

# Transitions: From Infancy through the School Years and Beyond

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# Newly diagnosed, now what?

- Take a deep breath
- Cry/Grieve
- Create a support network(spouse, family, friend, NFXF, local CSN group, Facebook, local SpED PTA, local groups, ARC)
- Top 10 List of What to do for the newly diagnosed :

[www.fragilex.org/newly-diagnosed/top-10-things-to-do-after-your-child-is-diagnosed-with-fxs/](http://www.fragilex.org/newly-diagnosed/top-10-things-to-do-after-your-child-is-diagnosed-with-fxs/)

NFXF Community Support Network(CSN) Map



[www.fragilex.org/community/community-support-network/](http://www.fragilex.org/community/community-support-network/)

# What's next?

- [www.thearc.org](http://www.thearc.org)
- Individual State division for disabilities (DHS, MDCH, DDD)
- [www.Wrightslaw.com](http://www.Wrightslaw.com)
- Familiarize yourself with “terminology”
- [www.frcnca.org/glossary-of-terms/](http://www.frcnca.org/glossary-of-terms/)
- Advocate: self, parent or professional
- CSRA, Equip for Equality



# Birth – 3 years of age

- Use your resources to educate, prepare and understand your rights
- AMAZING step by step of what to expect: [www.fragilex.org/treatment-intervention/education/birth-to-three-years-of-age/](http://www.fragilex.org/treatment-intervention/education/birth-to-three-years-of-age/)
- Terminology: Early Intervention, Service Coordinator, IFSP, Evaluation, Present Level of Performance, Goals, Services, Respite, SLP, DT, OT, PT
- Support: Bring someone to meetings, DOES NOT have to be a professional
- \*\*\*A parent can refer his or her child for an evaluation. It **DOES NOT** need to be completed by a physician or other professional

# Birth – 3 years of age -Continued

## **Where will services be provided?**

- In the child's "natural" environment (e.g., home, park, community)
- If it is not in the natural environment, providers must state why it cannot be completed there

## **Can services (like SLP and OT) be provided together?**

- Yes, they can and may be more successful
- May be difficult to coordinate, but might be incredibly beneficial

## **Were your rights explained, and were you provided with a copy?**

- If Yes is not the answer, then insist this happens before you move forward



## **How long will services be provided in the natural environment?**

- Until the day before the child's 3<sup>rd</sup> birthday

## **When should I expect the transition process to begin?**

- No less than 90 days prior to the child's birthday
- The next phase of services will be managed by the local public school district



**KEEP CALM  
AND  
TRANSITION**

[WWW.FRAGILEX.ORG](http://WWW.FRAGILEX.ORG)

# Preparing for Early Childhood Age 3-5



- Networking with other parents in your school district
- Speak to your Service Coordinator about available options
- Visit all available options (you are your child's best advocate)
- Prepare for your transition meeting/IEP
- Write your parent input statement and bring with you to mtg.

# Early Childhood 3-5 Continued

- Terminology: Least Restrictive Environment, IEP, Accommodations, Inclusion, Most Appropriate, Special Considerations, Resource, Instructional, AT, BIP, FBA, Adapted
- Bring a support person and treats, too
- For continuum of services, your child may start at an odd time based on their birthday





# Tips and tricks to make this transition successful

- Social Story
  - Set up a visit to school with staff present, but no other students with your child
  - Set up a visit when children are present.
  - <http://www.fragilex.org/treatment-intervention/consensus-on-clinical-practices/>
    - print out appropriate consensus document and provide it for staff
- Positive Student Profile
    - Likes/Things to Avoid
    - Strengths/Challenges
    - Accomplishments
    - Effective Strategies/Techniques
    - Interests
    - Parent vision for child
    - Miscellaneous

# Extended School Year(ESY)

- What is it?
- Where will it be?
- Who will be teaching? Are they special ed. teachers?
- Is there an option to have OT/PT/SLP etc. minutes not in class
- Social Story, meet with staff
- Just because they recommend/offer it, your child is not required to do it



# Transition to Next School Year

- Social Story
- Set up a meeting with the “team” prior to the start of the school year (treats, too!)
- Set up a visit to school with staff present, but no other students
- Appropriate Consensus Document
- Updated Positive Student Profile



# Moving on up!!! Elementary school

- Academics become the main focus
- Network to learn placement options
- Request to visit as many options as possible
- Your “most appropriate” placement may not be in your home school
- Consider an advocate
- “Least restrictive” does not mean “full inclusion”



# IEP for Elementary School

- Request that the new team observe child in current environment
- Request to have the current team and the new team present at the IEP
- Prepare your Parent input statement prior to the meeting
- Ask for a copy of the proposed goals prior to the IEP
- Bring objective support person/advocate and treats
- Accommodations/adaptations **MUST** be included in IEP



# Extended School Year



- Where will it be?
- Who will be teaching? Are they special ed. teachers?
- Who will be provided the additional services (OT, PT, SLP)?
- Will it be with Early Childhood children or elementary children?
- Risk vs. benefit of all the transitions
- Is there an option to have OT/PT/SLP etc. minutes not in class?
- Social Story, meet with staff
- Just because they recommend/offer it, your child is not required to do it
- It is your right to request an IEP, to discuss ESY, school transition, or concerns about previous plan. even if your IEP isn't due

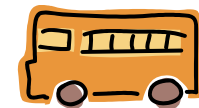
# Elementary here we come!

- Social Story
- Set up a meeting with the “team” prior to the start of the school year (treats too)
- Set up a visit to school with staff present, but no other students
- Appropriate Consensus Document
- Updated Positive Student Profile
- Consider talking with students about Fragile X and your child
- Work with social work to have peer support/lunch bunch/play group
- Repeat this each year with new team



# Moving to Middle School/Junior High

- Another big transition!
- Elementary and middle school team should meet together
- A “continuum of services in the least restrictive environment” is still required by law
- What is “least restrictive” and “most appropriate” for your child? It does not have to mean “full inclusion” in regular education classes
- Middle school and junior high programs often involve changing classes, which can be stressful for young adolescents with fragile X





# Moving to Middle School/Junior High

- Use the summer before the move and between school years, as “extended year” services provide the opportunity for half-day, less crowded, summer school options
- Work with a teacher or “buddy” to navigate the school, and develop visuals, color coded schedules, and memory devices that help the student navigate the new space. Pictures of teachers and rooms can be helpful.
- If the student now has to cope with new requirements (like a hall locker), practice it in the summer



# Moving to Middle School/Junior High

- The IEP is the “contract” between the school and the family and should govern both the goals and the placements
- Once again, families, with school staff, need to decide how much of the day should be spent in classes with regular education peers and how much in resource or special education rooms
- Families also need to include in the IEP the combination of academic, pre-vocational, and life skills areas they think are most appropriate
- “Related services”, such as speech-language and occupational therapy continue to be vital and must be included in the IEP

# Moving to Middle School/Junior High

- Students who may have been included in regular education classrooms throughout elementary school may now require more time in the special education room
- What classes are “most appropriate” for mainstreaming? If music and gym are too loud and overwhelming, perhaps hands-on art classes or computer classes may be better choices
- Junior high is a good time to provide another parent-led session about your child and fragile X syndrome for other children. “Best Buddies” or “Circle of Friends” might be offered to help your child make the transition and have friends in regular education classes.



# Moving on Up: High School

- The move to high school is another major transition for all young adolescents, but may be especially difficult for those with fragile X syndrome
- Middle school and high school staff meet with you when your child is in eighth grade
- The school might be much larger, as it serves students from several several junior highs
- Special education classes may be offered in one wing of a large high school, may be offered in special schools through a special education cooperative, or may be integrated throughout the school
- Again, use extended year to learn about the new space in a lower stress time
- Make visuals of new teachers, classrooms, lunchroom etc.



# High School Options

- The Individuals with Disabilities Education Improvement Act (2004) continues to govern the educational program for adolescents with disabilities
- How much time is appropriate in academic classes, and how much in vocational or life skills? Which related service need to continue?
- There may be basic reading or math classes offered within regular education programs, or there may be classes designed for students with learning disabilities that are appropriate for students with fragile X
- By age 14, individualized transition planning must begin to look at the courses a student should take to prepare for his or her graduation from high school
- Transition services are defined as, “A coordinated set of activities for a student, designed with an outcome-oriented process, which promotes successful movement from school to post school activities”

# High School Options

- By age 16, individualized transition planning must address instruction and any services needed for the student to prepare for life after high school
- A statement of interagency responsibilities or links that will help the student with the transition must be included. See if your school district offers workshops about “Next Steps” for parents
- It is helpful if the high school staff starts to include people from the local rehabilitation agencies or other adult providers in the IEP meetings
- A year before they turn 18 (or 21 in some states), students and parents must be informed of the rights, if any, that may transfer from parent to child. Teaching adolescents to be self-advocates, to the maximum extent of their capabilities, is essential at this age

# High School Options

- Depending upon the adolescent's needs, vocational placements might make up part of the day. Schools should have relationships with stores, senior citizen centers, churches, townships, etc. to provide job skills training.
- Speech pathologists and occupational therapists can provide their services in vocational settings to help with those placements and the requirements of a job site
- Parents need to work with the school to match the “fragile X learning style” with appropriate job sites and skills



# Transition Programs for 18-22 Year Olds

- IDEA requires transitional programs for those with disabilities
- Some schools have students walk through graduation after their four years of high school, receiving a “Certificate of Completion”, but not receive the diploma until completing the transitional program 3 years later
- Transitions Programs should be separate from the high school program to the extent possible
- They should provide more programming in the community
- A transitional apartment might be set up to practice meal planning, shopping, cooking, cleaning, and other activities of daily living
- Exercise might be through a community fitness center or YMCA program, rather than in the school gym





# Transition Programs for 18-22 Year Olds

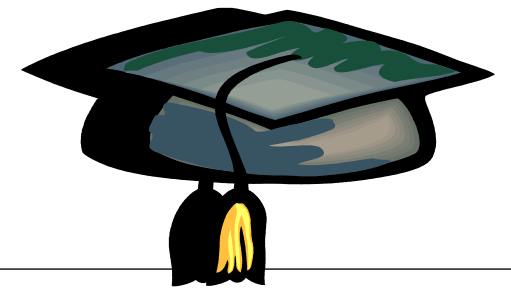
- Sites and goals: For some students, continued job training is a major goal; some schools do a good job of getting students employment based upon their vocational experiences in transitions
- For other students, technical colleges, community colleges, and four year institutions may take the place of or be integrated into transitions programs
- Self-advocacy should continue to be a goal
- Social skills programs can be designed to work on conversational skills and appropriate workplace communication

# Transition Programs for 18-22 Year Olds

- Independence: The use of public transportation can be an important goal. What kind of transportation would be needed to get to certain jobs? Does the young adult require a companion in order to use public transportation? Does the area offer a discounted fare card for those with disabilities? Is there a van service offered? Can the adult walk to work or from the bus/train stop to work and back?
- As young adults gain independence, can they use cell phones, computers, I-PADS? Debit cards?
- There is a need for continued therapy; in a recent survey of patients seen in a number of fragile X clinics around the country, the need for medications rose, as the access to therapy services declined (Kidd, 2013)

# The Move from School to Adult Services

- Or...what to do when the bus stops coming. Perhaps the biggest transition of all!
- IDEA no longer governs the services for adults after the 22<sup>nd</sup> birthday
- The Rehabilitation Act, a federal law, becomes the backbone of job training and rehabilitation services for adults
- A rehabilitation counselor helps determine “eligibility” for and then “availability” of services; young adults need an updated IQ test to qualify for services
- Services may be provided by a variety of community non-profits, if the young adult is not ready for independent employment or college or independent housing



# The Move from School to Adult Services

- Many areas of new knowledge that the family must gain; among those are (we will briefly make a few comments about each):
  - Government support
  - Financial arrangements, special needs trusts, estate planning
  - Levels of guardianship, powers of attorney
  - Types of day programs and funding for them
  - Employment: Independent, supported, sheltered
  - Volunteer work
  - Additional education
  - Living arrangements
  - Community supports: Social/recreational/religious



# The Move from School to Adult Services

- A few thoughts about each of these, with the caveat that some services vary from state to state (and we are not lawyers!)
- Government supports:
  - Most of our children are eligible for SSI, and when we retire, for SSDI (or when they have worked and contributed to Social Security); SSI can be used to pay the parents for rent, food, clothing etc. Expenditures must be documented and sent in regularly
  - Many are eligible for Medicaid, funded by both the federal government and state government, in addition to or instead of private health insurance, for health care, institutional long-term care, and community living services
  - States may pay for respite care and/or other supports

# The Move from School to Adult Services

- Financial arrangements: Special needs trusts
- We are not attorneys, but know that it is important to work with an attorney who specializes in services for families with a family member who has special needs. Ask, “How much of your practice is with special needs trusts?”
- Adults receiving SSI may not have more than \$2000 in savings or checking accounts that are not protected by a trust
- OBRA ‘93 Special Needs Trusts: If money is left in the trust at the time of a person with disability’s death, the trust must “pay back” the amount that has been paid by the state in Medicaid over the years. The trust may be used for expenses other than housing and food (which are to be paid from SSI)
- Special Needs Irrevocable Trusts: No “pay back” is required; money that may be inherited should be willed to a Special Needs trust

# The Move from School to Adult Services

- Levels of guardianship, powers of attorney
- We are not attorneys, but know that it is important to work with an attorney who specializes in services for families with a family member who has special needs
- If you decide to obtain full guardianship, you will need to go through the court system
- Powers of Attorney for both Health and Finance are needed to make decisions about your adult child; the forms need to be on file at your doctor's and dentist's office
- Joint checking account
- Representative payees can manage the funds of a person with disabilities

# The Move from School to Adult Services

- Types of day programs and funding for them
  - Visit a variety of programs in your areas, if more than one is available. What is the age group and independence level of the people in the programs you visit? What are the goals? Can you observe for a day?
  - States vary in their levels of financial support for day programs; some states have long waiting lists for financial support—get on the list as early as possible!
  - Can your adult child work with a job coach? Independently? Does he need a sheltered workshop? Is community volunteer work possible with the program?
  - Does the program provide life skills—cooking, shopping, etc.?
  - Does the program provide opportunities in the community?
  - What kinds of transportation are available for day programs and jobs? Who pays for those?



# The Move from School to Adult Services

- Employment: Independent, supported, sheltered
  - How much support and structure does your adult with fragile X need?
  - The national move is away from sheltered workshops, but would your adult benefit from the repetitive nature of those jobs?
  - Does the day or residential program that you are considering offer some job skills within it—crafts that are sold at farmer's markets, greenhouses, bakeries
- School to Work Opportunities Act of 1994
  - Transitional planning should begin while the student is still in school

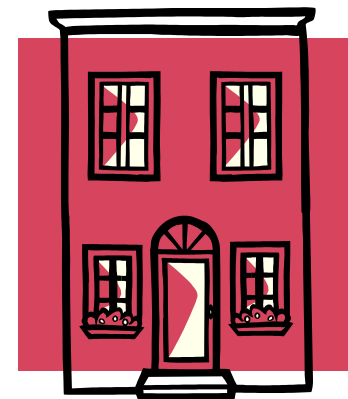
# The Move from School to Adult Services

- Volunteer work: Churches, synagogues, mosques, libraries, non-profits, food banks, and other facilities may offer opportunities for adults to volunteer their services
- Additional education: Many young women who have fragile X syndrome and some young men may be able to attend college programs, community colleges, college programs for those with learning disabilities or high functioning autism, technical colleges etc. This option is one that should be discussed throughout the transitional meetings in high school



# The Move from School to Adult Services

- Living arrangements
  - Or...”hoping my child dies five minutes before I do” is not a plan
  - When do you see your adult child benefitting from a move from his or her parents’ home to an apartment, group home, or other setting?
  - Begin investigating local housing facilities in your state and area, and get on waiting lists for appropriate ones
  - Some families have started their own group homes, and you might want to contact them
  - Volunteer, observe, visit the homes



# The Move from School to Adult Services

- Community supports: Social, recreational, religious
- Does your community offer special recreation services? Activities for adults with special needs? Special Olympics?
- Does your church, synagogue or mosque offer special groups for those with cognitive disabilities? Is there a role for your adult child at your place of worship (handing out bulletins, straightening up hymnals, assisting in Sunday school)?



# Conclusions and Questions

- It may all seem overwhelming, but with early and on-going planning, lots of record keeping, and the support of friends and other advocates, you will get your child through the system successfully and launched into adulthood!
- Questions??



# References

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