

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

Saturday, March 11, 2023

Down Syndrome Day With the Experts

Waisman Center



Waisman Center

Advancing knowledge of human development, developmental disabilities, and neurodegenerative diseases.

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.



Newsletter
2023, Issue 1

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

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.

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





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.



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

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

Source: <https://integratedtransition.waisman.wisc.edu/wp-content/uploads/sites/1767/2023/02/WITPP-2-Community-Transition-QR-2.13.2023.pdf>

Youth Fully Participating and Engaged in Their Community





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.

What makes a
good day?

Ask for
support

You have
time



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 18: 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](#).



Each family has a voice • Together, our voices will be heard
[familyvoiceswi.org](#)



Source: <https://integratedtransition.waisman.wisc.edu/wp-content/uploads/sites/1767/2023/02/WITPP-2-Community-Transition-QR-2.13.2023.pdf>

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.¹ 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.

Health Risks of Loneliness

Although it's hard to measure social isolation and loneliness precisely, there is strong evidence that many adults aged 50 and older are socially isolated or lonely in ways that put their health at risk. Recent studies found that:

- Social isolation significantly increased a person's risk of premature death from all causes, a risk that may rival those of smoking, obesity, and physical inactivity.¹
- Social isolation was associated with about a 50% increased risk of dementia.¹
- Poor social relationships (characterized by social isolation or loneliness) was associated with a 29% increased risk of heart disease and a 32% increased risk of stroke.¹
- Loneliness was associated with higher rates of depression, anxiety, and suicide.
- Loneliness among heart failure patients was associated with a nearly 4 times increased risk of death, 68% increased risk of hospitalization, and 57% increased risk of emergency department visits.¹

Reference

¹ National Academies of Sciences, Engineering, and Medicine. 2020. *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System*. Washington, DC: The National Academies Press.
<https://doi.org/10.17226/25663>

Focus on Friendship: Relationships, Inclusion, and Social Well-Being

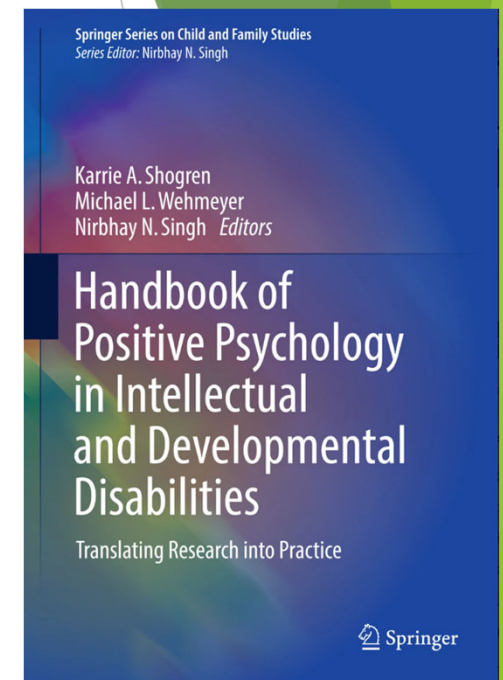
[Laura T. Eisenman](#) , [Brian Freedman](#) & [Marisa Kofke](#)

Chapter | [First Online: 23 September 2017](#)

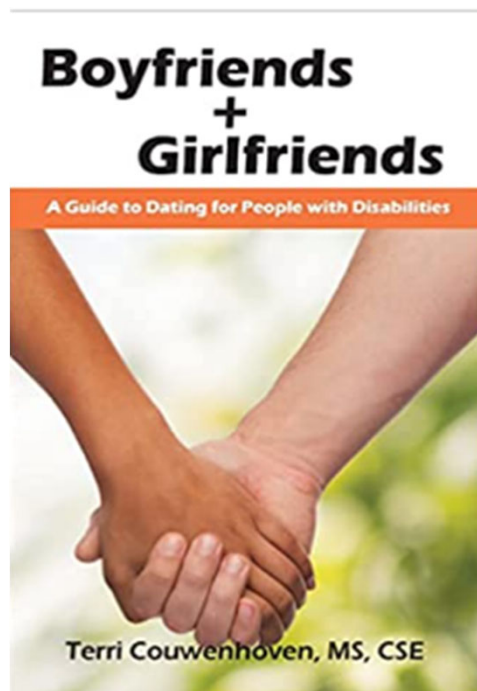
"...the purpose must be to support access to others, with and without disabilities, who can share in the experiences of companionship, commitment, and caring that characterize the friendships most desired by people with intellectual and developmental disabilities. Friendships, including intimate partner 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."

Eisenman, L.T., Freedman, B., Kofke, M. (2017). Focus on Friendship: Relationships, Inclusion, and Social Well-Being. In: Shogren, K., Wehmeyer, M., Singh, N. (eds) Handbook of Positive Psychology in Intellectual and Developmental Disabilities. Springer Series on Child and Family Studies. Springer, Cham. https://doi.org/10.1007/978-3-319-59066-0_10



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.

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Page 1

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!



DOWN SYNDROME BRAIN TRAIN

Dr. Brian Skotko, an international expert on Down syndrome, offers practical tips on how you might boost cognition and prevent Alzheimer's disease in your loved one with Down syndrome.

SMART: Socialize

STUDY 1

PNRD: 27130024

3,310 typical adults, ages 60-90, in the U.S.

- Individuals who were at risk of early dementia had smaller network sizes, lower community involvement, and a high reliance on family members or a few close friends.
- Social interactions likely limit the amount of time that our brain is unfocused and keep our brains active.

STUDY 2

PNRD: 08111753

2,249 typical women, ages 70+, in the U.S.

- Elderly women who had larger social networks had protective influence on cognitive function.
- Being around your friends, or social network, more seemed to protect the cognitive function in this population.

STUDY 3

PNRD: 17030301

800+ seniors in Chicago area

- Risk of Alzheimer's disease was more than doubled in lonely persons.
- Socialization seems to decrease risk of Alzheimer's disease.

HOW THIS RELATES TO DOWN SYNDROME

People with Down syndrome tend to be listeners rather than active conversationalists. We can change this by engaging them in more meaningful conversations that make them think by asking open-ended questions rather than closed-ended questions. It is especially important to be patient! Allow time for your loved one to think and engage in their social networks.

- ☒ Have a meaningful conversation with your loved one for 5 minutes each day by asking open-ended questions.
**if needed, augmentative and alternative communication methods may be used.*

Often, people with Down syndrome may need help maintaining their quality friendships. Neurotypical friends are wonderful, but are not necessary to create a quality friendship!

- ☒ Help your loved one identify 1-2 core friends that are not family members. Schedule time for them to talk through video chat twice weekly.

Although social media is a great tool to stay connected with friends, it is not a substitute for quality human contact.

- ☒ With the same 1-2 really good friends your loved one identified, schedule one-on-one time that is in person at least twice monthly.

People with Down syndrome should have less than 1 hour of screen time per day because this is a passive brain activity.

- ☒ Establish the rules for electronics in your house, especially video games.

CHALLENGER GOALS

In addition to completing the tasks listed above, work hard to accomplish these goals, too:

- Have only **1 TV in 1 room** in your house.
- No TV on in the background.
- No TV during dinner time. This is a perfect opportunity to complete the **first task** above!

Sign up for more information and tips at [downsyndromebraintrain.com](https://www.downsyndromebraintrain.com)

*PNRD: 6-04000-1000



DOWN SYNDROME BRAIN TRAIN

Dr. Brian Skotko, an international expert on Down syndrome, offers practical tips on how you might boost cognition and prevent Alzheimer's disease in your loved one with Down syndrome.

SMART: Socialize

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

Health 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.

Age 18-21

- 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).

Age 22-25

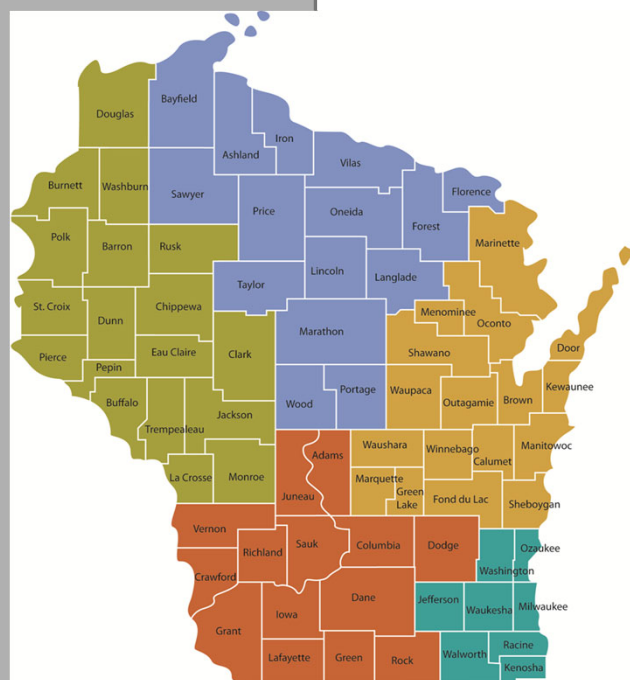
- Continue to get care from your adult doctor, learn to manage your health and health care, and update your medical summary.
- Be sure to stay insured. If you change your health insurance, make sure your doctor takes your insurance, and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit <https://gottransition.org/6ce/leaving-readiness-assessment-youth> and for a version for parents/caregivers, visit <https://gottransition.org/6ce/leaving-readiness-assessment-parent>.

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Got Transition ([GotTransition.org](https://gottransition.org)) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) (U1TMC31756). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government.

5 Regional Centers Wisconsin



Southern Regional Center

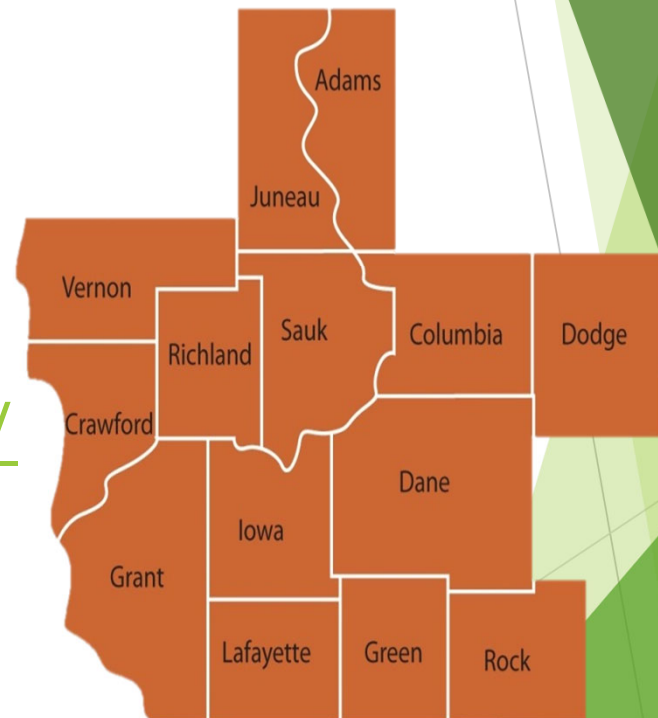
Location: Waisman Center, Madison

Phone: 608-265-8610

Toll Free: 800-532-3321

Director: Tim Markle

<https://cyshcn.waisman.wisc.edu/>



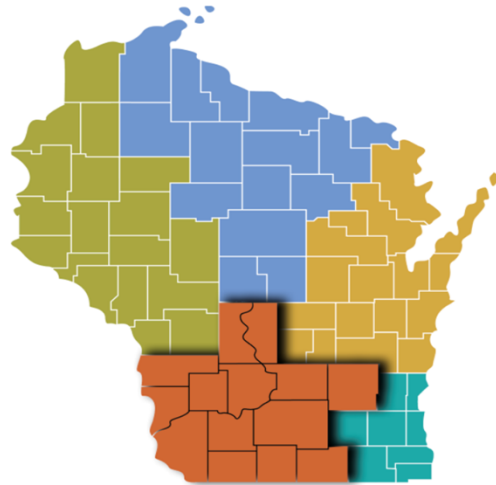
<https://cyshcn.waisman.wisc.edu/>



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.



Southern Regional Center
Children and Youth with
Special Health Care Needs

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



Appointments



Decisions



Medications



Health Insurance



Medical Summary

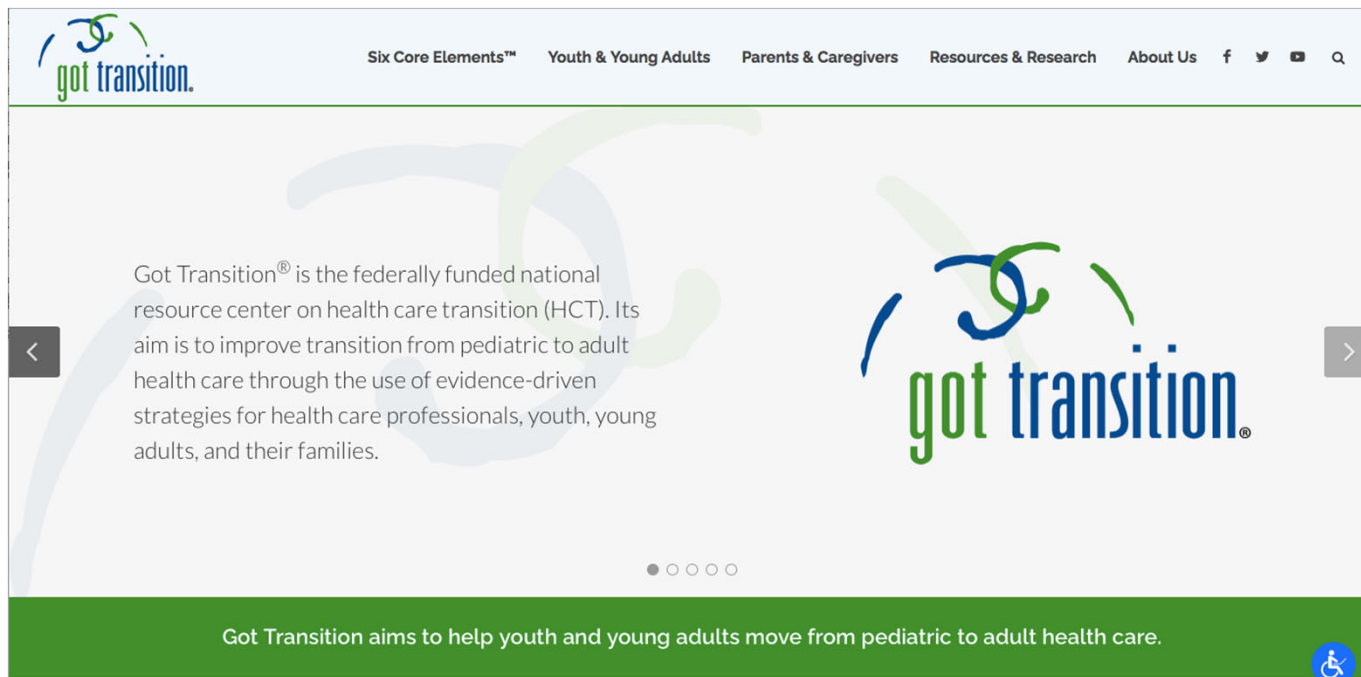


Emergency Contacts



About Me

GotTransition.org®



<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?

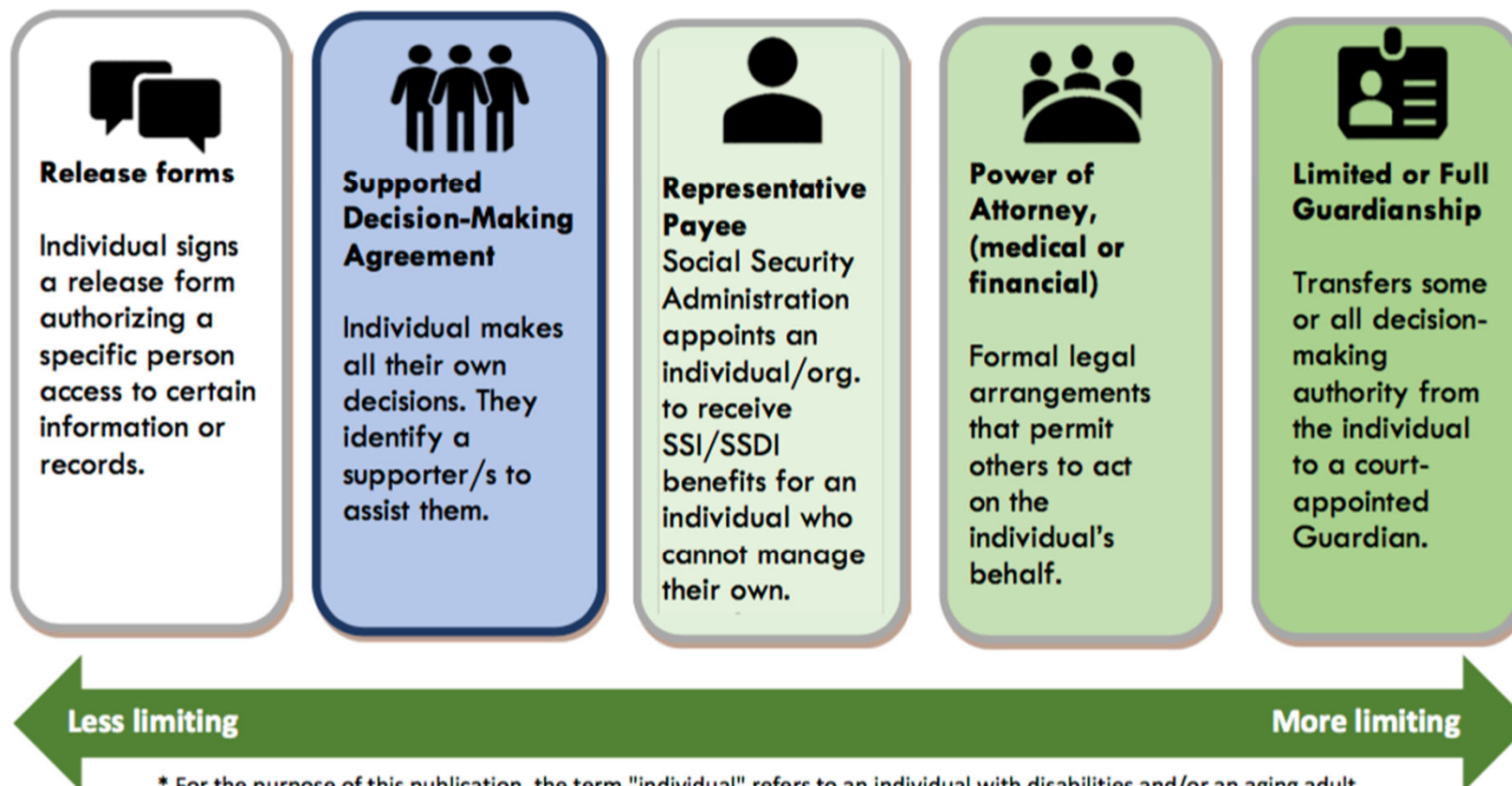
Medical
Release
Forms?



Guardianship?

Power of
attorney
for
healthcare?

Current decision-making support tools



* For the purpose of this publication, the term "individual" refers to an individual with disabilities and/or an aging adult.

<https://wi-bpdd.org/>



COVID-19 ▾

Home

About ▾

Get Involved

Resources ▾

Contact Us



We want to unite ALL of Wisconsin in supporting people with developmental disabilities to lead their most independent lives.

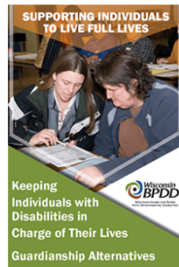


Our Toolkits

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?

Contact Information

- ▶ Julie Hajewski
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- ▶ Amy Lyle
- ▶ adlyle@waisman.wisc.edu