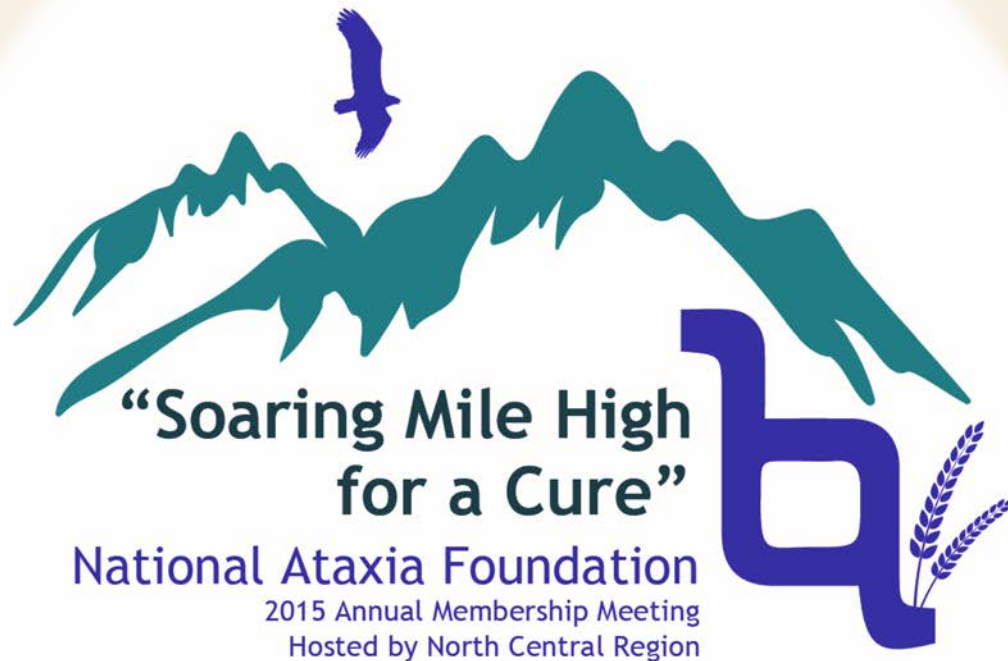


Becoming an Adult with Ataxia

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Presenter Disclosures

- Abigail Collins, MD
- The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:
 - No relationships to disclose or list



Overview

- ▶ “Adulthood” & Identity
- ▶ Stigma
- ▶ Specific Issues
 - ▶ Work and Education
 - ▶ Transportation
 - ▶ Advocacy
 - ▶ Adjustment & Mental Health
 - ▶ Research
 - ▶ Case Management



Overview

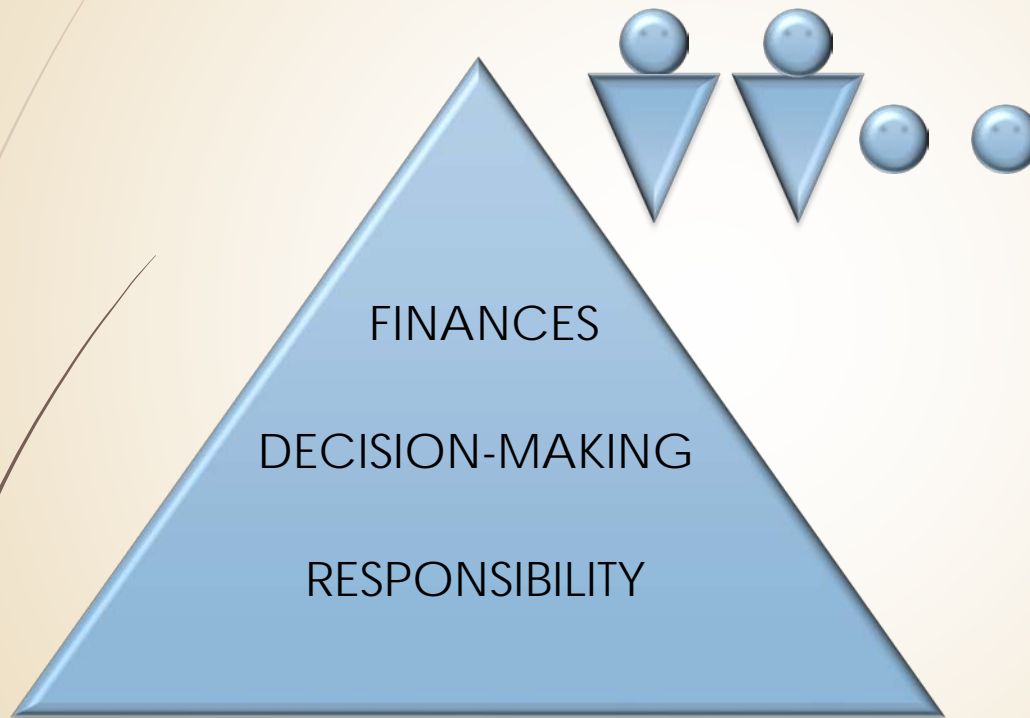
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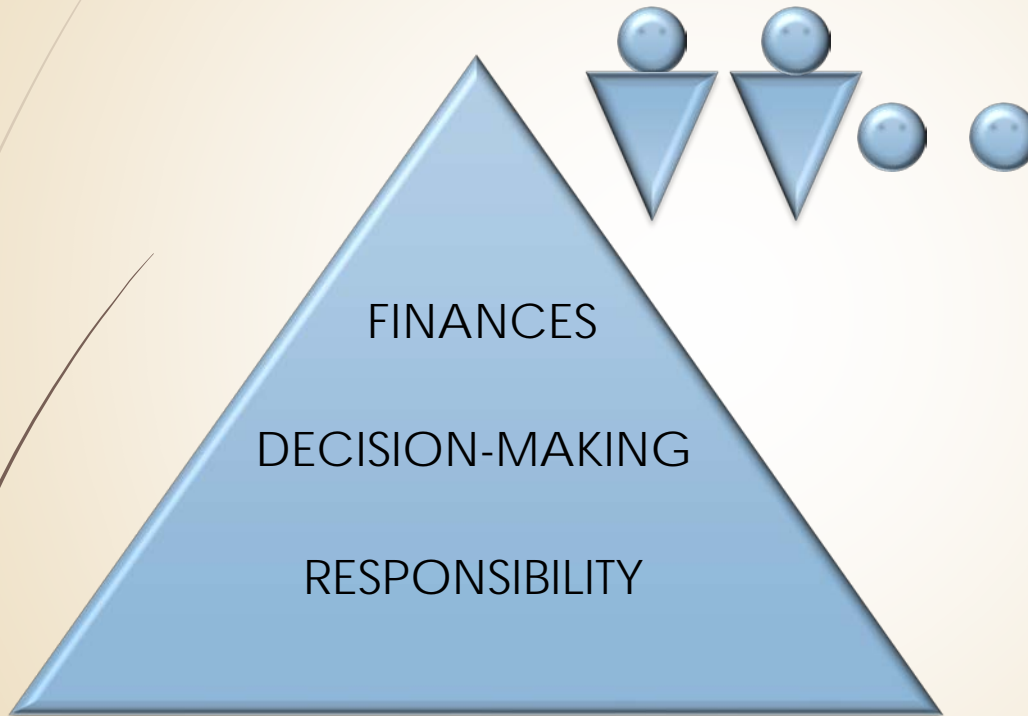
What is an adult?

- ▶ “Legal Age” of 18 years
- ▶ Accomplishment Oriented
 - ▶ Job
 - ▶ Home
 - ▶ Marriage
 - ▶ Children
- ▶ Process Oriented (Emerging Adulthood)
 - ▶ Financial independence
 - ▶ Accept responsibility
 - ▶ Make independent decisions

Transition from Dependence to Independence



Transition from Dependence to Independence with Ataxia

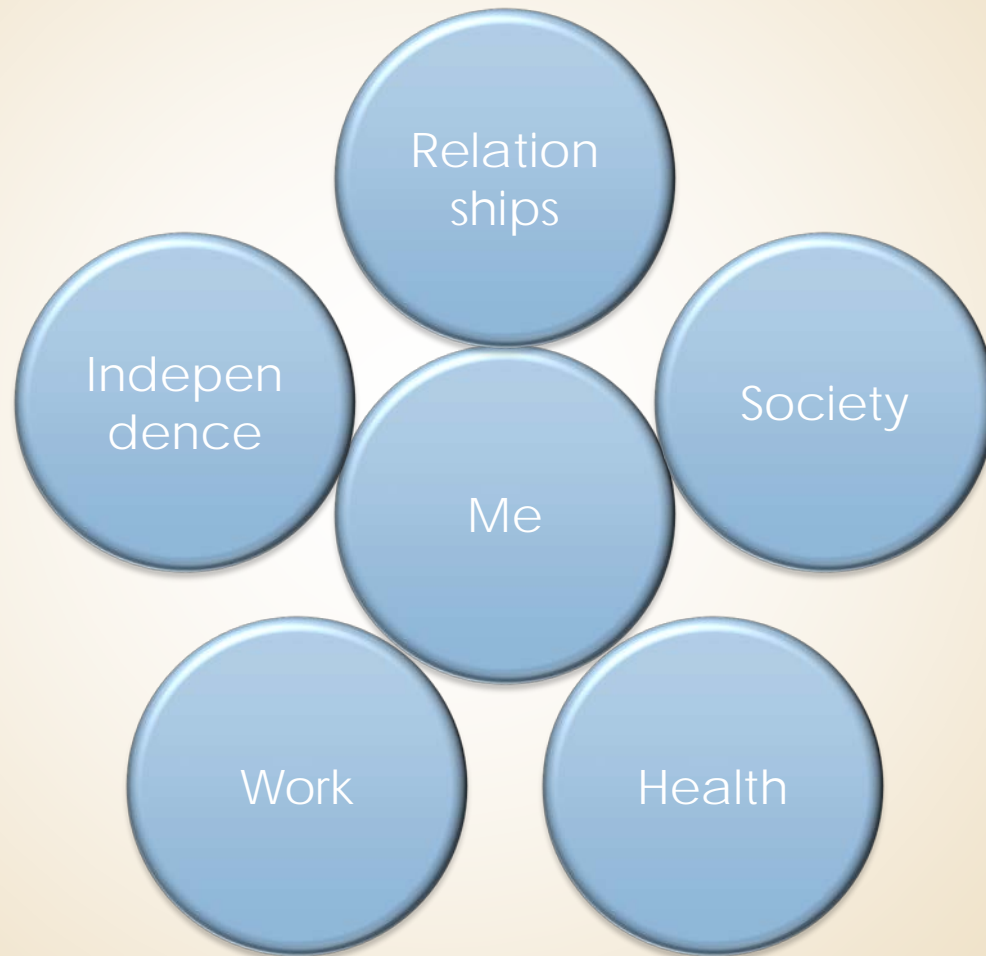


Developing an Identity

- ▶ External influences strong in early childhood
- ▶ In late childhood through early adulthood, identity is questioned and challenged
- ▶ Process results in being able to identify personal strengths, weaknesses and personal standards



Identity changes with context & age





Ataxia

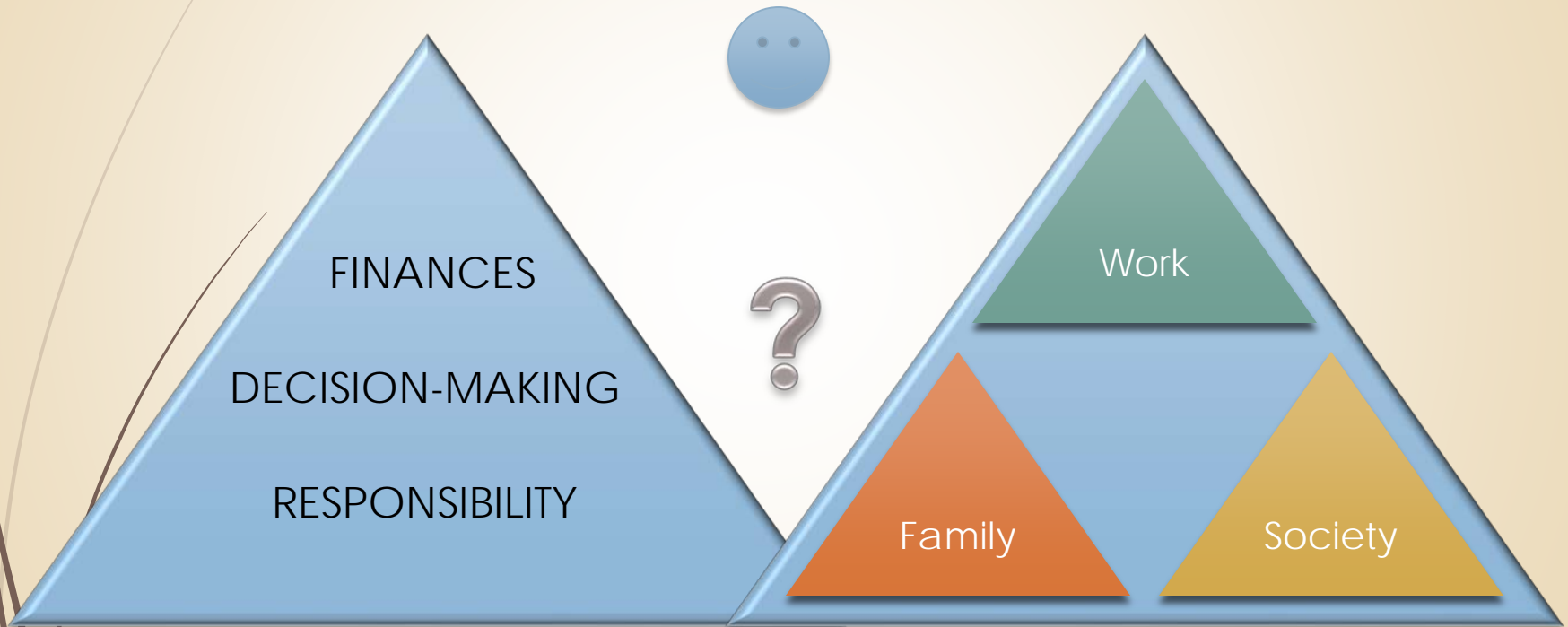
Independence

Relationships

Work

Society

Becoming an Adult with an Identity that Includes Ataxia





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Stigma

- ▶ Exists at any age due to motor symptoms
 - ▶ Staring
 - ▶ Stereotyping
 - ▶ Yelling & Belittling
 - ▶ Bullying & Victimizing
- ▶ Cognitive and emotional differences that accompany ataxia are even more misunderstood
- ▶ Self Stigma exists with decreased self esteem and feelings of vulnerability



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Work & Employability

- ▶ United States Department of Labor Statistics, 2014
 - ▶ 2/10 people with disabilities are in labor force
 - ▶ Unemployment rate of people with disabilities is twice that of people without (12.9% versus 6.1%)
- ▶ Dr. Corrigan, "People with neurological conditions are less likely to be hired and less likely to be provided with reasonable accommodations guaranteed by the Americans with Disabilities Act of 1990"
- ▶ Barriers to Employment
 - ▶ Lack of accommodations
 - ▶ Decreased ability to perform manual tasks or speak on phone
 - ▶ Fatigue
 - ▶ Cognitive Aspects of Ataxia (Rapid set shifting problematic)

Now what?



Laws and Regulations, 1

- ▶ Americans with Disabilities Act (ADA) of 1990
 - ▶ Civil Law which prohibits discrimination against people with disabilities in all areas of public life including jobs, schools, transportation, and facilities open to the public
 - ▶ Purpose is to make sure people with disabilities have the same rights and opportunities as everyone else
 - ▶ Individual areas are under specific governmental departments (DOT)
- ▶ Rehabilitation Act
 - ▶ Authorizes **funding** for various disability-related purposes and activities including state vocational rehab (VR) programs, independent living programs, training and research, and the work of the National Council of Disability



Laws & Regulations, 2

- ▶ Work Investment Act: Consolidates federal job training and employment programs to bring together a wide range of services into **One-Stop Career Centers**
 - ▶ Employment services
 - ▶ Vocational Rehab
 - ▶ Adult Education
 - ▶ Welfare to Work
 - ▶ Vocational Educational Activities



Work Programs

- ▶ Federal Programs for Adults with I/DD *not appropriate for people with ataxia*
- ▶ State Run
 - ▶ Colorado Office of Community Access and Independence, Division of Vocational Rehab
- ▶ Community Organizations
 - ▶ Contract to provide services

Resources vary locally



Denver Community Resources for Youth with Disabilities

2013

Developed For: The Office of Economic Development,
Division of Workforce Development Youth Services
Youth Transitions Grant
720-865-5700

SECTION 11: EQUIPMENT/SERVICE NEEDS/HOME ADAPTATIONS PAGE 48

- Digital Federal Credit Union- Access Loans
- Friends of Man
- Hear Now
- Home Builders Foundation
- International Hearing Dog
- Kids Mobility Network, Inc.
- MS Society- Colorado Chapter
- Rebuilding Together
- Telecommunications Equipment Distribution Program

SECTION 12: TRANSPORTATION

PAGE 51

Transportation Assistance

- American Red Cross
- RTD Access-A-Ride

Driving

- Performance Mobility
- Colorado Adaptive Driving Programs
- Division of Motor Vehicles- Oral Driver's License Testing
- Master Drive

SECTION 13: INDEPENDENT LIVING CENTERS

PAGE 53

- Association of Colorado Centers For Independent Living
- Mile High Independent Living Center



Aspects of a Useful Program

- ▶ Job & Vocational Training
- ▶ Transition Services*
- ▶ Job Coaching & Supported Employment
- ▶ Case Management
- ▶ Medicaid Services & Coordination



Transition Services

- ▶ Comprehensive Individualized Vocational & Psycho-Educational Services
- ▶ Career Guidance
- ▶ Basic Skill Development
- ▶ Paid/Volunteer Work Experience
- ▶ Job Seeking Skills
- ▶ Social Skills Development
- ▶ Job Coaching Services
- ▶ Placement Assistance & Follow Along



School Programs

- ▶ Individuals with Disabilities Education Act (IDEA)
 - ▶ Protects rights of children (ages 3-21) with disabilities by ensuring a free appropriate public education regardless of ability
 - ▶ Grants equal access to education and transition services
 - ▶ Provides special educational services in the least restrictive environment
 - ▶ Individualized Educational Program (IEP) will be implemented based on the child's specific needs
- ▶ Section 504 information of the Rehab Act of 1973
 - ▶ Organizations that receive federal funding are legally obligated to provide disabled students with equal benefits, services and opportunities
 - ▶ equal access to classrooms and may receive accommodations

College Programs

- ▶ US Department of Education, Office of Civil Rights
 - ▶ Students with Disabilities Preparing for Post-secondary Education
- ▶ Disability Services Office at every college
 - ▶ Intake
 - ▶ Support services
 - ▶ Note Taking
 - ▶ Test Accommodations
 - ▶ Resources available
 - ▶ Scholarships
 - ▶ Career Counseling



College Programs

- ▶ Not all colleges and universities offer same depth or breadth of services
- ▶ Articles rating different schools
- ▶ Websites outlining rights and aspects of a program to evaluate
- ▶ <http://www.bestcolleges.com/resources/disabled-students/>
- ▶ Assistive technologies by state
<http://www.ataporg.org/states.html>



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Transportation: Rides

- ▶ Disability.gov website has links
- ▶ State Government Programs through Department of Health and Human Services or DOT
- ▶ Access-A-Ride or Accessible Taxi Services
- ▶ Accessible Public Transportation
- ▶ Private Organizations
- ▶ Public Organizations
 - ▶ Easter Seals
 - ▶ Volunteer Services: National Center on Senior Transportation (provides rides for people with disabilities, too)
 - ▶ www.seniortransportation.net



Transportation: Driving

- ▶ Adapting vehicle to make it possible to drive
 - ▶ Private companies
- ▶ Accessible Vehicles (used market exists)
- ▶ Adaptive Driving Programs- Spaulding
 - ▶ Administered by an OT who is a certified driving rehab specialist
 - ▶ Assesses physical, visual and cognitive abilities to safely drive
 - ▶ Adaptive Equipment Assessment, Recommendations, Training and Prescriptions
 - ▶ Behind the wheel assessments and instruction



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Advocacy

- ▶ Refers to legal help provided to address disparities that are in violation of acts and laws
- ▶ Programs at Every Level:
 - ▶ National Disability Rights Network
 - ▶ National Disability Rights Advocates (national non-profit corporation)
 - ▶ State Run on state government website
 - ▶ State, private: Colorado Cross-Disability Coalition
 - ▶ Local: Advocacy Denver



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Combatting Stigma in Ataxia

- ▶ Where's our Michael J. Fox?
- ▶ "Cut the Bull" campaign to stop bullying of children with disabilities
- ▶ Simple Steps to Help
 - ▶ Get Connected with similarly affected young adults (ataxia social club)
 - ▶ Be Kind to Yourself
 - ▶ Dare to Share
 - ▶ Cane or Adaptive Equipment
 - ▶ "I'm not drunk I'm ataxicated" T-shirt
 - ▶ Say something simple

Adjustment & Mental Health





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Research on ADA

- ▶ Disability Studies Quarterly journal
- ▶ ADA Participatory Action Research Consortium
 - ▶ Evaluate disparities for people with disabilities after ADA implementation
 - ▶ Identify key factors contributing to persistent disparities
 - ▶ Benchmark participation disparities and highlight promising practices at state and local levels
 - ▶ Action-plan strategies for dissemination and utilization of findings to be used by ADA centers and other in community to affect positive change



Patient Centered Outcomes Research

- ▶ Patient Centered Outcomes Research Institute(PCORI) was developed as a component of the Patient Protections & Affordable Care Act of 2010
- ▶ www.pcori.org
- ▶ Research focuses on patient's needs and preferences, and focuses on outcomes most important to them
 - ▶ Survival
 - ▶ Function
 - ▶ Symptoms
 - ▶ Health-Related Quality of Life
- ▶ Identify and address barriers to implementation and identify strategies to lead to improved health care outcomes
- ▶ Millions of dollars being devoted to this



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Case Management

- ▶ Coordinator who is familiar with local services
- ▶ Assistance with navigating services and resources available, including vocational rehab
- ▶ Local charitable or private organizations
- ▶ County-based programs
- ▶ Hospital-based programs

Resources

- ▶ ADA information: <http://www.ada.gov>
- ▶ ADA-PARC:
http://centerondisability.org/ada_parc/index.php
which studies disparities that exist even with ADA law
- ▶ <http://www.parentcenterhub.org/repository/foradults/>
national organization with information about resources including links to local and state programs
- ▶ www.disability.gov
- ▶ <http://www.easterseals.com/our-programs/adult-services/>

Summary

- ▶ Becoming an adult is hard
- ▶ Becoming an adult with ataxia is harder
- ▶ Laws and Regulations exist to provide same rights and opportunities, but these are not always ideal
- ▶ Search the web for your local resources
- ▶ Enlist the help of a case manager to find the most appropriate opportunities and resources

