

## **Project Questionnaire**

**Title:** Living arrangements and long-term supports for adults with FXS.

### **Eligibility Criteria**

-Only family members are eligible to complete this questionnaire

-The term 'person' is used to refer to the adult individual with FXS who is the subject of the survey

-If you care for more than one individual with FXS please complete the survey in regards to the eldest individual

### **Eligibility Questions**

1. Does the individual with FXS have a full mutation of the *FMR1* gene?
  - Yes
  - No
  - Unsure
  
2. What is your relationship to the person with FXS?
  - Mother
  - Father
  - Other family member
  
3. How many individuals diagnosed with FXS do you care for?
  - 1
  - 2
  - 3 or more

### **A) Demographics/Caregiver Information**

1. Which race/ethnicity best describes you? (Please choose only one)
  - White
  - Hispanic or Latino
  - Black or African American
  - Native American or American Indian
  - Asian or Pacific Islander
  - Prefer not to answer
  - Other
  
2. Which region of the U.S. do you currently reside?

- Northeast (ME, NH, VT, MA, RI, CT, NY, NJ, PA)
- South (DE, MD, VA, WV, KY, NC, SC, TN, GA, FL, AL, MS, AR, LA, OK, TX)
- Midwest (OH, MI, IN, IL, WI, MN, IA, MO, ND, SD, NE, KS)
- West (MT, ID, WY, CO, NM, AZ, UT, NV, CA, OR, WA, AK, HI)
- Other: [fill in the blank]

3. What is the highest degree or level of school you have completed?

- Less than high school
- Some high school
- High school degree or equivalent (GED)
- Technical school/some college/associate's degree
- College degree (bachelor's)
- Post graduate degree (master's/doctorate)
- Prefer not to answer

4. What is your average annual household income?

- Less than \$50,000
- \$50-100,000
- \$100-150,000
- \$150-200,000
- More than \$200,000
- Prefer not to answer

## **B) FXS Individual Characteristics**

1. What is the sex of the individual with FXS?

- Male
- Female

2. Select the age group the person falls under

- 15-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- $\geq 55$  years

3. Does the person have any of the following conditions?

Matrix: 0 = no, 1 = unsure, 2 = mild, 3 = moderate, 4 = severe

- Intellectual Developmental Disability (IDD)
- Autism Spectrum Disorder
- Attention problems
- Hyperactivity
- Constant aggressive behavior
- Intermittent explosive disorder (sudden episodes of impulsive, aggressive, violent behavior) (Note: select mild if episodes are separated by months, moderate if separated by weeks, and severe if episodes occur weekly)
- Self-injury
- Anxiety
- Depression

4. Does the person have any additional medical issues? (select all that apply)

- Seizures
- Gastrointestinal (GERD, acid reflux)
- Sleep disorders (insomnia, sleep apnea)
- Hearing loss
- Vision (strabismus, lazy eye)
- Cardiac (mitral valve prolapse, aortic root dilated)
- None
- Other: [fill in the blank]

5. How would you rate this person's overall health?

- 1 = very poor
- 2 = poor
- 3 = fair
- 4 = good
- 5 = excellent

6. Does the person require assistance with the following skills?

Matrix: 0 = independent or does on own, 1 = does with help, 2 = does not do at all

- Making his/her own bed
- Doing household tasks, including picking up around the house, putting things away, light house cleaning, etc
- Doing errands, including shopping in stores
- Doing home repairs, including simple repairs around the house, non-technical in nature; for example, changing light bulbs or repairing a loose screw
- Doing laundry, washing and drying
- Washing/bathing
- Grooming, brushing teeth, combing and/or brushing hair
- Dressing and undressing
- Toileting
- Preparing simple foods requiring no mixing or cooking, including sandwiched, cold cereal, etc.
- Mixing and cooking simple foods, fry eggs, make pancakes, heat food in microwave, etc.
- Preparing complete meal
- Setting and clearing table
- Drinking from a cup
- Eating from a plate
- Washing dishes (including using a dishwasher)
- Banking and managing daily finances, including keeping track of cash, checking account, paying bills, etc. (Note: if he/she can do a portion but not all, check 'does with help')

7. Does the person do any of the following activities? (select all that apply)

- Volunteer
- Work, part-time
- Work, full-time

### **C) Living Arrangements/Supports**

1. Where does the individual with FXS currently reside?
  - Residing with parents or family members [*branch to Q2/Q3*]
  - Host/Group home [*branch Q6-10*]
  - Residential facility [*branch Q6-10, Q12*]

- Independent apartment/house with support (staff may come throughout day or week) [*branch to Q3*]
- Independent living or with a partner [*branch to Q3*]
- Other: [fill in the blank] [*branch to Q3*]

2. How much do the following factors apply to the reason they live at home?

Matrix: 0 = not a reason, 1 = minor, 2 = neutral, 3 = moderate, 4 = major reason

- Parent desire
- Individual with FXS desire
- Limited residential options/currently on waitlist
- Not satisfied with available residential services
- Rejected from residential placement/group home: [*provide reason*]
- Child unable to live independently
- Have not considered other living arrangements

3. What future living arrangement have you considered most for this person? (If same as where they are currently living, select that choice)

- Live with family members long term [*branch to Q5*]
- Host/Group home [*branch to Q4*]
- Residential facility [*branch to Q4*]
- Independent apartment/house with support [*redirect to Q11, Q13*]
- Independent living or with a partner [*redirect to Q11, Q13*]
- Not yet considered/Unsure [*branch to Q5*]
- Other: [fill in the blank] [*branch to Q4*]

4. Have you made plans or proceeded to enroll them in out-of-home living arrangements?

- No [*branch to Q5*]
- Yes [*branch to Q6-10, Q12*]

5. Reason(s) you have not started planning or considered alternative living arrangements:

(select all that apply) [*redirect to Q11, Q13*]

- Lack of information
- Lack of time
- No residential services near me

- Not satisfied with living arrangement options
- Confused on where to start
- Overwhelmed with information
- Not a concern yet/still have time
- Other: [fill in the blank]

6. How important were/are the following factors when searching for a residence?

Matrix: 0 = have not considered 1 = not important, 2 = slightly important, 3 = moderately important, 4 = very important, 5 = extremely important

- Location
- Price
- Health services
- Educational services
- Recreational activities
- Staff to resident ratio
- Available activities
- Ability to visit
- Day programs

7. Which of the following factors were/are difficult to satisfy during your search? (select all that apply)

- Location
- Price
- Health services
- Educational services
- Recreational activities
- Staff to resident ratio
- Available activities
- Ability to visit
- Day programs

8. If your child has behavioral issues, did/does it affect finding a residence?

- My child does not have behavioral issues
- No, it did not affect it

- Yes, it did affect it: [which behavioral issues and how ]

9. How much does the residential facility cost annually?

- Less than \$50,000
- \$50-100,000
- \$100-150,000
- More than \$150,000
- Prefer not to answer

10. How do you afford/plan to afford this residential service? (select all that apply)

- Public funding (i.e. Supplemental security income, Medicaid waiver)
- Special needs trust (ABLE Act)
- Self-pay by parent/caregiver
- Insurance
- Income from person's job
- Other: [fill in the blank]

11. How would you rate their satisfaction with their currently living arrangement? [*not branched*]

- Very Dissatisfied: [provide reason]
- Dissatisfied: [provide reason]
- Neutral
- Satisfied: [provide reason]
- Very satisfied: [provide reason]

12. Does the residential facility provide any of the following health services? If yes, select your satisfaction level with them.

0 = unsure if provided, 1 = does not provide, 2 = provides, not satisfied, 3 = provides, neutral 4 = provides, satisfied

- Residential medical care or nursing
- Physical therapy
- Speech therapy
- Behavioral therapy
- Psychological support staff

- Occupational therapy or direct support professionals
- Dietician/nutritionist

13. What would be the ideal living arrangement for the individual with FXS? [free response]  
[not branched]

#### **D) Future Concerns**

1. How concerned are you about the future in the following areas?

Matrix: 1 = not at all concerned, 2 = slightly concerned, 3 = somewhat concerned, 4 = moderately concerned, 5 = extremely concerned

- Who will care for them when I am no longer able to
  - Financial support
  - The availability of resources
  - The quality of resources
  - The transition to different long-term supports/living arrangements
  - Abuse when I am not here anymore
2. Have you started making plans to address these concerns?
- Yes: [explain how]
  - No: [provide reason(s)]
3. In the future, how will the person be supported financially? (select all that apply)
- Public funding (i.e. supplemental security income, Medicaid waivers)
  - Special needs trust (ABLE Act)
  - Self-pay by parent/caregiver
  - Insurance
  - Income from their job
  - Unsure
  - Other: [fill in the blank]
4. Who will oversee their medical decisions when you are no longer able to?
- Close family member (sibling, aunt, uncle)
  - Friends/other family
  - Residential facility director

- My child will make his/her own decisions
- Have not considered/unsure
- Other: [fill in blank]

5. Who will oversee their financial decisions when you are no longer able to?

- Close family member (sibling, aunt, uncle)
- Friends/other family
- Residential facility director
- My child will make his/her own decisions
- Have not considered/unsure
- Other: [fill in blank]

**E) Free Response (Optional)**

1. Please share any additional concerns you have regarding future long-term supports/living arrangements for the individual with FXS that were not covered in the questionnaire.
  
2. If applicable, please share your experiences addressing these concerns.