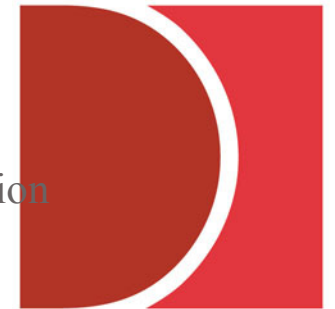




# Finding Adult Services in Your State

Karen Riley, PhD University of Denver

Jayne Dixon-Webber National Fragile X Foundation



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# Goals of the presentation

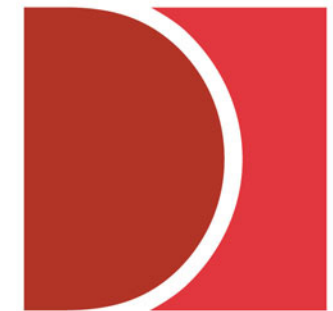
- Participants will learn about the types of services that may be available when your child becomes an adult.
- Participants will learn about the adult services in Colorado.
- Participants will learn how to find out about the adult services in their own state.
- Participants will be exposed to the content that will be provided on the new NFXF website.
- Participants will be given time to discuss how to create a link for their own state.



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# First - we did not do this alone!

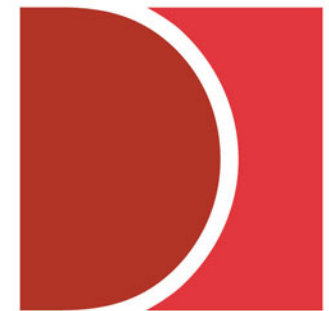
- This was a class project for DU Child, Family and School Psychology Department Low-Incidence Disabilities Course
- Combined course with graduate students in School Psych and Library and Information Sciences
- Adla, Aimee, Alisa, Felicia, Kathryn, Kim, Kirsten, Lesa, Marcy, Tegan, Tianna, Vivienne, and Vy
- Susan, Kinshasa, Lauren, Danica, Lucy, Chris, Amy, Nicole



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# Introduction

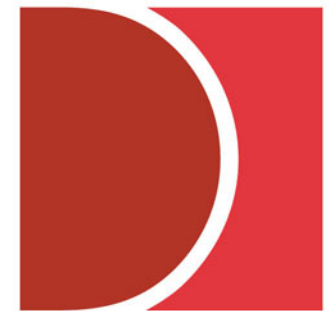
- What did we do?
- Who was involved?
- Why is this important?
- Model template



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# Transition

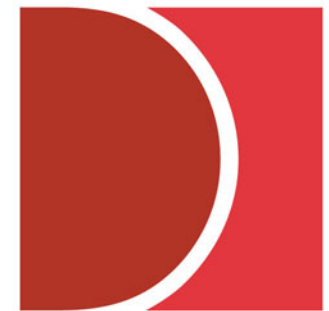
- Although the concept of transition to adult services may seem simple, the process of planning and obtaining services for adults with special needs is a complicated maze filled with blocks in services, twists and turns without support, and lengthy trails that can lead anyone astray.
- Transition involves a comprehensive and individualized process to obtain services that best support a student with special needs move from post-secondary education to employment, independent living, and community participation.



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# General Considerations

- Adult services are engaged differently than children's services.
- Disability alone does not mean individuals will be served.
  - Eligibility criteria may be narrower and services are not mandated or always individualized.
- Wait lists do exist in adult agencies and are often lengthy.
- Families must engage adult agencies much more actively and persistently.
- Initial rejection for services is frequent but can often be appealed.
- Anticipating what services will be needed and beginning applications before adulthood is recommended when possible.



# The Website

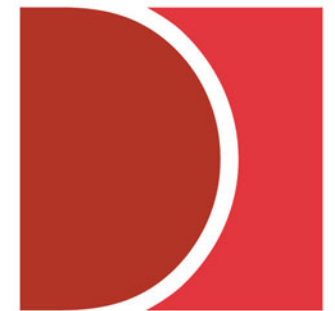
It is crucial for parents of children who are 14 years of age to begin eligibility to adult services in light of the fact that most programs have long waitlists.





New section of NFXF Website

*Transitioning into Adult  
World*

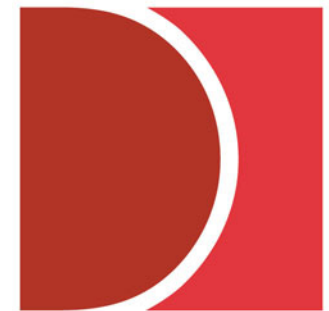


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# Transitioning into Adult World

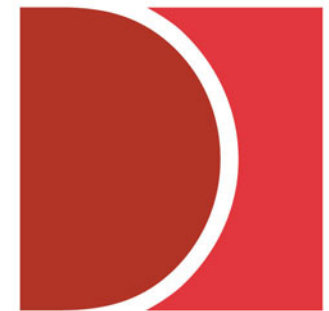
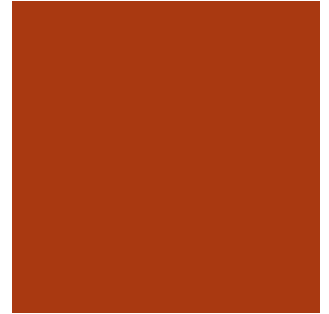
- Adult services regarding living support
  - Group homes, assisted living, and social support.
- Employment programs
  - vocational rehabilitation, job banks for people with disabilities, person centered planning programs, and job search training.
- The legal section
  - IEP planning in schools, protections from abuse and neglect under the Americans with Disabilities Act, and legal resources.



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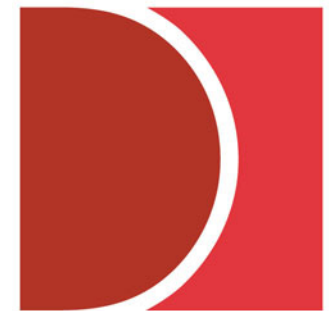
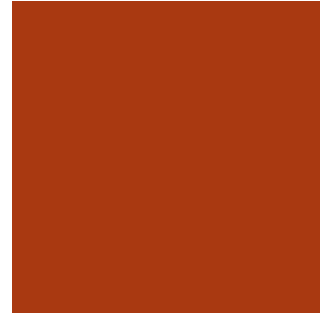
# Transitioning into Adult World

- Social Security Disability Insurance
- Individualized Service and Support Plan (ISSP) that includes behavior supports through a Community Centered Board (CCB) or regional agency,
- Supports Intensity Scale (SIS) Assessment through a Case Management Agency in order to get access to Home and Community Based Services (HCBS) and Supportive Living Services (SLS) Waivers.
- Medicaid and Medicaid Waiver system
- NFXF- Article and Brochure
- Recommended SSI Attorney for support



# Transitioning into Adult World

- Transitions for families
- Advocacy organizations
- Parent groups
- Many other resources for teens and adults with Fragile X in Colorado

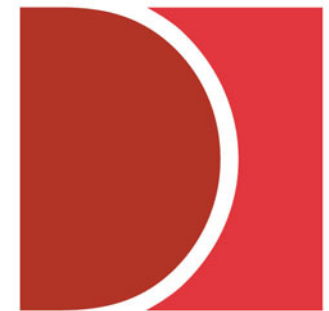
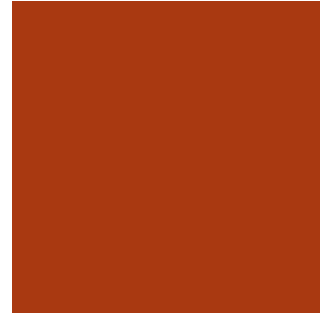


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# Transitioning into Adult World

## ■ FAQ

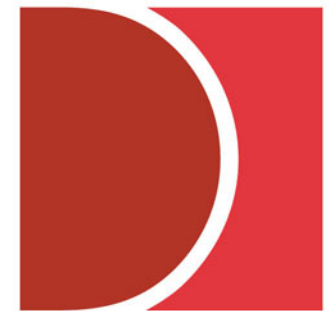
- What will my child get at 21?
- What happens if I die and my child is living with me?
- What if my child starts having behavior issues and cannot live with me?
- How do I get my child a job coach and who pays for it?
- [Link for General NFXF website FAQ](#)



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# Transitioning into Adult World

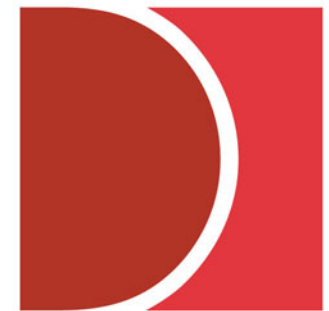
- Where to begin
  - Know your child and your situation
    - Be realistic
  - Know your rights
  - Know that children's services are different from adult human services
  - Know when you can begin the process of accessing adult services



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# Transitioning into Adult World

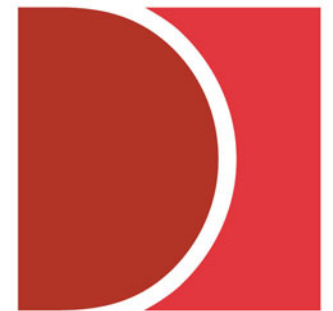
- Glossary of terms
- Lists of websites and contact numbers
- Check and recheck!!



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It is called transition, but there is a **clear line in the sand** representing the day when child services end and adult services begin. Know where that line is for your child in your state.



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# Colorado

- Adult Protective Services
- Colorado's Department of Education has a comprehensive Transition Toolkit
- Recommended age to begin transition - 8th grade or 14 years old
- Colorado's Division of Vocational Rehabilitation (DVR)
- Colorado's Division for Developmental Disabilities (DDD)

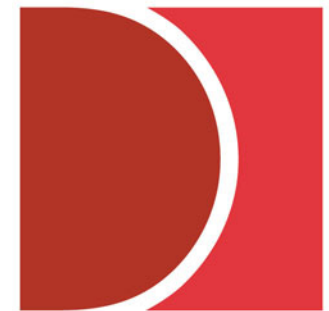


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# Process

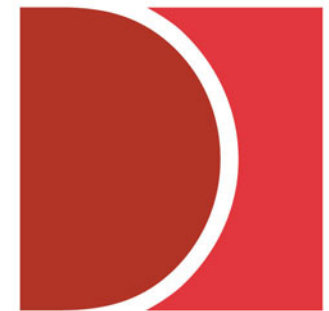
- Establish headings and categories
  - This was a fluid process with a great deal of overlap
- Exploring typical areas
- Snowball approach
- Check existing resources
- Check accuracy of websites, phone numbers and contact individuals
- Work backwards to establish a framework for a timeline



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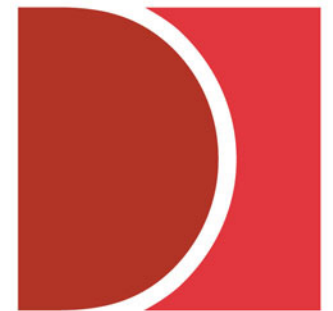
# How can you do this for your own state?

- This is a difficult but very rewarding experience.
- Colorado section designed to be used as a template
- Find a partner
- Set realistic guidelines and timelines
- **Remain focused**
- No not focus on the outliers
- Make sure it is appropriate for all levels of readers
- Work with NFXF



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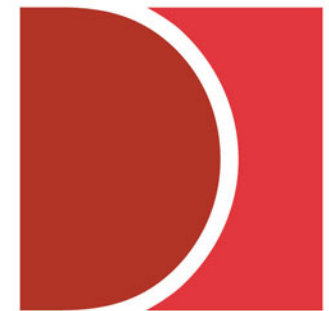
# Questions



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# Problem solving

- How can we move this forward?
- What should be the plan?
- Who should be involved?
- How can NFXF support this effort?



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