

Transition to adulthood resources for families and adolescents with disabilities

1. Websites with information on resources

- PACER Center
 - Provides information, advocacy, and training for parents and professionals about children's rights in the educational system.
 - o Offers nationally recognized publications and workshops.
 - o Resource: "10 Tips That May Help Your Child's Transition to Adulthood"
- The Arc Minnesota
 - Provides advocacy and support for people with intellectual and developmental disabilities.
- Minnesota State Resources list for persons with developmental disabilities
- Courage Kenny Rehabilitation Institute
 - Nonprofit organization offering rehabilitation, recreational, vocational, community living and mental health services.
 - Multiple metro locations (phone: 612-863-4000)
- Got Transition® resources and research special populations
 - Provides resources and research on health care transitions for young adults with disabilities.
- Minnesota Department of Human Services
 - Provides information on:
 - Developmental Disabilities (DD) Waiver: Provides funding for home and community-based services for children and adults with developmental disabilities or related conditions. To be eligible for DD Waiver services, a person must meet all these criteria: be determined to have a developmental disability or related condition, be determined to likely require the level of care provided to individuals in an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD), be eligible for Medical Assistance, and make an informed choice requesting home and community-based services instead of ICF/DD services.
 - Community Access for Disability Inclusion (CADI) Waiver: Provides funding for home and community-based services for children and adults, who otherwise require the level of care provided in a nursing facility. To be eligible for CADI Waiver services, a person must meet all these criteria: be eligible for Medical Assistance, be certified disabled (by the State Medical Review Team or Social Security), be determined to require the level of care provided to individuals in a nursing facility, have an assessed need for supports and services over and above those available under other funding sources, and choose care and services in the community instead of a nursing facility.
- Check resources related to the child's specific disability of diagnosis.
 - Examples:
 - The National Down Syndrome Society
 - Autism Speaks

2. What you can do at home

- At-home transition skills:
 - Focus on developing independence skills from preschool through adolescence.
 - o Encourage practice of learned skills in everyday situations.

- Use visual aids (e.g., checklists) to facilitate learning.
- Consider evaluations to support independence:
 - Neuropsychological or psychological evaluation
 - Developmental and Behavioral Pediatrics consultation
 - Occupational therapy
 - Physical therapy
 - Speech therapy
- Books about self-care and independence
 - o "Steps to Independence" by Bruce Baker & associates (1997, Paul Brookes Publishers).
 - Description: This book outlines a practical and scientifically based approach to teaching basic self-care and community-living skills, as well as techniques for managing problem behaviors and relationships.
 - "Spectrum of Independence: How to Teach Your Neurodiverse Child Daily Life Skills" (March 2025).
 - To be published in March 2025.
- Apps for smartphones and tablets

There are several apps for smartphones and tablets that may help your teen or young adult learn skills and real-life routines. Some options include:

- Functional Planning System.
- CanPlan and Choice Works: Learning to complete daily routines.
- Category the APPy lite: learning to categorize abstract information.
- o My PlayHome and PlayHome Store Teaches home living and money management.
- Visual Currency Calculator.

3. Help from the community

- Educational and vocational transition:
 - Under an IEP, young adults are eligible to receive educational support from the school district until age 22. After high school, this is frequently in the form of vocational support and learning independent living skills. You can request that your child meets with someone from Vocational Rehabilitation as part of transition planning. Find your person here: VRS Student Career Services Staff / Minnesota Department of Employment and Economic Development (mn.gov)
 - Video: VRS Student Career Services Connecting Students to Work (mn.gov)
 - Work with the school to make sure the post-secondary Transition Plan they develop is appropriate to your child's needs, strengths and interests.
 - Help your high school age child develop job, employment and self-advocacy experiences through Pre-Employment Transition Services.
 - Video: <u>Pre-Employment Transition Services (youtube.com)</u>
 From PACER.org: <u>Help Your Young Adult Learn About Accessing Accommodations</u>
 After High School
- Employment
 - Minnesota Department of Economic Security, Vocational Rehabilitation Services (VRS)
 - After high school, your child may wish to contact the local Vocational Rehabilitation office to help obtain appropriate employment. This office may also help them access school opportunities. Going forward, your child may qualify for accommodations under the Americans with Disability (ADA) act given their medical history and current challenges.
 - Workforce Centers

- One-stop career centers designed to provide a full range of assistance to job seekers.
- Offers training referrals, career counseling and job listings.
- The One-Stop Career Center System is Coordinated by the Department of Labor's Employment and Training Administration (ETA). The ETA has a clickable map of One-Stop Centers' web sites for each state and a list of state, regional and local center contacts. You can also find a center by calling the help line at (877) US-2JOBS.

o <u>CareerCircle</u>

 Online service organization focused on creating employment opportunities for job seekers with disabilities and helping employers find talent.

Assistive technology

 The Simon Technology Center at PACER offers a free consultation for ideas about assistive technology options.

Housing

- Minnesota Association of Centers for Independent Living
- o Minnesota Department of Economic Security, Vocational Rehabilitation Services
- o Minnesota Association of Centers for Independent Living

Relationships and sexuality

- o Mad Hatter Wellness (comprehensive sex ed curriculum).
- Books by Terri Couwenhoven, MS, CSE:
 - "The Boys' Guide to Growing Up: Choices and Changes During Puberty"
 - "The Girls' Guide to Growing Up: Choices & Changes in the Tween Years"
 - "Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality"
 - "Boyfriends & Girlfriends: A Guide to Dating for People with Disabilities"
- "S.T.A.R.S.: Skills Training for Assertiveness, Relationship-Building, and Sexual Awareness" by Susan Heighway and Susan Webster.
- "The Facts of Life....and More: Sexuality and Intimacy for People with Intellectual Disabilities" by Leslie Walker-Hirsch.
 - Parents' Sex Ed Center, Advocates for Youth.
- Supportive decision making or guardianship
 - Parents/guardians may be interested in identifying potential supportive decision-making options to assist their teen or young adult in managing adult life. It is often helpful to work with expert advocates to consider topics like:
 - Long-term financial planning.
 - Health care and health insurance options.
 - Options for exercise, social and leisure recreation.
 - Support for learning and maintaining skills in areas of daily living, such as selfcare, domestic chores, and safety awareness.
 - This <u>video</u> from The Arc Minnesota talks about decision making around guardianship options issues.
 - Guardianship:
 - Guardianship would be the most extreme form of support and would require the family to work with an attorney to make sure the teen or young adult meets the legal definition for guardianship. This would need to be renewed every 6 years until the age of 30.
 - For additional information and resources on the guardianship process, please contact your child's social worker, visit the Minnesota Association for

<u>Guardianship & Conservatorship</u>, or call the Guardianship Information Line at 1-844-333-1748.

- Supported decision making
 - A less-restrictive option is called supported decision making. This may be an appropriate choice if your child can identify someone to be a proxy-decision maker and understands the basics of Health Care Directives and Power of Attorney. No attorney is needed; the family can complete the documents on their own (Health Care Directive and Power of Attorney).
 - The Arc's Guide to Decision Making Supports (Guardianship) provides a helpful overview of types of decision-making support. Keep in mind, these decisions can be time-limited and should be re-visited at least once a year, while also supporting your child in efforts to continue developing independence skills.

4. Additional resources for clinicians

• <u>Got Transition's Six Core Elements of Health Care Transition</u>™ define the components of a structured transition process and include customizable sample tools available in multiple languages for each core element. <u>View their implementation guides.</u>