The Road to Adulthood: A Brief Exploration of Youth to Adult Transition

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Down Syndrome Day With the Experts
Waisman Center
Presenter

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Transition - Planning for the future - starting now!
Family Voices of WI Transition Fact Sheets

Family Voices of WI is creating fact sheets for families of youth with intellectual or developmental disabilities. The fact sheet below provides a brief overview of integrated transition. It is the first in a series currently being developed. Additional fact sheets will cover specific transition topics in greater depth. These fact sheets are being developed in partnership with the Wisconsin Integrated Transition Planning Project and will be available in both English and Spanish (in process).

Introduction to Integrated Transition/Introducción a Una Transición Integral Para Jóvenes y Familias

This fact sheet is meant to start you planning for your child’s transition to adulthood and everything that goes along with it.

Web version (English)»
Print version (English)»
Versión Impresa (Español)»

Source: https://integratedtransition.waisman.wisc.edu/resources/family-voices-of-wi-transition-fact-sheets/
Integrated transition planning is a path to living a full, meaningful and connected life as a member of the community.

Integrated Transition Planning
Bringing the Pieces Together

A child's transition to adulthood can leave you feeling overwhelmed and unprepared. There are significant changes that come with your young adult's 18th birthday. Parents and guardians have extensive to-do lists with finding new programs, new community supports, LOTS of paperwork, and legal decisions to be made. But rest assured that resources are available to help your family navigate these waters.

What is “Integrated” Transition Planning?
Integrated transition planning means planning for what will change as your child becomes an adult, focusing on creating a path to living a full, meaningful and connected life as a community member. It’s planning with attention to all of the pieces of the transition puzzle, including: employment, healthcare, housing, post-secondary education.

Pieces of the Transition Puzzle
These questions are pieces of the transition puzzle that you might want to think about.

Home: Will my child live at home or move out?
Education: Will my child graduate at 18 or continue through age 21? Does my child want to go to college or technical school?
Employment: What type of work does my child want to do? And, which supports may be needed to make them successful?
Community: What will my adult child want to do for fun, to make friends and stay active? Are programs available in the community?
Health: Can my child take care of their own health care and insurance needs? Will my child need to move to new adult medical providers?

Dream about your child’s best life as an adult. Let this vision drive your advocacy to ensure your child gets the services and supports they need during this time of transition.

Source: https://familyvoiceswi.org/resource-library/wisconsin-integrated-transition-planning-project-introduction-to-integrated-transition-for-youth-and-families/
Pieces of the Transition Puzzle

Home
• Live at home?
• Move out?

Education
• Continue through 21?
• College?

Employment
• What type of work?
• What supports?

Community
• What to do for fun?
• Programs?

Health
• Increased involvement
• Move to adult providers

Source: https://familyvoiceswi.org/resource-library/wisconsin-integrated-transition-planning-project-introduction-to-integrated-transition-for-youth-and-families/
**Wisconsin Integrated Transition Planning Project**
Youth Fully Participating and Engaged in Their Community
January 2023

**Integrated Transition Planning** for youth with disabilities is a path to living a full, meaningful, and connected life as a community member. It means planning for what will change as your child becomes an adult. Every child is different, so all the ideas might not be right for your family. This fact sheet helps families start planning for their child’s transition to adult life and how they can be fully engaged in their community.

**Imagine Their Best Life** As your child prepares for adulthood, think **broadly** about their future. Together you can think about health, leisure activities, culture, learning, friends, employment, housing, faith, and more.

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**Activity**

Take a minute to dream about your child’s best life as an adult. What do you imagine?

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Take a minute to dream about your child’s best life as an adult. What do you imagine?

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WHERE DO I BEGIN?

Learn What Makes Your Child Happy
Pay attention to the things that interest your child and what they like to share with friends, family and teachers. Talk with them about what makes their day a good day. Then use these ideas to find opportunities to get involved in their community.

Ask for Support
You don’t have to figure this out alone! There are a lot of professionals that have information to complete this puzzle with you. If your child is enrolled in long-term care, ask their service coordinator about community supports for adults. Connect with your local Independent Living Centers, your child’s high school special education or IEP team, and when your child is age 17 ½, contact your county Aging and Disability Resource Center (ADRC).

You Have Time
Transition is important but you don’t need a complete picture of your child’s plan immediately. Take the time to think about all of the puzzle pieces mentioned in this fact sheet. And know that your child will continue to grow and develop new interests along the way. When this happens, revisit these areas and add or change their schedule when it makes sense and contributes to their overall well-being.
PIECES OF THE TRANSITION PUZZLE

Health and Wellness
Think about adaptive fitness programs, sports leagues or other ways to get regular exercise.
Start: Special Olympics Wisconsin programs offer fun ways to connect with others and stay active.

Leisure Activities and Community Connections
Your local YMCA or recreation department may offer clubs, arts and crafts, and adaptive programming. Public libraries, service clubs and local charities plan activities or volunteer opportunities.
Start: Visit your community or local government’s website.

Culture and Arts
Many communities have local theaters, museums and art centers with discounted tickets, free performances, or other programs that adults can participate in with others in the community.
Start: Go to your community art center’s website.

Lifelong Learning
Colleges across the state have disabled student programs and services for students to request accommodations. Some universities have post-secondary programs for students with intellectual and learning disabilities on campus.
Start: See Midwest Inclusive Post Secondary Alliance (MIPSA) or thinkcollege.net websites.

Life Skills
Courses for cooking, money management, and staying healthy and safe are good options for everyone. There are online and in-person courses.
Start: Check with Independent Living Centers and the Healthy, Safe and Connected Toolkit.

Employment
Jobs let you meet new people, learn new skills and ideas, and connect you to the community. Your child’s interests and skills can guide them to a job that is the best fit.
Start: Read Before Age 38: Employment Planning.

Housing
If your child wants to move out of your home as an adult, there are options like living independently with support, with friends or other adults.
Start: Contact your county’s Aging and Disability Resource Center (ADRC) when your child is 17 ½ to learn about community-supported living and other housing options.

Civic Engagement
Is your child registered to vote? If your family has guardianship your child can still keep their voting rights. If your child wants to be politically active, try taking part in the annual Disability Advocacy Day or join a chapter of People First Wisconsin.
Start: Go to WI Disability Vote Coalition and the Guardianship and Voting guide.

Spirituality and Faith
Your adult child can stay involved or become connected to a house of faith or spiritual community. Many faith communities offer activities, outings and clubs to get to know other members.
Start: Your house of faith may have a website with event information. If not, drop by their offices.

Relationships and Sexuality
Like their peers, your child might want to date, find a long-term partner, or even get married. Resources are available to learn about healthy and respectful relationships.
Start: Visit Healthy Relationships and Sexual Health for People with Disabilities.

Learn more on the Family Voices website’s Resource Library.

Health risks of loneliness - we all need connection

A report from the National Academies of Sciences, Engineering, and Medicine (NASEM) points out that more than one-third of adults aged 45 and older feel lonely, and nearly one-fourth of adults aged 65 and older are considered to be socially isolated. Older adults are at increased risk for loneliness and social isolation because they are more likely to face factors such as living alone, the loss of family or friends, chronic illness, and hearing loss.

Loneliness is the feeling of being alone, regardless of the amount of social contact. Social isolation is a lack of social connections. Social isolation can lead to loneliness in some people, while others can feel lonely without being socially isolated.

Reference

"...the purpose must be to support access to others, with and without disabilities, who can share in the experiences of companionship, commitment, and caring that characterize the friendships most desired by people with intellectual and developmental disabilities. Friendships, including intimate partner relationships, are an important key to their social well-being."

"Practitioners, peers, and family members can support people with intellectual and developmental disabilities to develop friendships by working from a strengths-based perspective to build communicative competencies, promote acquisition of social knowledge about self and others, and establish positive identities that do not pathologize disability. Disability communities that value disability identity also represent important contexts—whether located in online social media or other venues—for examining friendship and social well-being."
Dating!!!

Planning a Date

Meet Cristina and Jacob.

Cristina likes Jacob. She wants to go on a date with him.

She decides to call Jacob on the phone and ask him on a date.

Hi Jacob! Would you like to go on a date with me?

Yes!

When you ask someone on a date, ask them in person or call them on the phone. Do not ask them in front of other people or on Facebook or other social media.

Source: https://adscresources.advocatehealth.com/assets/1/13/Planning_a_Date.pdf?1775
Ideas for supporting meaningful social connection in transition...and beyond!

- Include social relationships and friendships in Transition IEP goals (this can be incorporated into volunteering, job experiences, exploring hobbies,...)

- Explore the great programs you already know! DSAW and Gigi’s Playhouse both have lifespan programming that focuses on social connection and building friendships

- Pick one area of the Family Voices transition puzzle resource list (e.g. culture and the arts, spirituality and faith), explore, and have fun!
5 minute meaningful conversation each day - ask open-ended questions

Help identify 2 core friends and video chat 2 times/week

With same 1-2 good friends, schedule 1:1 time, in-person, 2 times/month

Establish rules for electronics in your house, especially video games

Source: https://www.downsyndromebraintrain.com/products-1
Statewide Initiative

HEALTH TRANSITION WISCONSIN
SUPPORTING YOUTH TO ADULT HEALTHCARE

Purpose
Ensure that “high-quality, developmentally appropriate, health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood”

-Pediatrics, 2018
Definition

Heath Care Transition is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician.

-White, 2018
Timeline of Transition

Health Care Transition Timeline
for Youth and Young Adults

**Age 12-13**
- Learn about your health condition, medications, and allergies.
- Ask your doctor questions about your health.
- Ask your doctor if and at what age they no longer care for young adults

**Age 14-15**
- Find out what you know about your health, health care, and family medical history. Both you and your parent/caregiver can take Got Transition’s Transition Readiness Assessments* and discuss this together and with the doctor.
- Carry your own health insurance card.
- Learn more about your health and what to do in case of an emergency.
- Practice making a doctor’s appointment and ordering prescription refills (either by phone, online, or through an app).
- Begin to see the doctor alone for part of the doctor’s visit to help gain independence in managing your health and health care.

**Age 16-17**
- Make doctor’s appointments, see the doctor alone, ask the doctor any questions you have, and refill medications.
- Ask the doctor to talk with you about your privacy rights when you turn 18.
- Work with your doctor to make a medical summary. Keep a copy for yourself.
- Before you turn 18 and become a legal adult, figure out if you will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your parent/caregiver about the age you want to transfer to a new doctor for adult care.
• You are a legal adult at age 18 and are legally responsible for your care. Parents/caregivers cannot access your medical information or be in the doctor's visit unless you agree.
• Work with your current doctor to find a new adult doctor, if needed. Make sure that the new doctor accepts your health insurance.
• Update your medical summary with your doctor. Have your doctor send this to your new adult doctor. Keep a copy for yourself.
• Call your new adult doctor to schedule the first appointment. Make sure the new office has your medical information, and learn if there are any charges at the visit.
• Learn if there are additional changes at 18 that affect you (e.g., health insurance, Social Security Income).

• Continue to get care from your adult doctor, learn to manage your health and health care, and update your medical summary.
• Be sure to stay insured. If you change your health insurance, make sure your doctor takes your insurance, and learn if there are any charges at the visit.


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Regional Centers

Wisconsin
Southern Regional Center

Location: Waisman Center, Madison
Phone: 608-265-8610
Toll Free: 800-532-3321
Director: Tim Markle

https://cyshcn.waisman.wisc.edu/
Connect with us

Call: 1-800-532-3321 or 608-265-8610
Please leave a message. If you could spell out your email address in your message, that will help us to follow up with you more quickly. When we call back, we may call from a number that shows as blocked. We use a Language Line for translating languages other than English.

Email: cyshcn@waisman.wisc.edu

Who we are

The Southern Regional Center (SRC) is dedicated to supporting all families with children and youth with special health care needs/disabilities and the providers who serve them. The SRC is staffed by specialists who can help get answers, find services, connect you to community resources, provide trainings and support you on your journey. Our Center serves the following counties: Adams, Columbia, Crawford, Dane, Dodge, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock, Sauk and Vernon, shown in orange on the map.

Stay updated, informed and involved

The Southern Regional Center (SRC) uses a listserv to inform families about upcoming trainings and events in our region and opportunities for state and national input. Families have joined us in reviewing the Navigation Guide and starting Conversations on Showing Up for Kids!

Send an email to join-src4family@lists.wisc.edu. You can unsubscribe at any time.

Join us on Facebook: https://www.facebook.com/SouthernRegionalCenter
Eight Health Tools

**Health Transition Wisconsin**
Supporting Youth to Adult Health Care Transition

https://healthtransitionwi.org/

https://healthtransitionwi.org/youth-families/

Step-by-Step

Check out these additional resources to take charge of your health care!

- Resources
- Build Your Bridge Workbook
Eight Health Tools

- Adult Providers
- Decisions
- Health Insurance
- Emergency Contacts
- Appointments
- Medications
- Medical Summary
- About Me
Got Transition® is the federally funded national resource center on health care transition (HCT). Its aim is to improve transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families.

Got Transition aims to help youth and young adults move from pediatric to adult health care.
https://gottransition.org/resource/?hct-family-toolkit

A FAMILY TOOLKIT: PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION

Developed by Got Transition® and its National Health Care Transition Family Advisory Group
Decision-Making Tools

- Supported Decision-Making?
- Medical Release Forms?
- Guardianship?
- Power of attorney for healthcare?
Current decision-making support tools

**Release forms**
Individual signs a release form authorizing a specific person access to certain information or records.

**Supported Decision-Making Agreement**
Individual makes all their own decisions. They identify a supporter/s to assist them.

**Representative Payee**
Social Security Administration appoints an individual/org. to receive SSI/SSDI benefits for an individual who cannot manage their own.

**Power of Attorney**
(medical or financial)
Formal legal arrangements that permit others to act on the individual's behalf.

**Limited or Full Guardianship**
Transfers some or all decision-making authority from the individual to a court-appointed Guardian.

* For the purpose of this publication, the term "individual" refers to an individual with disabilities and/or an aging adult.
We want to unite ALL of Wisconsin in supporting people with developmental disabilities to lead their most independent lives.
Our Toolkits

Better Together. Working with individuals, families, and other disability and health organizations, we pool our experience and expertise to bring you the following resources.

We have a great selection of resources available for free! By clicking the button below you can view our toolkits, brochures and many other resources that you can order.

[Order Resources]

Supported Decision-Making and Guardianship Alternatives

There are alternatives to guardianship. Supported decision-making empowers individuals with disabilities to make informed decisions about their life that protect their rights and ensure their safety and privacy. It involves family and friends working together to help them make complex decisions.

Take Charge of Your Health Care

Talking to medical staff and organizing all your medical information is a huge task. This kit helps individuals with developmental and intellectual disabilities gather their information and advocate for their own health care. It includes forms to track health concerns, appointments and treatments.

Wisconsin’s Living Well Healthy, Safe, and Connected Toolkit

People with disabilities need to be healthy, safe, and connected. This toolkit will give people simple ways to be sure you know how to do all three. We want you to have the information and tools to stay healthy, safe, and connected throughout your lifetime and not just during an emergency.
Thank you!
Questions?

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