

Integrated transition planning for youth with disabilities creates 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. We know that every child is different, so every idea might not be right for your family. This fact sheet focuses on planning for transition from pediatric (child-centered) to adult healthcare systems.

Start the Process Early

Families can prepare youth for healthcare transition. This can start as early as age ten or when they are developmentally ready. One example is to talk about daily medications. Explain what each medication does, what each looks like, and when it's taken. Visual schedules and other tools can be used. At doctor visits, encourage and coach your youth to speak directly with medical providers, ask questions or explain concerns. You may need to ask or model for the provider how to speak directly to your youth.

During a youth's teen years, continue to encourage them to take more responsibility for their health care, such as checking in at clinic visits, carrying a list of emergency contacts or entering them into their phone contacts, refilling prescriptions, and preparing questions before appointments. If providers send you electronic reminders, ask that they are also sent to your teen's phone.

Tip for Families

A great way to start preparing your youth for transition is to encourage them to speak alone with their medical providers. Before a visit, write down or record in their communication device a few questions they can ask their doctor. For more information, Got Transition® provides a list of differences between the pediatric and adult healthcare systems and transition tips.

gottransition.org/resource/?pediatric-vs-adult-care-differences

Self-Advocacy is Key: As with other parts of a youth's transition to adulthood, learning to advocate for themselves around their health and medical needs is essential. Identifying with, and explaining their diagnoses are important steps toward independence. When a child is old enough to understand their diagnosis, parents can help them choose if they want to disclose their personal information at school, at a job or to others in the community.

Right to Privacy: Parents are surprised to find out when their child's rights to privacy changes. In most systems, at **age 12**, children have the right to speak to their doctor alone about their health care, including reproductive and sexual health topics. Prepare yourself by asking the medical provider how they handle this change for their patients and talk with your child before their visit.

Important

Be sure to check that any new medical providers accept your insurance and/or Wisconsin Medicaid. Also, check with your pharmacy and medical supply or adaptive equipment companies to learn about coverage changes that may occur at age 18.



When Will my Youth Transition to Adult Healthcare Providers?

If the healthcare providers are pediatricians or pediatric specialists, the youth will need to move to adult providers at the age of 18, 21 or 26 depending on the clinic or health system's guidelines. If the youth sees a family medicine doctor, there will be changes in consent and privacy. Talk with your child's primary care provider about the steps to take toward transition and ask for recommendations for adult providers who have experience with the youth's condition or diagnosis.

Tip for Families

Contact Covering Wisconsin, **877.942.6837** or coveringwi.org to find affordable health coverage for young adults. And, read our [Health Coverage Options for Young Adults](#) fact sheet for more resources.

Differences between Pediatric and Adult Healthcare Offices

Parents tell us that the move from having their child at a children's hospital to a general hospital can be startling. Wisconsin's children's hospitals are family-focused and offer coordinated care if multiple medical specialists are needed. While it is not universal, starting at age 18, youth will be admitted to a hospital facility or unit that cares for adults. Related to consent rights, providing family input, staying overnight in your adult child's room, and/or coordinating their care, may take more assertive parental advocacy and self-advocacy by the young adult.

Differences that Families Notice

One big difference is the environment of the adult provider's waiting area and office. The colorful waiting rooms decorated with child-friendly pictures are gone. While most adult healthcare providers try to be warm and welcoming, children's providers tend to emphasize this more.

Finding New Adult Healthcare Providers

When looking for a new doctor, think about the location, the accessibility of the clinic and exam rooms, the provider's familiarity with your young adult's medical condition, and whether the provider can coordinate care with other specialists. Even if your young adult stays with their current doctor after age 18, be aware that if they are admitted to the hospital, they will be placed in a hospital for adults rather than a children's hospital. For more information, see [The Pacer Center's Transition to Adult Health Care](#).

Legal Considerations

Starting at age 18, or as young as age 12, federal law requires parents get written consent from their young adult (the patient) to keep access to their medical records and communications with their medical providers. This includes electronic access, like MyChart or similar platforms. The youth needs to sign a **Release of Information** form to continue your access to their records. Talk with your clinic or health system to find out what they require.

In the case of mental health care, state law allows minors to maintain privacy from their parents as young as age 14. Learn more about these changes at [Transition for Youth with Mental Health Needs](#).

Families need to discuss whether guardianship, or other less restrictive options, like Supported Decision-Making Agreements, need to be activated to support a youth's healthcare decisions. To learn more about these and other legal tools see the [Supported Decision-Making Toolkit](#) and our [Supported Decision-Making](#) fact sheet.



INFORMATION AND RESOURCES

- **Health Transition Wisconsin** has learning sessions, including Build Your Bridge and Dreaming Differently, videos and transition planning tools. healthtransitionwi.org/families-youth.
- **Wisconsin's Children's Resource Centers** offers one-on-one support and referrals, training, and resources dhs.wisconsin.gov/wiscway/index.htm.
- **Got Transition** includes online tools and information gottransition.org/parents-caregivers.
- **Pacer Center** has online resources and other learning opportunities pacer.org/transition/learning-center/health/transition-to-adult-health-care.asp.



Learn more about transition planning on the Family Voices website
familyvoiceswi.org/resource-library



Each family has a voice. Together, our voices will be heard.

familyvoiceswi.org