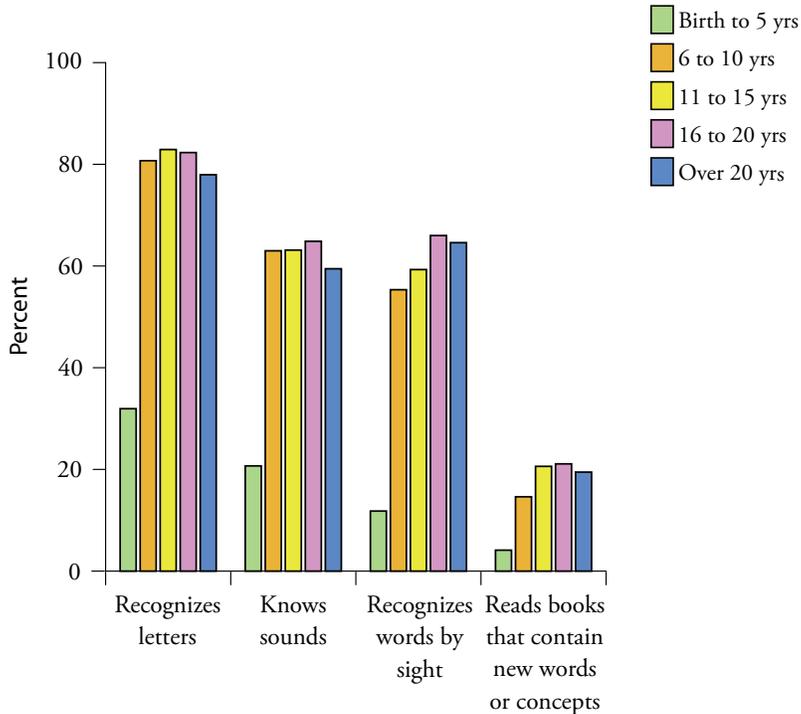


Highlights

- Increases in articulation skills were seen across the five age categories for females.
- Between 6 and 10 years of age, 85% of females were able to pronounce words clearly, 71% spoke at a normal volume, and 75% spoke clearly.
- By age 20, over 90% of females had mastered these skills.

7. Reading Skills

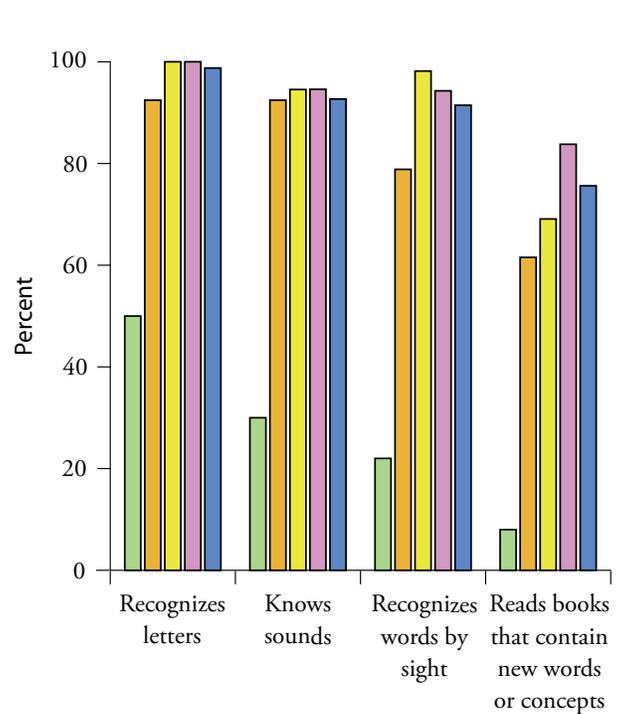
Figure 7a. Males with Full Mutation



Highlights

- The majority of males learned reading skills by 6 to 10 years of age.
- Very few males learned these skills in adolescence and adulthood.
- By age 20, the majority of males could recognize letters (78%), knew sounds (59%), and could recognize words by sight (65%).
- Fewer adult males than females were able to read books that contain new words or concepts (19%).

Figure 7b. Females with Full Mutation



Highlights

- Similar to males, there was a substantial increase in reported reading skills by 6 to 10 years of age for females.
- Most females had mastered reading skills in adulthood, with nearly all able to recognize letters (99%) and words (91%), and to know sounds (93%).
- More females than males could read books containing new words or concepts (76%) at age 20 years or older.

Acknowledgment

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For more information...

Please visit the National Fragile X Foundation Web site at http://www.fragilex.org/html/fx_survey.htm

Suggested citation

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These results also have been published in the American Journal on Intellectual and Developmental Disabilities:

Bailey, D.B., Raspa, M., Holiday, D., Bishop, E., & Olmsted, M. (2009). The functional skills of individuals with fragile X syndrome: A lifespan cross-sectional analysis. *American Journal on Intellectual and Developmental Disabilities*, 114, 289-303. Available at <http://aaid.allenpress.com/aamronline/?request=get-static&name=ajmr-info>

Questions?

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