

13TH INTERNATIONAL FRAGILE X CONFERENCE

FROM WONDER YEARS TO GOLDEN YEARS: MAKING THE TRANSITION TO ADULT SERVICES

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Begin in High School

- ▣ Getting Started
 - IDEA specifies age 16, but many states start earlier
 - If your child needs it, you can start earlier

What to Do?

- ▣ Google - "Your state" transition for students with disabilities
 - Should have information about transition programs
 - May have a checklist format, examples of goals/obj

What to Do?

- ▣ Ask about activities at your school
 - Job experiences in high school
 - Senior centers, restaurants, book stores, wash buses
 - May not be able to keep when graduate
 - 18-21 program
 - Focus of program
 - Varies greatly

What to Do?

- ▣ Call your local disability center
 - Ask about services/wait lists at age 21
 - What are the types of services?
 - How do I learn about them/what is available?

What to Do?

- ▣ Call your local Arc
 - If you don't have one in your county, call the nearest one/state office
 - Ask them about state services/classes they offer
 - Google: "Arc of 'Your State'"

What to Do?

- ❑ Talk to other parents in your area/LINKS
 - Will be knowledgeable about services/ideas
 - Can often give you tips
 - Tap into the knowledge of parents with older children

At Age 18

- ❑ Government-issued photo ID - DMV
 - Selective Service registration
 - Register to vote
- ❑ Guardianship (& options)
 - Research pros/cons of each
 - Each state is different
- ❑ Social Security Income (SSI)

Post-Secondary Options

- ❑ Paid/Supported Employment
- ❑ Volunteer
- ❑ Day Programming
- ❑ Workshop
- ❑ College

When School Ends

- ❑ IDEA is over, no adult equivalent
- ❑ Parents are responsible for setting up the daily schedule

State Funded Programs

- ❑ Different levels of funding
 - Live at home
 - Live away from home
- ❑ Based on need
- ❑ Most states have wait lists – few years to many years

State Residential Options

- ❑ Each state provides an array of residential programs
- ❑ These vary not only by state but by localities within each state
- ❑ The range of residential services also varies among provider agencies
- ❑ Some provider agencies do residential and day-programming

Residential Options

- ❑ Independent Apartments - with varying amounts of supervision.
- ❑ Group homes.
- ❑ Host homes (where a child lives with another family)
- ❑ Communal
- ❑ Transition should be gradual and planned.

Private Pay

- ❑ Whatever you set up
- ❑ The sky is the limit.

Finding a Job

- ❑ Vocational Rehab
- ❑ Parents find the job
- ❑ Job coaching

- ❑ Volunteer

Recreation Activities

- ❑ Encourage daily activity
- ❑ Contact your local recreation center
- ❑ Special Olympics

Making the Actual Transition at the End of School

- ❑ It is a big change
- ❑ Make as seamless as possible
- ❑ Set up so there is not a lot of change

Example of Transition

- | | |
|-----------------------|-----------------------|
| ❑ In School: | ❑ No School |
| - School | - Sleep in |
| - Work | - Work |
| - After work activity | - After work activity |

What Can You Do Now?

- ▣ Always think of ways your child can become independent
 - Focus on one thing at a time
 - Come up with (agree on) an activity
 - Model it, do it together, wean away
 - Consider a picture schedule
 - Make it a part of your daily routine

Websites

- ▣ NEXF Website – Adults: Life Planning
<http://www.fragilex.org/treatment-intervention/adults-life-planning/>
- ▣ NEXF Adolescent & Adult Project
<http://www.fragilex.org/treatment-intervention/adults-life-planning/adolescent-and-adult-project/>
- ▣ 2012 State Medicaid Rankings
<http://www.disabilityscoop.com/2012-state-medicaid-rankings/>
- ▣ NICHCY – Transition to Adulthood
<http://nichcy.org/schoolage/transitionadult>

Websites

- ▣ Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities
<http://www2.ed.gov/about/offices/list/ocr/transition.html>
- ▣ Transition of Students With Disabilities To Postsecondary Education: A Guide for High School Educators
<http://www2.ed.gov/about/offices/list/ocr/transitionguide.html>
- ▣ College
<http://www.fragilex.org/treatment-intervention/adults-life-planning/planning-for-college/>

The Adult World

- ▣ It is an exciting time – the next stage in the adventure with your child.
- ▣ It can take some time to get used to for both you and your child.
- ▣ Your child can continue to have a productive life.