

Case Study: Fragile X

Part 1: Getting to Know Ethan

Ethan and His Family

Ethan is a 5-year-old boy preparing to transition from his inclusive preschool program to a public kindergarten classroom. He lives in a suburban neighborhood in North Carolina with his mother, Tasha (32), father, Brian (34), and older sister, Lily (8). Tasha works as a librarian, and Brian is an office manager for a regional company.

Ethan was diagnosed with Fragile X Syndrome at 18 months following concerns about delayed speech, sensory sensitivities, and repetitive behaviors. Genetic testing confirmed a full mutation of the FMR1 gene. Since diagnosis, Ethan has received early intervention services through IDEA Part C and transitioned to preschool special education services at age three.

Ethan is a joyful and energetic child who loves music, water play, and building with blocks. He has a strong memory for routines and enjoys watching videos of familiar songs. He is sensitive to loud noises and crowded environments, often covering his ears or retreating to quiet spaces. Ethan communicates using short phrases and gestures, and he benefits from visual supports and predictable routines.

Medical and Developmental History

Ethan was diagnosed with Fragile X Syndrome following genetic testing that confirmed a full mutation of the FMR1 gene. From an early age, his developmental profile reflected many of the hallmark features of the condition. His expressive language was notably delayed, while he could understand simple instructions and recognize familiar words, he struggled to form phrases and often relied on gestures or echolalia to communicate.

Sensory sensitivities were also evident. Ethan reacted strongly to loud noises, often covering his ears or retreating to quiet corners of the classroom. He was particularly sensitive to touch, resisting certain textures and becoming overwhelmed during activities like finger painting or group play. These sensitivities contributed to challenges with transitions and changes in routine, which could trigger anxiety or behavioral outbursts.

Repetitive behaviors such as hand flapping and scripting were part of Ethan's daily rhythm, especially during moments of excitement or stress. Despite these challenges, Ethan showed emerging social interest. He watched his peers closely and occasionally joined in play, though his interactions were brief and often required adult facilitation.

To support his development, Ethan receives speech-language therapy twice a week, focusing on expanding his expressive vocabulary and improving conversational turn-taking. He also participates in occupational therapy, which targets sensory integration and fine motor skills,

helping him tolerate classroom materials and build independence in tasks like drawing and self-care. Additionally, behavioral support is provided to help Ethan regulate his emotions and navigate social situations more effectively.

His Individualized Education Program (IEP) includes goals that reflect these priorities: increasing expressive language to 4–5 word phrases, improving self-regulation during transitions, and expanding peer interactions through structured play and teacher-facilitated engagement.

Discussion Prompts:

- What strengths and interests can be leveraged to support Ethan’s learning and engagement in kindergarten?
- How might Ethan’s sensory profile influence his classroom participation?
- What considerations should be made when planning transitions between preschool and kindergarten for children with FXS?

Part 2: Screening and Assessment

As part of Ethan’s transition planning, his preschool team conducted a comprehensive evaluation to assess his readiness for kindergarten. The team included a developmental pediatrician, speech-language pathologist, occupational therapist, special educator, and school psychologist. Assessments included the Vineland Adaptive Behavior Scales, Preschool Language Scale (PLS-5), and classroom-based observations.

Ethan demonstrated strengths in receptive language and visual memory. He followed multi-step directions when paired with visual cues and was able to identify familiar objects and people. His expressive language was limited to short phrases, and he often relied on echolalia or scripted speech. The speech-language pathologist recommended continued use of visual supports and modeling to expand his spontaneous language.

The occupational therapist noted challenges with fine motor coordination, including difficulty with grasping writing tools and manipulating small objects. Ethan also showed signs of sensory defensiveness, particularly with textures and unexpected sounds. Recommendations included sensory breaks, noise-canceling headphones, and a quiet corner in the classroom.

Behavioral observations revealed that Ethan struggled with transitions and group activities. He became anxious when routines changed and required adult support to re-engage. The team emphasized the importance of a structured environment with clear expectations and consistent routines.

Discussion Prompts:

- What assessment tools are most appropriate for evaluating children with FXS during transition planning?
- How can interdisciplinary teams collaborate to create meaningful and functional goals for children with FXS?
- What role does family input play in shaping transition plans and classroom supports?

Part 3: Transition to Kindergarten

Ethan's transition to kindergarten was thoughtfully and collaboratively planned by his preschool team, the receiving school staff, and his family. Over the course of several meetings, the team reviewed Ethan's developmental progress, discussed placement options, and designed a transition plan that emphasized continuity, predictability, and individualized support.

To help Ethan prepare for the change, he visited his future kindergarten classroom multiple times, accompanied by a familiar adult. These visits allowed him to explore the space, meet his new teacher, and practice daily routines in a low-pressure setting. In addition, the team created a personalized photo book featuring images of Ethan's new classroom, teacher, and schedule. This visual tool became part of his bedtime routine and helped him build familiarity and comfort with the upcoming transition.

Social stories were also introduced to explain what kindergarten would be like, including new activities, classroom rules, and expectations. These stories were read regularly at home and school to reinforce understanding and reduce anxiety. Recognizing Ethan's need for peer connection and support, the team arranged for him to be paired with a peer buddy who could assist him during group activities and transitions.

To ensure that Ethan's new teachers were well-prepared, the preschool team provided training on Fragile X Syndrome. This included information about sensory sensitivities, communication strategies, and behavioral supports tailored to Ethan's needs. The receiving staff expressed appreciation for the guidance and felt more confident in their ability to support him.

Ethan's Individualized Education Program (IEP) was updated to reflect his kindergarten goals. These included using four- to five-word phrases to express needs and ideas, participating in small group activities with adult support, and tolerating sensory input through the use of coping strategies such as sensory breaks and quiet spaces.

Tasha and Brian expressed gratitude for the team's thoughtful planning and felt reassured by the supports in place. Ethan began kindergarten with excitement and has gradually adjusted to the new environment. His teacher reports that he enjoys music time, responds well to visual

schedules, and is beginning to engage with peers during structured play. The transition, while carefully scaffolded, has opened new opportunities for Ethan to grow socially, emotionally, and academically.

Discussion Prompts:

- What strategies can educators use to support successful transitions for children with FXS?
- How can classroom environments be adapted to support sensory regulation and communication?
- What role do families play in shaping transition plans and supporting continuity across settings?