



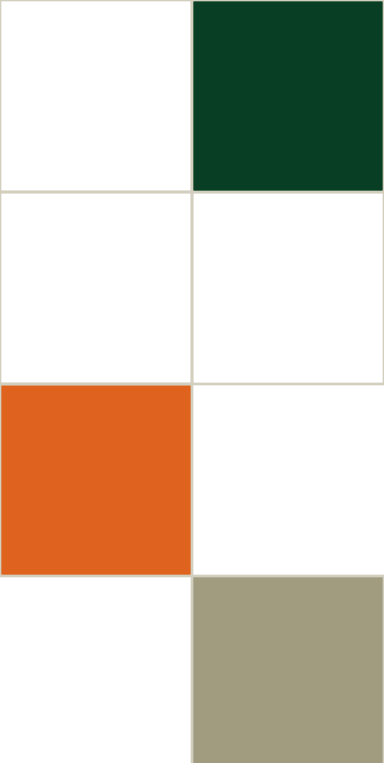
An Examination of IEPs

...and What They Tell Us About Educators' Knowledge of FXS

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Kaitlin Young, Medical Student
Richa Panara, Medical Student



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A project to examine individual educational plans

- An outgrowth of the mission of the South Florida Fragile X Clinic to improve outcomes for children with FXS
- What should be included in IEPs (brief review of effective learning strategies for individuals with FXS)
- What did we find in the IEPs
- Why our findings are important
- How we can increase educators knowledge of FXS

The South Florida Fragile X Clinic (SFFXC): *Who We Are*

- Daniel Armstrong, Ph.D. - Director, Mailman Center for Child Development
- Deborah Barbouth, M.D., F.A.A.P., F.A.C.M.G. - Medical Director/Clinical and Biochemical Geneticist
- Eugene Hershoren, M.D., F.A.A.P. - Developmental and Behavioral Pediatrician
- Monica Dowling, Ph.D. - Child Psychologist
- Robert Fifer, Ph.D. - Audiologist
- Claudia Coron, M.S. - Speech/Language Pathologist
- Michelle Schladant, Ph.D., M.S., Ed. - Assistive Technology and Educational Specialist
- Myriam J. Polo, M.S. OTR/L - Occupational Therapist
- Mary Joeth Miranda, M.S.W. - Social Worker
- Kaitlin Young, M.D. Candidate – Volunteer
- Richa Panara, M.D. Candidate – Volunteer



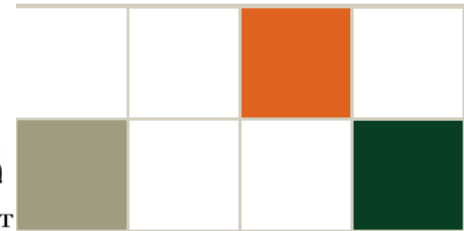
The South Florida Fragile X Clinic (SFFXC) is a part of the Fragile X Clinical & Research Consortium (FXCRC), a group of clinics and research facilities that are committed to aiding those affected by Fragile X syndrome (FXS)



South Florida Fragile X Clinic: *What We Do*

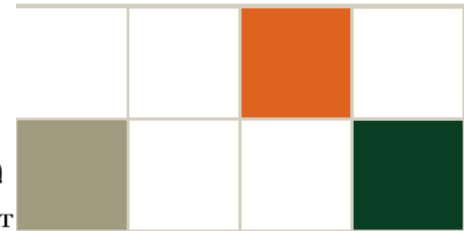
A multi-disciplinary team of medical professionals; we

- Provide genetic counseling
- Diagnose and treat developmental and behavioral issues
- Introduce patients and their families to Assistive Technology (AT)
- Review IEPs and inform educators about strategies that have been proven effective for individuals with Fragile X
- Introduce patients to opportunities for participation in clinical research
- Welcome families from different backgrounds with our bilingual staff



SFFXC's strategies for improving the education of our patients

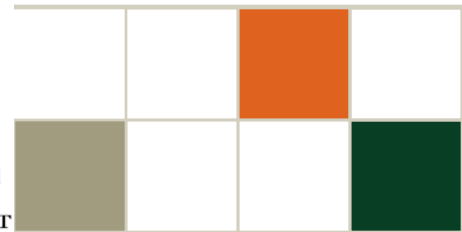
- Conduct comprehensive psycho-educational evaluations
- Produce individualized reports for educators
- Discuss results and recommendations with parents
- Provide CD of recorded parent feedback session for sharing
- Conduct school visits
- Review videos of children/adolescents at school or in therapy
- Hold informative conferences for educational and medical professionals (at least one per year is devoted to FX)



What We Know about FXS and Education... typical recommendations

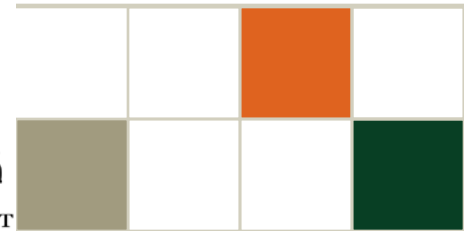
Implementation of an appropriate curriculum:

- Use of manipulatives, concrete objects and real world examples that tie concepts to basic life skills.
- Use of simple sentence structure and familiar vocabulary as well as instructional routines
- Redundancy and repetition in teaching new concepts
- Emphasis on simultaneous not sequential processes
- Use of cloze or fill in the blank procedures, working from whole to part approaches and backward chaining
- Thematic units so that new information is interrelated conceptually



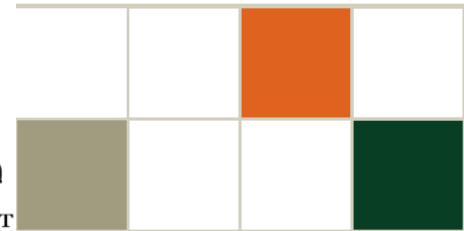
Use of evidence-based educational practices (programs and methods) for individuals with developmental disabilities

- *Teaching Reading to Children with Downs Syndrome: a Guide for Parents and Teachers* (Woodbine House)
- *Teaching Math to People with Down syndrome and Other Hands-On Learners* (Woodbine House)
- Balanced literacy (Four Blocks model)
- Picture-assisted reading and writing strategies
- Games that focus on recognizing words or word meanings
- Predictable books
- Meaningful tasks and outcomes
- High interest materials



Assistive technology (no tech, low tech, high tech) for behavior support, participation and access to curricular content

- Visual systems (color coding, first-then, token boards)
- Visual schedules (daily, task, mini)
- Calculator/coinulator
- Digital/e-books
- Topic boards with words and pictures
- Picture cue cards
- Audio/video coaching
- Templates for writing
- Whiteboards
- Social scripts
- Communication device



An emphasis on increasing social skills through

- Participation in a formal and informal social skills groups/experiences
 - Lunch bunch, after school clubs, peer buddy, peer network
 - Videomodeling
- Recreational opportunities in the community
 - Summer camps
 - Outdoor activities such as Horses for the Handicapped
- Adult interaction and play
 - Games can be simply fun or more academically oriented (e.g., word bingo or treasure hunts in which child hunts for pictured items or words on cards).

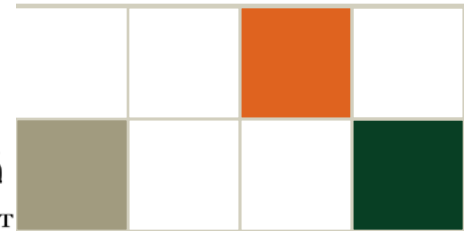


Implementation of pre-vocational/vocational training at school and at home

- Teach work-related and real life skills including cooking, laundry, gardening, etc.

Ancillary therapies (SP, OT), making use of visual supports, including topic boards, social scripts, picture cue cards, etc.

Parent/staff training to increase consistency across all settings, environmental structure and routines, and positive adult-child interactions.



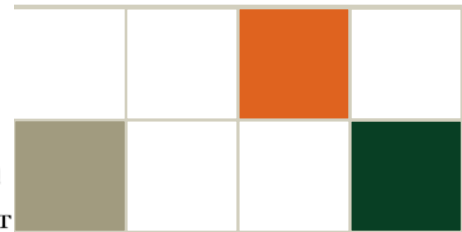
Increase individual's ability to provide basic information about him/herself and to acquire information about physical development, including sex education

- Target essential information and stress meaningful and functional activities
- Create an All About Me book
- Use visuals and charts to provide information and reminders of “rules” about boundaries, touching, etc.
- *Sexuality Across the Lifespan* (FL DD Council),
Teaching Children with Down Syndrome about Their Bodies, Boundaries and Sexuality (Woodbine House)



How our FX patients are being educated...

- Reviewed chart of 40 patients ages 3-22 (full mutation)
 - 73% had IEP
 - Eligibility for services:
 - 52% Language Impaired
 - 38% Intellectual Disability
 - 31% Autism Spectrum
 - 14% Developmental Delay
 - 7% Specific Learning Dis
 - 3% Emotional-Behavioral
 - 4% Hearing Impaired
- Of those with an IEP:
 - 17% mention FX
 - 29% indicate AT needed
 - 43% identify behavior needs
 - 38% recommend OT
 - 34% suggest S/L Tx
 - 7% discuss the use of ABA



Strategies included on IEPs

- Visual schedule (%)
- Work routines (%)
- Preferential seating (%)
- Token economy (%)
- Visual approach for reading (%)
- Math manipulatives (%)
- Math software (%)
- Backward chaining (%)
- Scheduled breaks (%)
- High interest activities (%)
- Visual cues/supports (%)
- Checklists (%)
- Social scripts (%)
- Calculator (%)
- Alternatives to writing (%)
- Recorded books (%)
- Teaching triads (%)
- Transitional object (%)
- Communication aid (%)



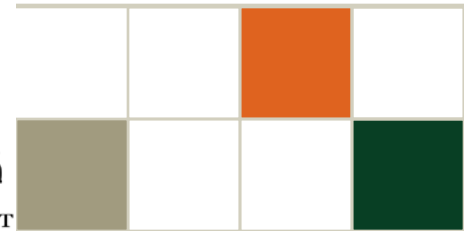
Example of typical IEP (grade 1, 40% ESE, ASD, FXS noted)

- Curriculum goals:
 - Sound matching
 - Sequencing numbers
 - Write name independently
 - Recognizing colors
- Social/Emotional goals:
 - Attend, take turns with verbal
 - Refrain from getting loud, leaving when upset
 - Calm self with verbal reminder
- Communication goals:
 - Use 3-5 word phrases
 - Answer 5 personal questions
- Independence goals:
 - Comply with request to wait
 - Ask to use bathroom
- Accommodations/supports:
 - Manipulatives
 - Opportunities for movement
 - Alert before transition
 - Directions in small steps
 - Ignore disruptive behavior
 - Multisensory presentation
 - + reinforcement following rules
 - Daily social skills instruction
 - Adapted PE
 - Visual schedule



Why it matters...

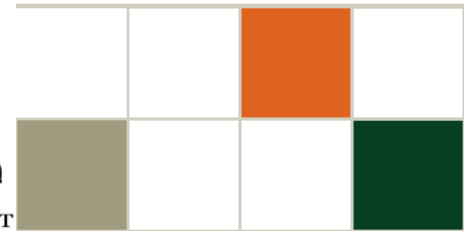
- A study by Finucane et al. (2013) found that special education and ABA professionals have much to learn about FXS, most
 - **Did not have basic knowledge about FXS**
 - **Did not understand the importance of the FXS etiology with regards to behavior and learning**
 - **Did not utilize resources specific to FXS**
- When the educational plan does not include an understanding of the behavioral phenotype, but rather requires behavior that is incompatible with what is possible, the intervention will fail.
- When the intervention fails, the situation may needlessly deteriorate.
- If professionals lack rudimentary knowledge of FXS, how can they develop, implement and evaluate interventions...



FXS as a model for education in Neurodevelopmental Disorders (NDDs)

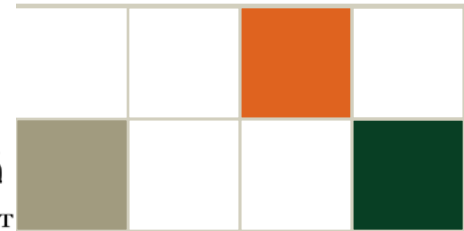
2012 study in *The School Psychologist*, McCary et al. described the importance of establishing a diagnosis for children with NDDs:

- Specific etiology can direct treatment
- Early determination of diagnosis can:
 - Provide the opportunity for early intervention with therapies
 - Educate families regarding prognostic information
 - Decrease treatment costs by up to 65%
 - Allow families to connect with support groups and community resources
 - Assist parents with future family planning



Where do we go from here?

- Participate remotely in IEP meetings via skype or teleconferencing
- Visit schools and provide f/u
- Create partnerships with schools to hold educational training sessions
- Provide extensive documentation about specific strengths and weakness of individuals with FXS
- Refer to websites offering video training (AbleNet University)
- Collaborate with community agencies (CARD)
- Include training for teachers and parents in IEP
- Provide hands on training in our AT demonstration lab
- Continue formal conferences
- Focus on the critical transition IEPs: kindergarten entrance, MS, HS
- Expand website and online courses



Resources

- NFXF Adolescent and Adult Project
- NFXF Educators Guide
- NFXF *Quarterly* (AT and the IEP)
- FX Clinical & Research Consortium on Clinical Practices (consensus guidelines)
- www.Do2Learn.com
- www.aacintervention.com
- <http://praacticalaac.org>
- *Teaching Exceptional Children* (Council for Exceptional Children)
- www.ablenetinc.com/au AbleNet University (free webinars)



Thank you!

- To the parents and children who have participated in our projects, making this presentation possible
- To the clinic staff for their support and patience
- To our students



Questions



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References and Further Information

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