



NATIONAL **FRAGILE X** FOUNDATION
FRAGILE X CLINICAL & RESEARCH CONSORTIUM

National Fragile X Foundation
Treatment Recommendation

LANGUAGE IN FRAGILE X SYNDROME

*What to expect and implications
for assessment and intervention*

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Language Overview

While the majority of individuals with FXS will develop spoken language at some point, there are typically global delays of expressive and/or receptive language in the process. It is important to remember that even when individuals are not speaking, they are still communicating, although sometimes this can look like challenging behaviors. In addition, families need to be aware of the impact sensory processing / integration may have on speech and language (see *Hyperarousal in Fragile X Syndrome*). Thus, collaboration between parents, speech language pathologist (SLP), occupational therapist (OT), and behaviorist will often be essential throughout the lifespan.

Individuals with FXS can have a range of cognitive abilities that must be taken into consideration when discussing language development and outcomes. It is useful to think about the developmental level of the individual, e.g., if cognition is at an earlier stage of development, then language will likely be at a similar level. This is useful when planning what skills to expect and how to support language growth. This document will provide information about what language development may look like for individuals with FXS. We will discuss receptive language (what is understood), expressive language (how an individual communicates), pragmatics (how language is used), and speech (how sounds and words are produced). Just as in other areas of development, there is a wide-range of abilities in both males and females, though in general females with FXS tend to have milder delays in language development.

Receptive Language

Receptive language refers to how your child understands language. For most individuals with FXS, language understanding develops faster than language expression. This means that individuals are understanding more than they can tell us. Growing research indicates that understanding of vocabulary is a strength in FXS, possibly tied to their strong long-term memory. Comprehension of complex language may be more challenging, with one example being that complicated directions can be hard to follow without supports.

Expressive Language

Expressive language refers to how your child uses language to express themselves. Some research has found that first words in FXS often appear on average between 15-25 months, but there may be children who begin earlier or later than this. Nonverbal communication, such as waving “bye” or shaking head yes/no, may also be delayed.

Once individuals with FXS begin talking, they tend to have stronger vocabulary than grammar skills. This means that individuals may know many words, but they may have difficulty with aspects like using past tense “He jumped” and verbs “the frog **is** swimming”. Perseverative or repetitive speech is an almost universal trait and becomes particularly apparent in children and adults with FXS. Repetitive questioning can be a sign of anxiety or can reflect the person’s difficulty with ordering the things that are going to happen in the day (or week, etc). It can also be a reflection of the strong interest in specific actions or interests that results in being “stuck” on topics or phrases.

Pragmatic Language

Pragmatic language, everyday social language skills, such as turn taking, eye contact, and conversational skills can be challenging in FXS. For example, the way you ask for a drink is different when you’re at a nice restaurant than when you’re in your own house. In FXS, these difficulties with pragmatic language are also impacted by anxiety and attention span. The most common characteristics of the pragmatic language difficulties are difficulties in back-and-forth interactions, the presence of repetitive language, ability to tell a story, and to understand sarcasm or jokes.

Speech

Individuals with FXS sometimes make articulation errors similar to those seen in young children with typical language development (e.g., saying “tat” for “cat”). When children are older, single words are usually understandable, but listeners may have difficulty understanding them in conversations. This may be because of articulation errors and/or variable or rapid rate in their speaking.

Implications for Assessment and Intervention

There is an ongoing need for research in the area of FXS assessment and intervention and; therefore, the information in this section partially relies on evidence from other areas such as intellectual and developmental disability (IDD) and autism.

Assessment

A speech and language assessment (sometimes referred to as a speech and language “evaluation”) is a critical first step in understanding the individual’s communication strengths and challenges. Team evaluations including multiple clinicians and disciplines, such as speech-language pathologists, occupational therapists, behavior specialists, as well as educators, are often warranted as these areas overlap and influence one another.



During this process it is important for caregivers to describe their child's strengths and express their concerns and to also provide input to the team on what they see or hear. What parents see at home may vary widely from what the assessors experience in an evaluation.

As speech and language assessment will often include both formal and informal measures. Formal assessments are standardized measures that have specific rules indicating how they are given, to ensure they are given the same way each time. Formal assessments compare results to a large same age sample and provide standard scores. Clinicians need to choose assessment tools that are relevant to the areas being assessed and ensure there is an adequate number of items at the appropriate difficulty level. This can be challenging as many assessments that focus on early language skills are meant for younger ages; therefore, these assessments may provide developmental information, but will not provide valid scores for older ages. This might mean that clinicians use tools that don't provide standard scores, such as checklists of different language skills, or some of the informal measures described below. Vocabulary ability, both receptive and expressive, can often be assessed with the standardized measurement tools. By combining these direct assessments with a caregiver report measure (e.g., the communication composite from the Vineland Adaptive Behavior Scales-Third Edition or the Children's Communication Checklist-Second Edition) a clinician can obtain a more complete understanding of an individual's language ability.

Informal assessment tools often include caregiver interviews, observations, and language samples to get a more robust picture of how the individual is communicating. Furthermore, progress monitoring, an integral component of therapy, allows the clinician to indicate the individual's response to intervention and to determine strengths and areas of need.

Observations can vary depending on the individual's age and interests. Observations are useful to understand how the child interacts with others, including any behaviors, speech, and language being used. For younger children, play observations are useful to better understand play and gesture development as well as communication abilities.

Language sampling is an important component of a comprehensive speech and language assessment and is designed to get an understanding of the individual's language use in naturally occurring contexts. This measure has been shown to be an effective tool for assessment to determine utterance length, expressive grammar, and many aspects of pragmatic language.

Assessment results indicate the present levels of performance, and this should drive the focus of intervention. There is no “one size fits all” approach, but are instead, general guidelines to be considered on an individual basis.

Intervention

Speech and language intervention is often warranted for individuals with FXS throughout their life. In the U.S., early childhood, birth to three services are provided through Early Intervention which is provided by the individual states. Once a child turns three, service provision shifts to the public schools, where it remains until the age of 22. After aging out of the school system, therapy provision can be challenging and varies widely based on the location of the individual. The focus of intervention will shift as the individual develops and the needs/contexts for communication change. Each person’s individual speech and language needs must be considered and plans need to be developed based on these individual needs.

Early Childhood

A proactive approach including early intervention and caregiver coaching will be useful for many families. Caregivers play an essential role in the early intervention process and are a critical member of the Individualized Family Service Plan (IFSP) team. Training caregivers in routine-based interventions can be useful at this stage so strategies can be implemented throughout the day and across activities (e.g., mealtime, bath time, teeth brushing, bedtime). Using consistent language during common events and naming items as they appear or are used throughout the day, allows for children to learn the language associated with the task and can help them match meaning to the words. As children become more familiar with the words being used, caregivers can let them take a “turn” in saying what the next step is. An example of this could be during a routine such as tooth brushing, a possible series of comments is shown below:

- “Time to brush teeth.”
- ****pause****
- “Put on the toothpaste.”
- ****pause****
- “Squeeze, squeeze, squeeze.”
- ****pause****
- “Brush, brush, brush.”



Caregiver responsivity should be a focus at this young age and throughout the lifespan as it has been linked to better language outcomes. This can include teaching caregivers to recognize communication attempts and model more advanced forms of language (e.g., when a child reaches for a desired object, model a sign or use a single word). Consistently responding to the individual's communicative attempts can, in general, improve communication and decrease frustration.

Individuals in the prelinguistic phase (not yet using words) need interventions that can build skills that are precursors to spoken language. This will include gesture and play development, joint attention (purposeful coordinated attention between two people), and communicative intent.

- Singing your favorite song in an exaggerated tone boosts young children's attention and language development. These songs can also be paired with gestures to increase motor imitation (e.g., "Head, Shoulders, Knees, and Toes")

Caregivers can work closely with their SLP to learn language facilitation techniques that can be implemented into daily routines. Language facilitation may include parallel talk, talking about what the child is doing, or self-talk, or the adult talking about what they are doing. Arranging the environment to set up communication temptations (e.g., having items out of reach or preferred items that are difficult to operate) can also help to facilitate language as the individual needs to communicate to get what they want. When individuals begin to use spoken language, implementing strategies such as expansions (expanding what a child says by one to two words) are effective in continuing language development. Repetition and exposure to language in a variety of settings are important for learning and carryover of skills.

Augmentative and alternative communication (AAC) will likely be beneficial for both receptive and expressive communication, especially in individuals with limited to no spoken language. AAC can be implemented in the early childhood years through adulthood. AAC includes a variety of modalities such as sign language, picture-based systems, and speech-generating devices. The use of pictures or symbols can be useful for receptive language as the message is consistent and the visual remains, which can aid in processing the information. For expressive language, AAC can be a useful tool as it provides an immediate means for communication across activities and parents and teachers. There is strong evidence that using AAC helps promote language development; families do not need to worry that it will delay the use of spoken language.

Shared interactive book reading is another powerful tool that can begin in early childhood and continue into the school age years and beyond. Shared book reading provides opportunities to improve receptive and expressive language outcomes, as well as print awareness. Caregivers are encouraged to have fun when sharing books as this will help to keep the child engaged. Using different voices to portray characters and varying the inflection when reading is engaging and also models the use of language. Selecting books that are developmentally appropriate and motivating for the child will help to promote engagement.

For more information about intervention during early childhood, see: [Early Childhood Developmental and Educational Guidelines | NFXF \(fragilex.org\)](https://www.fragilex.org/early-childhood-developmental-and-educational-guidelines)

School Age

In the school age years, the focus of intervention moves from the home to the school. While caregivers still play an extremely important role, they may not be as directly involved in service provision. SLP school interventions may include direct service delivery models such as push-in (services in the classroom) or pull-out services; either of these service delivery models may be in a group or individual format. The amount and type of service delivery will be based on the IEP goals that are developed and agreed upon by the team. Sensory and behavioral needs and their relation to speech, language, and pragmatics will continue to need to be addressed throughout the school years. Caregivers are strongly encouraged to seek collaboration as a part of the IEP to ensure they communicate with team members on a regular basis. Documenting collaborative services on the IEP is also recommended. In this way, the team is making the time and prioritizing collaboration, which will help with carryover of skills across settings and consistency amongst team members.

Intervention in the school age years often continues to focus on receptive/expressive language development as well as speaking in social situations. The use of visuals, such as adding visual labels and using visual daily/activity schedules is often helpful for both receptive and expressive language. Visual schedules can be designed in a variety of ways and need to be individualized based on the individual's strengths and needs. The types of symbols used (e.g., real pictures, icons), number of symbols, and the layout of the symbols are considerations for the team when developing schedules.

Repetitive questioning can be addressed with several approaches, including by asking the question back to the person with FXS, by limiting the number of times the question can be asked and receive an answer, and by giving the person a visual to look at to answer their own question. Visual schedules provide predictability and can help to decrease anxiety and perseveration (repetitive questioning or repetitive speech). Daily schedules often are useful to help with transitions during the day. Activity schedules are designed to provide guidance on the steps needed to complete an activity. This may be for routine activities of daily living such as brushing teeth, washing hands, getting dressed, but this strategy is useful for other non-routine activities as well. It is suggested that the activity schedules be posted in the place where they will be used (e.g., the brushing teeth schedule posted above the bathroom sink).

As during early childhood, interactive book reading continues to be a strategy that can be used both at school and at home. A variety of speech, language, and literacy skills can be targeted through the use of shared book reading, which can be individualized based on the individual's developmental level and interests. Children often like to read the same story numerous times, and this is encouraged as it can build sequencing and narrative skills.

For more information about intervention during the elementary school years, see:

[Fragile X Syndrome Elementary School Recommendations](#)

For more information about intervention during the middle and high school years, see:

[Educational Guidelines for Fragile X Syndrome Middle School and High School | NFXF](#)

For more information about IEPs and related services, see:

[OT, SLP, AT & IEP ... Making Sense of Special Education Alphabet Soup \(fragilex.org\)](#)
[and Preparing for Your Child's Individualized Education Program \(IEP\) \(fragilex.org\)](#)

Post Secondary - Adulthood

As individuals transition into adulthood, the focus may shift from receptive and expressive language skills to how to best accommodate communication needs. This includes considering what individuals need in all their various settings: vocational, recreational, and home. Growing evidence indicates that supporting social skills and language is strongly linked to increased independence. As in previous years, it is important to consider the role that sensory and behavioral needs play in daily functioning.

Accommodations that are frequently useful can be similar to what was used at earlier ages, including low technology options such as printed visual schedules that assist in daily routines and transitions. Posting these in the places where they are used (e.g., the steps for sorting recyclables posted by the appropriate bins) can help maximize their usefulness. In addition to low technology options, exploring the use of mainstream high tech assistive technologies may also be helpful. For example, applications for a phone or tablet or video modeling for daily activities may be useful.

It is important to consider the need of continuing speech-language services in adulthood. As demands change, the support of a professional can assist with those different needs. This can include helping assess the communication demands of new settings as well as helping individuals develop the skills to meet those demands. SLPs can also help determine what accommodations will make individuals successful as they exit the school system and find their place in their communities.

Conclusion

Supporting individuals with FXS with their speech and language development is something that should be considered across the lifespan. Many of the strategies (e.g., shared book reading, expansion of phrases) are ones that can be used regardless of age and are useful across a wide range of communication ability. Caregivers and professionals should not hesitate to “borrow” from other ages to find appropriate assessment and intervention tools. The most important consideration is what the individual needs at that time, and choices should be focused on what is developmentally appropriate.

Another common theme is that a variety of factors impact communicative ability. These can include the setting in which communication occurs, the sensory regulation of the individual in that moment, the demands of the specific task, and so on. To be successful, it is crucial that all parties communicate, including teachers, therapists, caregivers, employers, residential workers, family members, etc. Supporting interaction and communication among the previously mentioned collaborators will ensure the highest possible communication outcomes.



Author Note:

This guideline was authored by Anne Hoffmann, PhD, CCC-SLP and Kerrie Lemons Chitwood, PhD, CCC-SLP, and was reviewed and edited by members Fragile X Clinical & Research Consortium. It has been approved by and represents the current consensus of the members of the consortium.

The Fragile X Clinical & Research Consortium was founded in 2006 and exists to improve the delivery of clinical services to families impacted by any Fragile X-associated Condition, and to develop a research infrastructure for advancing the development and implementation of new and improved treatments. Please contact the National Fragile X Foundation for more information at (800) 688-8765 or www.fragilex.org.