

The Fruits of a Community's Long Labor

This column usually focuses on behavioral issues and then offers suggestions or remedies based on research and experience. This issue, however, will divert slightly from that format. Instead, we will celebrate the fruits of many people's labors by highlighting successes from some very special people who have fragile X syndrome (FXS). As I reflect on these successes and the history of my involvement with these individuals and those who have supported them, I am filled with excitement and enthusiasm. I am in awe of the energy, dedication and devotion they have shown through the years.

When I think back on my own professional experiences, there was a time when we were working hard simply to identify those affected by FXS and in some way quantify what we were seeing in them as a group. We were occupied with defining phenotypes and developing intervention strategies that were effective. This was important work, and it established the foundation for further study of the condition and its clinical underpinnings. But it was not nearly as exciting as the present. The hard work done by many back then has resulted in a number of wonderful stories that I want to share in this column.

Two years ago a couple brought their 8-year-old son with FXS to me to evaluate. They had read about effective educational strategies in the literature and wanted to access those strategies for their son. They knew he was capable, but he had not been able to learn how to read. They sought out intervention strategies to increase his probability of success. The evaluation enabled them to advocate for certain supports and teaching methods in his school. As their efforts grew, the district found a gifted teacher for their son and afforded her telephone consultation with me to develop additional interventions as needed. The young man is now reading and spelling better than anyone had anticipated. He is included in a general education classroom and is learning to make friends-all because two parents and a teacher joined together to accomplish great things!

Another couple worked diligently with their parents to establish a trust to support independent living for their adult son with FXS. His mother found a home in a middle class neighborhood in the Midwest. She worked tirelessly to convince the neighbors that the four boys moving into this house would be good citizens and even better neighbors. She contacted a number of businesses that donated materials for the remodel as well as gym equipment and furnishings. When their son turned 30 they moved him into the house with three other young men with similar challenges, and the rest is history-a beautiful history of sheer determination!

Across the country on the west coast, another family handed their young son with FXS drumsticks and a drum set. His father (a professional drummer) provided him with opportunities to drum with him and learn music. As this shy young man matured, he

became more and more accomplished, eventually joining the marching band in his high school-capped by performing a solo concert. All of this was accomplished because his parents refused to believe he was incapable of achieving his goal to be a drummer and play in the band.

Another mother in the south contacted a district's director of special education and requested that her son's teaching staff receive training on best practices with those affected by FXS. She had faith that her son could learn more adaptive behavior even though he was struggling with significant self-injurious outbursts. She was convinced that with proper intervention, his behavior would improve and he could be included with typical peers. The director heeded this mother's efforts and contracted for services to develop strategies and train the teaching staff. In addition, the staff was given the opportunity to conference with experts monthly by phone to continue developing interventions that worked to maintain the boy's adaptive behaviors. Currently, his success is continuing as he participates in activities with his typical peers and is thereby further motivated to reduce self-injury.

Four sisters in the Midwest with FXS became motivated to make educational materials for others affected by the condition. They learned to cut and laminate, package and mail out the products. Their efforts have provided materials to hundreds with FXS. Their success was rooted in motivation to help others with their own condition, a foundation of support from their parents, and an overall sense of compassion.

A 40-year-old man in the west affected with FXS always wanted to learn to read. He was very aggressive and violent as a child and adolescent and was never emotionally stable enough to be educated with much success. His mother weathered a long storm of psychiatric placements and hospitalization but she never lost sight of his dream. As he grew older, she sought out private tutoring and for Mother's Day last year received a DVD of her son reading to her. Imagine the impact this beautiful gift had on her-and her son. It was only possible because she refused to believe he was too old to learn and to accept that his potential faded with age.

A father from Germany attended the 2008 International FX Conference in St. Louis and heard about clinical and educational techniques that could change the outcome of those affected by FXS. He decided to take that information back to his country, where he worked for a year organizing an educational conference that reached an astounding 300+ teachers and parents in Germany. His dedication to his son prompted him to bring possibilities to others in his home country so that they too might experience success.

There are many more such stories of families and support workers who have been motivated by these very special people with FXS to push through brick walls and climb mountains supporting the development of their potential. I am humbled to have been among them and to call them colleagues and friends in this remarkable Fragile X community.

Navigating the Road to Inclusion

Including special needs children in general education classes is grounded in special education law. But however sound the theory and purposeful the law, having special needs students successfully included with typical peers often eludes reality.

The momentum to include students with FXS in the general education mainstream grew out of the Individuals with Disabilities Education Act (IDEA). The assertion that children with disabilities had a civil right to attend school in their home school setting grew out of Civil Rights litigation. The emphasis to include students with FXS in general education classrooms has been noted throughout the literature. Perhaps the impetus for this movement comes from the fact that children with FXS have a considerable interest in people—one of the hallmarks of this population is a strong desire to interact socially. This often makes inclusion more viable and increases the success rate.

It is important to remember, however, that levels of affectedness vary from one individual to another, and placement options must include enough flexibility to meet individual needs. There are occasions when inclusion can wind up being restrictive to children with severe needs.

Symons, Clark and Roberts, 2001 studied the classroom engagement of elementary school children with FXS and determined that the engagement was strongly related to the environmental and instructional quality propagated by the teachers and classroom. How the teachers structured and arranged the classroom environment was much more important to student engagement than were specific aspects of the child's Fragile X status, medication use or dual diagnosis. This research clearly defines a number of environmental and instructional factors that are important when choosing a general education classroom.

Successful inclusion cannot be accomplished without a systematic, sequential process. Just placing the student with FXS in a general education classroom with a para-professional close by does not necessarily constitute success. As a matter of fact, students with FXS are often excluded because they are unsuccessful in their included environment. The criteria to assess success in the classroom often rests on the student rather than the education team. Without appropriate supports, students with FXS will fail to access certain aspects of the school curriculum.

Likewise, the mere placement or proximity to typical peers is insufficient in achieving an appropriate education for students with FXS. In order to design effective outcomes, the parents and school team need to define the purpose of the inclusion. In other words, there needs to be a reason for the student to be included. Otherwise, the time spent in the general education classroom may reduce the time needed for other services that are often equally or more important to the child's individual educational

needs. The chart that follows defines a number of the necessary supports given specific targeted outcomes associated with the inclusion of an individual with FXS.

Outcome	Necessary Supports
Social	<ul style="list-style-type: none"> • Viable peer group • Social facilitator • Flexible setting • Opportunities for natural contexts
Behavioral	<ul style="list-style-type: none"> • Appropriate role models • Structured and predictable schedule • Cooperative learning opportunities • Organized classroom • Professionals familiar with FX behavioral interventions
Academic	<ul style="list-style-type: none"> • Specialized instruction specific to FX learning style • High interest content • Enrichment opportunities • Emphasis on visual presentation • Opportunities for priming or pre-teaching • Collaboration between Sped and general education staff
Vocational/Prevocational	<ul style="list-style-type: none"> • Viable work models • Positive work environments • Flexible breaks • Consistent staff

After the desired outcome is established, the team needs to design certain strategies to assist the student to be successful in the general education classroom. If the student outcome aims for participation in the general education curriculum, it is often important to prime or pre-teach certain concepts or lessons beforehand. Collaboration between the special education and general education staff is critical to accomplish this level of coordination. When effectively done, this priming will help link individual instruction into larger group activities. This can also be effective when the desired outcome is to increase social interactions with typical peers.

The level of prompting and facilitation should be determined based on the need of the individual. It is always best to use the least intrusive level of facilitation as possible. The student's behavior and level of participation will dictate the need for more or less teacher or para-professional support. Because children with FXS respond better to visual input, effective prompting can often include visual schedules or icons. This enables the student to participate with less dependency on the attending adult. In addition, it is best to have the classroom teacher responsible for redirection and facilitation because that is most like what is done for typical peers. Classroom rules and behavioral expectations should be the same for students with FXS unless there is a

Behavior Intervention Plan (BIP) in place, which usually defines certain behavioral characteristics to be a manifestation of the disability. In those cases, special considerations are required.

Transitions can be difficult for students with FXS, and they are very common in the general education setting. Providing a predictable schedule with visual supports is important. If the student is aware of the change ahead of time, the element of surprise is eliminated. In addition to providing a visual schedule and other structured strategies, teachers can use using a less direct approach such as side dialoguing among the adults in the classroom to alert the student to pending changes. (“So Ms. Johnson, it looks like we’ll be ready to dismiss the students for lunch in five minutes.”)

It is often prudent to afford the student with FXS an opportunity to carry equipment from the gym back to the classroom or assign him or her some particular job to complete as part of the transition time. This may help reduce the anxiety associated with the change.

Because students with FXS learn incidentally, including them to absorb information in this manner is significant. It is also important, however, to be sure the student is in fact learning the information. The para-professional assigned to the student should take notes on the subject matter discussed in the general education classroom and then ask the student questions about the content later in the day.

Recently, after observing several special needs students in their included environments, I was struck by the poorly planned execution of their inclusion. Each had a para-professional in close proximity, tending to the student as if the para-professionals were teaching a class within a class. The tutorial relationship between the student and para-professional precluded those with FXS from being able to participate in the natural interaction within the general education class. In one setting, the students were grouped in sets of four and the students with FXS sat at their own table with two para-professionals and no general education peers. The obvious question was: How does this qualify as inclusion? Inclusion is *not* “making students with FXS look typical;” it is instead helping them bring their own unique qualities into the general education classroom, with full access and acceptance, to the benefit of all.

Hopefully, with good planning and emphasis on desired outcomes, the intent of IDEA will continue to bloom into positive and fulfilling experiences for students with FXS—and for those with whom they share a learning environment.