

**Voice of people with Fragile X syndrome and their families: Reports from a survey on treatment priorities**

Q1. Which of the following best describes you?

- I have Fragile X syndrome
- I am a family member or caretaker of someone with FXS
- I am a professional who works with a person with FXS

Q2. What is the age of the person with FXS with whom you have the connection? Or your age if you have FXS.

- Male: Birth to 5 years old
- Female: Birth to 5 years old
- Male: 6 to 12 years old
- Female: 6 to 12 years old
- Male: 13 to 21 years old
- Female: 13 to 21 years old
- Male: 22 years and older
- Female: 22 years and older

Q3. Check the five characteristics that have the greatest impact on the life of the person with FXS. Prioritize 1, 2, 3, 4, 5.

- Anxiety—anticipatory, e.g., of new/upcoming events
- Auditory processing difficulties—being able to listen to instructions and react to them
- Autism
- Communication delays—initiation (asking for help) and social (turn-taking)
- Hyperactivity
- Learning or Intellectual disability (problems with abstract thinking, learning)
- Memory—short term
- Memory—long term
- Motor delays (e.g., low muscle tone, poor fine motor skills, poor balance)
- Motor stereotypes (hand-flapping, spinning around)
- Perseveration—speech (repeating things over and over)
- Seizures
- Sensory processing difficulties
- Short attention span
- Social anxiety
- Speech/Language delays—receptive (understanding spoken language)
- Speech/Language delays—expressive (speaking spoken language)
- Visual information processing difficulties
- Other – Describe

Q4. Rank these three areas from one to three to the extent it affects the person's daily life—with one having the greatest impact and three having the least impact:

- Behavior
- Intelligence
- Physical abilities

Q5. Check the top five areas of daily life the person with FXS is most affected by. Prioritize 1, 2, 3, 4, 5.

- Ability to learn academic skills/reading/math
- Ability to take care of self-care skills/hygiene/cooking
- Ability to speak/communicate
- Ability to be left alone/spend time alone
- Ability to control behavioral outbursts
- Ability to attend and perform at school
- Ability to find/maintain job
- Ability to make and maintain friends
- Ability to live independently
- Ability to establish and maintain a relationship
- Ability to be like other people his/her age.
- Ability to attend events where there are a lot of people/noise
- Willingness to go to new places
- Willingness to travel/ go on vacation
- Other—Describe

Q6. Which five specific aspects of daily living with FXS are the most challenging? Prioritize 1, 2, 3, 4, 5.

- Always thinking—how are things going, what do I need to do next? Needing to always be ‘one step’ ahead
- Checking in/setting up daily programming—school, work, etc.
- Doctor/dentist appointments—finding/attending
- Doing activities with friends—both child’s and adult’s
- Extra costs—therapies, medications, clothing, glasses, laundry
- Extra time it takes to do everything
- Finding respite
- Food—Always hungry/wants to eat out
- Handling behaviors (negative)—tantrums, aggression, spitting, cussing
- Hygiene—shower, toileting, hair cuts
- Impact on non-affected family members
- Medications—getting prescriptions/not running out/ making changes
- Need for constant supervision
- Needing to make sure everything is “set” for the day—routine, visuals
- Person doesn’t understand directions/can only do one thing at a time
- Person is unable to tell you what he/she wants/needs
- Running errands—how many stops can I make? What environments could be hard/noisy?
- Sleeping
- Worry about the future
- Other—Describe

Q7. List three of your favorite things about the person with FXS. (Or three things you like about yourself).

Q8. What are the top three aspects of Fragile X syndrome that you would like to see a drug treatment address, list in order of preference, with the most important one first.