



Transitioning a Child with Extraordinary Needs to Adulthood: Important Programs to Consider

Compiled by Linda Petersen
parent of a young adult with extraordinary needs

Important Note: This document is intended to provide a starting point for parents of children who will need extra care beyond their 18th birthdays. The programs referenced often change due to administrative decisions and legislation, and administration is different in different parts of the United States. Please use this as a place to begin—a guide for knowing what might exist in your area, and suggestions for programs to seek and questions to ask. This document is not meant to replace direct information from the various agencies and government programs referenced or legal advice from an attorney.

Because the writer of this document is from Wisconsin, many references are specific to that state. However, the reader can look for similar programs in other states. All embedded links were current at the time of publication.

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The transition of any child to adulthood is a major stepping stone, but transitioning a child with extraordinary needs to adulthood takes even more planning, decision-making, and knowledgeable timing.

Some of the questions to be asked and decisions to be made include these topics:

- work and/or school
- changes in health care
- housing
- decision-making authority
- finances
- ongoing supports
- sources to go to for help

Many children with disabilities, chronic medical needs, and emotional/behavioral challenges may have had supports and programs assisting them throughout childhood. However, most of these programs are only for those under 18 years of age, or 21 and under for public education. When your child becomes 18, a lot changes. Knowing in advance about these changes and planning for them will make the transition much smoother and, hopefully, less unnerving.

Postsecondary Transition Plan

In Wisconsin and many other states, the school must have a Postsecondary Transition Plan (PTP) included in their Individualized Education Program (IEP) once the child turns 14. Included in the plan should be activities that occur while in school to help the child meet their goals after high school. Goals may be getting a job, training for a job, going to college, and/or living independently.

In Wisconsin, these transitional services, if needed, can continue in the public school setting until the end of the school year in which the student turns 21 years old. Someone who continues in the public school past the 12th grade is often called a “super senior.” You and your IEP team will decide what that would look like. It may be an individualized program for daily living skills or may be an organized vocational program with several participants. The programs may be customized to offer just a few hours a day to a full school day. Each school has its own offerings for this programming. You may want to not only check your school district’s programming, but also neighboring school districts if transporting your child to a different school district and doing open enrollment is an option for you.

After completing the traditional 12th grade, what is the next step? It could be a job, further job training, technical school, college, transitional “super senior” programming, or a combination of those.

See the FAQ at www.witransition.com for information regarding school transition in Wisconsin.

Check with your school district regarding local transition practices.

Division of Vocational Rehabilitation (DVR)

Another important piece of transition is getting your child enrolled in the Division of Vocational Rehabilitation (DVR). DVR is a program to assist individuals with disabilities with job exploration and skills training, with a goal of the individual being able to obtain and maintain competitive employment.

Who qualifies: People who have a physical or mental impairment that makes it hard for them to get or keep a job and who need vocational services to deal with their disability limitations for employment qualify for DVR.

How to apply: Fill out an online application on the Division of Vocational Rehabilitation website for your state. Then have some patience; it tends to take some time. They will contact you to set up an initial interview and collect information to determine if your child qualifies. Meetings with a DVR representative often can happen at school.

While your child is still in school, DVR can start with job interest exploration, skills training (which may include life skills, work skills and employment soft skills), interviewing skills, and discussions about what training may be needed following high school. Think ahead about what things your child enjoys and things your child can do. These things may be able to be incorporated into a job.

Further information about DVR: The Division of Vocational Rehabilitation is an important funding source. They help people get competitive community employment and assist them with keeping their jobs. After enrolling in DVR, an individual is assigned a DVR counselor. The counselor creates the plan of what services will be given and paid for. Other agencies are selected to actually provide the services.

Some possible services that could be included:

- Vocational counseling
- Job development/assessments—analyzing what jobs the individual can do
- Job coaching/skills training
- Job shadowing
- Short-time work experiences
- Job trials
- Job search and placement
- Assistance in job application/resume creation
- Assistance with interviews
- Transportation to a job
- Training/education if needed for a specific job
- Benefits analysis

Working with DVR is not long-term. DVR assists and funds services until a person successfully has a job for at least 90 days. Then the staff will close the person's case. After that, employment supports such as job coaching and transportation can continue with funding from a long-term care program (to be discussed later).

Project Search

Another good program to consider is Project Search. Project Search is a vocational program through which a school district, DVR, and a major employer collaborate to give students training in job skills. Training includes things such as filling out a job application, writing a resumé, interviewing, and gaining job experience as interns at the company associated with Project Search for the length of a school year. The program is for students aged 18 to 21 who have completed their regular high school programming but have not yet “officially graduated” (i.e., are in that “super senior” time frame). Enrollees must also be enrolled in DVR and have been or become enrolled in a long-term care program (to be discussed later). Project Search also requires participants to accept official graduation from their high school at the end of their Project Search year; in other words, even if they are under 21 years old, they will no longer qualify to stay in high school.

Education After High School

Under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, a student with disabilities has the right to reasonable accommodations at a **college or technical school** that receives federal funding. It is not like an IEP for high school. The course content or standards are not altered, but certain accommodations may be allowed, like extra time or use of assistive technology. Each school is different, so you need to check with the Disability Services office at the individual institution.

Other options for education beyond high school are **Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID)**. These college programs for students with intellectual disabilities provide a mix of courses specific for those with disabilities and other courses that include people without disabilities. See www.thinkcollege.net for a directory of programs and more information.

Decision-Making

Another big topic to consider is this: Is your child able to handle the decisions that are placed on an adult?

Consider that unless legal steps are taken in advance, you will not be able to make decisions for your son or daughter once they turn 18. You may be the parent, but after 18 all those papers you used to sign to give permission are no longer for you to sign, as permission will be up to your adult child. There is a learning curve for any young person, but you need to evaluate if your child is cognitively able to understand if they should sign a contract or consent to surgery, or at least understand that they need more assistance or information first. Do they understand it might not be a good idea to give a stranger \$1000 because they want them to be their friend? Think of all the decisions you need to make as an adult. If your child will not be able to make those decisions safely, you might want to consider guardianship.

Guardianship

Qualifications for adult guardianship: The individual needs to be at least 17 years and 9 months old or older at the time of the court hearing (but see below as you will want to start the process sooner); lacks evaluative capacity—the ability to understand essential information and use the information to make a decision and communicate it; has an impairment like a developmental disability, mental illness, or brain disorder; and is at risk of harm.

Guardianship requires a lot of careful thought. That is why you should start thinking about and researching it well in advance and figure out what is right for your child. In the State of Wisconsin, for example, guardianship forms have many lines for various rights with checkboxes for if a person “retains that right,” “limits that right,” or “is incapable of exercising that right.” The boxes could be quickly checked and all rights taken away, but that may not be in the best interest of your child. These should be considered carefully, only limiting the rights that need to be limited. Keep in mind, while you might start out as your child’s guardian, when you no longer can do the job, someone else will need to take over.

A resource that gives excellent information for the State of Wisconsin is “Guardianship of Adults,” which is put out by the state’s Department of Health Services (DHS) and is available online. It explains the guardianship process and goes over rights and powers, helping to explain what each item implies and what you should consider when deciding to limit or not limit it. Guardianship paperwork for the State of Wisconsin is available at www.wicourts.gov: click on Forms>Circuit Court>Guardianship>Due to Incompetency.

“**Guardian of Person**” deals with healthcare, living situation, marriage, etc.

“**Guardian of the Estate**” deals with decisions related to property, money, and contracts.

To get adult guardianship, the hearing cannot be before the person is 17 years and 9 months old. But before the hearing you will need to do your research, have your child’s physician or psychologist fill out a report for the court, file a petition for guardianship, and have your child meet with the guardian ad litem. The petition papers to begin the process cannot be filed until the person is 17 years and 6 months old. After a person turns 18, the guardianship process is a lot more complicated and best left to the lawyers.

Guardianship is done in the jurisdiction where the ward lives. Guardianship paperwork is the same statewide but is regulated at the county level. Guardianship varies by state. Each county also varies in some of the policies, such as how much you can spend on an item before needing a judge’s approval.

Guardianship goes through the county Register in Probate. That is where you would file the petition for guardianship. They cannot give you legal advice, but they can tell you about the county’s policies of guardianship, how long it will take from the time of filing the petition to the hearing date, and attorneys who may serve as the guardian ad litem (a lawyer representing the child’s interests). They may also be able to tell if your county has a program where lawyers offer free advice, which would usually be a brief 10-minute consultation on specific questions.

Obtaining guardianship requires a hearing in court in front of a judge with the prospective guardian(s), your child, and the guardian ad litem. It is not necessarily as scary as it may sound.

Other low-cost information sources: Many jobs offer employee assistance programs that include a legal consult. Lawyers may offer a low-cost initial consultation. While some counties

allow parents to seek guardianship without a lawyer representing the potential guardian(s); a guardian ad litem attorney for the ward is required. Check with your county Register in Probate office to see what is required in your area. Another source of help in Wisconsin is Wisconsin Guardianship Support Center: <https://gwaar.org/guardianship-resources>. The support center has lawyers who can advise you on general guardianship questions.

Even if you hire a lawyer to do the paperwork, do your research so that they don't just check all the boxes to keep all rights away, unless that's what your child really needs!

Power of Attorney for Health Care

Every adult, disabled or not, who doesn't already have a Guardian of Person, should have a Power of Attorney for Healthcare. This document tells doctors who you would want to make medical decisions for you if you are unable to do so. For example, if you were in an accident and would benefit from one of two possible surgeries, the person you appointed could consent to the surgery they believe you would have chosen if you could speak for yourself.

Who can sign a power of attorney: You must be at least 18 years old and "of sound mind". Someone who is judged to be incompetent would need to have a Guardian of Person.

If someone becomes incompetent before signing a power of attorney, they may need to go through guardianship to have healthcare decisions made.

Forms for Wisconsin and further information can be found at <https://www.dhs.wisconsin.gov/forms/advdirectives/adformspoa.htm> .

States vary somewhat in forms. Search for your state's "Advance Directives" or "Power of Attorney."

Power of Attorney for Finances

If your young adult is not "incompetent" and is able to sign legal documents on their own but needs help managing their finances, a Power of Attorney for Finances may be an alternative to a Guardianship of Estate.

With a durable power of attorney, a person doesn't give up their right to control their finances, but they also give an agent the authority to handle those finances. The person still has access to their money, which has pros and cons to it.

Forms for Wisconsin and further information can be found at <https://www.dhs.wisconsin.gov/forms/advdirectives/adformspoa.htm> .

Supported Decision-Making

As of 2018, Wisconsin law formally recognizes supported decision-making agreements for adults with functional impairments as legal documents. Some other states also recognize these agreements. The National Resource Center for Supported Decision-Making website www.supporteddecisionmaking.org gives information on individual states.

Supported decision-making is not a form of guardianship or power of attorney. The person makes all their own decisions. The supported decision-making form formally lets other people

like doctors, bankers, teachers, etc. know that you have one or more specific supporters you would like to help you with decisions in certain areas and that you give consent to have information related to that decision shared with the supporter(s). You may still need to have release of information forms signed.

Note: You can still use supporters for decisions, as we all do, without this document.

Supported Decision-Making forms are online and are easy to fill out and sign.

For Wisconsin Supported Decision-Making forms and further information, see <https://wi-bpdd.org/index.php/supporteddecision-making>.

Supplemental Security Income (SSI)

There are Federal and State components to SSI. SSI provides monthly payments to meet basic needs for food, clothing, and shelter. The basic amount of SSI is the same nationwide. The amount received for the federal portion varies depending on your living arrangement and countable income. Many states add money to the basic benefit.

Eligibility:

- Have a qualifying disability, or be age 65 or older
- Have limited income
- Have limited resources

Generally, if you are working and earning more than \$1,470 per month (effective January 2023), social security will not find you disabled.

Resources need to be less than \$2,000. See below.

The Disability Determination Services agency (DDS) decides whether or not you are disabled according to the SSA definition of disability. An impairment is considered severe if it significantly limits your physical or mental ability to do basic work activities.

Applying: If your child is already getting SSI as a child, they will need to re-apply as an adult.

Your child can apply for adult SSI shortly before their 18th birthday. Contact your local social security office and set up an appointment with a representative. You can start the application online, but you will still need an appointment with a representative to complete the application.

If you do not have guardianship, the young adult will need to be present and sign documents.

A representative payee will need to be appointed if they cannot manage their own benefits.

Since SSI is meant to provide for food and shelter, if the person is not paying for their share of living expenses and food, their SSI amount is reduced by one-third. So, even if your young adult continues to live with you, it may benefit both of you if you charge them room and board.

The amount of Federal SSI is adjusted monthly based on other income received. Wages, gifts, interest income, and other benefits are reported, and the SSI amount for the following month is adjusted. In-kind income is also counted. In-kind income is food or shelter a person gets free or for less than market value. A formula is used so that if the young adult works, not all of the

wages count against their SSI. However, the person can make too much money and lose their SSI benefit. (See Benefits Analysis below.)

What does "limited resources" mean? An individual is allowed no more than \$2,000 in resources (assets). Countable resources include cash, bank accounts, stocks, mutual funds, cash value of life insurance, property, and anything else that could be changed into cash and used for food or shelter.

If your child has resources over this amount, it should be used on your child before applying.

An ABLE account can also be used to help manage a person's resources while they receive SSI and/or Medicaid. ABLE accounts will be discussed further below.

When a person gets SSI, they may also get Medicaid/Medical Assistance (MA) from their state. MA eligibility is a requirement of long-term care support. Both of these will be further discussed below.

Sources to find additional information: The Social Security Administration website at <https://www.ssa.gov> is an important source of information to understanding SSI. Additionally, a publication called "One Step Ahead" by Roy Froemming is available online and contains a wealth of information on how SSI works and important information on how to manage it.

Benefits Analysis

A **benefits analysis** can be done to help determine how working would affect their benefits—the maximum that person can make in their situation and still get SSI, what the break-even point is with working and benefits, etc. The agency that does the analysis may also be able to direct the person to additional benefits they may qualify for. A benefits analysis can be put into the plan with DVR, and DVR will refer the individual to a benefits specialist and pay for the analysis. If your child is not enrolled in DVR, contact your county's Aging and Disability Resource Center (ADRC) for assistance.

Medicaid (MA)

When you get SSI, you may get Medicaid (sometimes also called Medical Assistance, or MA). Medicaid is run by the state. The program details and eligibility criteria vary from state to state. A person may be automatically enrolled when they qualify for SSI. Many states also have MA for low-income people. Check with your county's Aging and Disability Resource Center. Medicaid also has the same \$2000 resource (asset) limitations.

MA pays for doctor and hospital bills. It is secondary to any other health insurance you may have. So, if someone is covered by their parents' health insurance or Medicare, it goes through the other insurance first before going through MA for payment. If a person has MA and the facility providing services accepts MA assignment, there may have little or no bill. But a word of caution: Because MA tends to actually pay the facilities very little, not all providers accept MA assignment. This is particularly true of dentists. If they know you have MA, they may not be able to accept you as a patient even if you have other insurance or means of payment.

MA can also assist with medical transportation. The MA recipient simply calls the contracted agency and tells where and when the medical appointment is, and they set up and pay for

transportation, or they provide gas mileage reimbursement at a set rate per mile if you have your own transportation.

For more information: Medicaid varies state to state. See www.medicaid.gov and click on your state. Contact your county's ADRC or economic support department for enrollment or additional information.

Long-Term Care Support (sometimes called Medicaid Waivers)

Each state has their own names and programs for long-term care support. The point of these programs is to provide the support people with a disability need to be able to live in a home setting instead of an institution.

Resources to find information for your state: Check the website for your state's department of health services (DHS), search for your state's Medicaid waivers program, or contact your county's ADRC (Aging and Disability Resource Center).

Eligibility:

- Be 18 years of age or older
- Be a frail elder or an adult with a disability
- Be eligible for Medicaid
- Be functionally eligible: need the level of care that would meet the state's eligibility requirements for services in an institutional setting; a functional screen is done to verify

How to enroll: Apply through your county's ADRC.

Wisconsin has two long-term care support programs. One is called **IRIS** and the other is called **Family Care**. IRIS stands for "Include, Respect, I Self-direct." With IRIS, the individual decides how to use the funds allotted to them and who provides the services. They are responsible for hiring and supervising providers. With Family Care, Family Care decides and gets services for the individual. What type of living situation the person wishes to be in may influence which program to select. Once a person qualifies for long-term care waivers, the ADRC can help decide which program may be best for that person's situation.

There are layers to these programs: A screening specialist meets with the individual (and their guardian) to go through a functional screen each year to determine continued eligibility and level of need, which determines the level of funding available to the individual.

In the case of IRIS, an IRIS consultant agency is chosen and an IRIS consultant assigned. This consultant will help develop a plan for services within the budget allotted. The consultant also helps with the necessary paperwork. A financial agent, who actually pays for the services, is chosen.

Some included services:

- Adaptive technology
- Adult day care center
- Education and training for the recipient and their workers
- Counseling and therapeutic services
- Individual directed goods and services
- Daily living skills training
- Day services
- Home-delivered meals
- Home modifications (like ramps)
- Housing counseling and startup
- IRIS self-directed personal care
- Prevocational services
- Vocational futures planning and support
- Nursing services over Medicaid coverage
- Personal emergency response system
- Residential care apartment complex
- Adult family home
- Support broker
- Supported employment
- Supportive home care
- Transportation-for employment, community, and non-medical needs

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs both have the same disability/medical requirements. SSI is for people with a qualifying disability, limited income, and limited resources. SSDI are payments based on someone's work record. A person must work for a certain number of months at a certain level of income to qualify for SSDI. The number of months working that are needed to qualify varies by age at which the person became disabled. Someone can receive both SSI and SSDI at the same time.

When a person first applies for SSI, the Social Security Administration also checks if they qualify for SSDI. If the person starts working, they may at some point qualify for SSDI after they are already on SSI. In that case, social security will notify the person that they should complete an application with a representative. If a person qualifies for SSDI, a monthly payment amount will be set for the year based on previous work history. Each year, this amount will be adjusted based on what the person continues to earn at their job and a cost-of-living increase. The SSI amount the person receives will be reduced due to the amount received from SSDI. If a person continues to work and the SSDI amount increases, eventually SSDI could fully replace the SSI for that person.

SSDI has an income limitation but no resource (asset) limitation. The maximum amount of money a person can earn while receiving SSDI is \$1,470/month gross (as of 2023) which would be considered “substantial gainful activity.” As of 2023, any monthly earnings over \$1,050 per month will automatically trigger what is called a trial work period. As long as the person does not work more than nine months within a 60-month period earning over \$1,050 and remains medically disabled, they will keep benefits. If the person is earning between \$1,050 and \$1,470 per month during that time, an evaluation will be done to see if they are able to perform substantial gainful activity.

While a person gets SSDI, they also qualify to get Medicare. There is a 24-month waiting period to get Medicare once an individual qualifies for SSDI. In Wisconsin when an individual is on both SSI and SSDI, they will continue to receive Medicaid and once they receive Medicare, the Medicare premiums will be taken care of by Medicaid. Because Medicaid rules vary by state, check how your state handles Medicare premiums of Medicaid recipients.

Remember Medicaid goes with SSI. If a person no longer receives SSI (for example, due to the amount of increased SSDI) the SSI-based MA will stop. But a person still can qualify for Medicaid with a disability, low annual income, and assets less than \$2,000. But that person would need to reapply through the county. A person can also apply with the county to get Medicare premiums paid through Medicaid.

Neither SSDI nor Medicare has an asset limitation.

An adult child may also qualify for SSDI through their parents’ earnings records, if either parent receives SSDI, social security, or dies. Consult with the Social Security office for information and to apply.

Medicare

After a person qualifies for SSDI benefits for 24 months, that person then qualifies for Medicare. Medicare is federal health insurance for anyone age 65 and older and some people under 65 with certain disabilities or conditions. Medicaid may pay or help with Medicare premiums and other medical expenses not fully covered by Medicare. If a person still receives SSI, they still qualify for Medicaid. If they no longer receive SSI, they may apply to get or keep Medicaid through that state if income and resources are limited. Because Medicaid varies state to state, check with your state MA agency or county economic support dept.

Other resources:

- www.ssa.gov
- www.medicare.gov

ABLE Accounts

ABLE stands for Achieving a Better Life Experience. ABLE is a special account that can be established for people with disabilities who qualify.

This account *does not* count against the \$2,000 asset limit for SSI or MA, provided the ABLE account balance is below \$100,000.

If people give money directly to someone receiving SSI or MA, that money must be reported to Social Security and that would reduce the person's benefits or possibly may eliminate them from programs. However, anyone could contribute to an ABLE account for the person's benefit without jeopardizing the programs. The total of contributions allowed for one year is \$17,000 (as of 2023). The beneficiary of the account can also contribute to it and can in that way lower their assets to stay below the \$2,000 limit required for SSI and MA. (If the person is working, their contributions may increase the total contribution limit; see rules of ABLE accounts.)

ABLE accounts are not taxed. The funds in the ABLE account can be used to purchase a "qualified disability-related expense" which is defined as any expense related to the person's disability that assists them in increasing and/or maintaining their health, independence, and/or quality of life. This could be a wide variety of things, such as expenses related to housing, education, transportation, training, and more.

An ABLE account can be very helpful for several reasons. It gives a place to save money for future expenses and gives a place where other people can give the disabled person money without jeopardizing the programs that person depends on. It also helps in managing the person's own finances to prevent countable resources from going over the allowed \$2,000.

Upon the beneficiary's death, Medicaid can request payback from the ABLE account for Medicaid costs that were used while having the account.

Eligibility: People who have significant disabilities that onset before turning 26 years of age may be eligible. If those people are already receiving benefits under SSI and/or SSDI, they are automatically eligible. If a person is not receiving SSI and/or SSDI, but still meet the age of onset disability requirement, they could still be eligible if they meet Social Security's criteria of significant functional limitations and receive a letter of certification from a licensed physician (MD or DO). A person doesn't need to be under 26 to open an account, but their disability must have occurred before 26.

Many states, but not all states, have ABLE accounts. Wisconsin currently, as of 2022, does not have an ABLE account option. But a person can choose an ABLE account from a different state. Many, but not all, ABLE account administrators accept out-of-state participants. Different accounts have different features, so it is best to review them to decide which is best for your situation. A person is only allowed one ABLE account at a time but can switch accounts if they like.

How to get started: Go to the ABLE National Resource Center at www.ablenrc.org to see the different options and how to sign up. This website tells what you need to know about ABLE accounts and even has webinars to listen to.

Note: An ABLE account is not a special needs trust or a replacement for one. The two work differently and have different rules and benefits. You may want to have one of each.

Transitioning to Adult Healthcare

Parental medical information: Once your child turns 18 years old, you will not be able to get medical information for or about your child UNLESS your young adult signs a medical release of information form giving you permission for this information, or you are their guardian and have filed guardianship papers with their medical providers.

Your child may have had a pediatrician and/or pediatric specialist, and now is the time to transition to an adult provider. Their current provider may guide you as to when they think that transition should occur. When looking for an adult provider, you can ask for recommendations from their current provider or ask other families who have young adults with disabilities. Additionally, many clinics have referral assistance to find an appropriate provider for your young adult's condition(s).

Because this new provider hasn't been with you through the years, it would be helpful to give the new provider a summary of your child's important medical history. For specialists, include where they were previously seen for that specialty and recommended follow-ups for the specialty.

Transition is also a good time to promote your child's increasing participation in their medical visits. As they are able, have your young adult check in for appointments on their own, carry their own insurance card(s), and discuss issues with the doctor. Teach your child how to talk about their disability and their needs and what is appropriate to share with whom.

Housing

There are several options to decide between when it comes to housing. With the right support services in place, a number of possibilities exist. Housing could be rented, owned by a parent and rented to the individual, owned by the individual, or owned by a trust for the benefit of the individual.

Here are some possible housing options to consider:

- At home with parents or other family caregiver(s)
- A separate living space within the family home
- A separate apartment/duplex/condo next to family members
- Shared living in a house or apartment with a roommate or roommates that can support the person (The roommate may be a student studying special education or social work, for example, and be paid to provide supportive home care and/or given reduced or rent-free housing in exchange.)
- On their own and having support services come into the home
- In a supervised/supported apartment where staff and support services are available
- A housing community that has is a mixture of residents, some with disabilities and some without, that share community spaces with support services available.
- Residential Care Apartment Complexes (RCAC)—independent apartment complexes where five or more adults live, each with their own lockable apartment.

Residents can receive up to 28 hours of supportive, personal, or nursing services per week

- An Adult Family Home (AFH)—a place where three or four adults, not related to the operator, reside and receive care and services above room and board but no more than seven hours of nursing care per week
- Community Based Residential Facilities (CBRFs)—places where five or more adults, not related to the operator, reside and receive care and services above room and board, including up to three hours of nursing care per week.
- Skilled Nursing Facilities—providers of care for people who require more complex care

Possible support services:

- Supportive Home Care can support individuals with meal prep, bathing, dressing, housekeeping, and companionship.
- Home Care Nursing is nursing care provided in the home.
- Adult Day Care is a facility that individuals can go to for part of a day and get assistance with activities of daily living, supervision, and/or protection in a group setting.
- Respite Care provides services that allow the regular caregiver time off.

Resources to locate the support services you may need:

- Your county's ADRC
- Your long-term care consultant
- The Center for Independent Living in your area

Spiritual Care

Even for teens without disabilities, the transition from childhood to adulthood can be a challenging time spiritually. Will the child who regularly worshiped and prayed to God because that's what their parents continue to stay close to their Lord on their own, in adulthood? During this transition time, it can be helpful for parents to talk with their young adult children about this topic. Find out what would be the most helpful to them in staying close to their Savior. In the Wisconsin Evangelical Lutheran Synod (WELS), we have various spiritual resources for adult with disabilities available through WELS Special Ministries and Jesus Cares Ministries. A number of books on Amazon and in bookstores have ideas for families and churches, such as *Autism and Your Church: Nurturing the Spiritual Growth of People with Autism Spectrum Disorder* by Barbara J. Newman. Most importantly, help your child develop a plan with leaders at your local church. Together, consider these questions:

- How can your child continue to receive instruction in God's Word? (This should not end at confirmation; continued Bible study is very important!)
- Will your child have transportation needs to get to worship services, and can the church help with that?

- Are there things that the church could do to enable your child to worship more easily, such as providing large print, sound-blocking headphones, an area for movement during the service, and the like?
- How can your child use their God-given abilities to serve within the church?

While financial, health, housing, and other planning can be complex and time-consuming, spiritual planning is also important. Nothing is more valuable than your child's soul!

Other Things to Think About

If your young adult doesn't have a driver's license, they should get a **state ID card** when they turn 18.

Every male needs to register with **selective service** within 30 days before or 30 days after his 18th birthday. Register online at sss.gov or at a post office; some high schools also have someone who can act as a registrar.

Is **your will** up-to-date? The people you selected to be **guardians** for your children in your will when your children were young may not be willing to be the guardians of an adult with special needs. Also, does your will include a **special needs trust** for your child? Receiving a direct inheritance would likely knock someone out of programs like SSI, Medicaid, and long-term care support waivers that they use to fund needed services. A special needs trust allows funds to be kept for the benefit of a person with disabilities without jeopardizing their benefits. Use an experienced lawyer for a special needs trust.

If something happens to you (the caregiver, support person, and/or guardian), does anyone else know how to help your child? One recommendation is to have a three-ring **care binder** with information that someone could follow if you were unable to help your child.

Care Binder Example

Here are examples of what I included in the binder for my son:

- **First calls**—who to call if something happened to me, such as my other son who could help in an emergency and the person we have recommended to be a guardian if my husband and I can't, the Register in Probate for my son's guardianship, the Social Security Office, my son's employer, and his IRIS consultant
- **What I do when**—what I need to do for my son daily, every other week, monthly, quarterly, yearly, and as it happens
- **Current medications**—what each is for, who prescribed it, and any special information; medication allergies and pharmacy name and phone number
- **His current medication schedule**
- **List of his doctors**—name, specialty, location, phone number, and how often he usually sees them
- **Phone numbers of special people in his life**
- **Summary of his medical history**— a brief narrative of important events, then categorizing his issues by systems, similar to how doctors categorize: musculoskeletal,

cardiac, psychologic, etc. (also includes family history and where I keep further medical records)

- **The programs he uses**— a section for each program, how it works, and what someone helping him would need to do about it
- **Guardianship papers**
- **General information about his condition**
- **His resume with references**

I also have a copy of his autobiography he wrote for an assignment in grade school.

Additional Transition Resources

In addition to the resources noted in the individual sections, here are some places to find information on transition and programs available for transitioning young adults:

- www.pacer.org —PACER is the Minnesota Parent Training and Information Center
- www.dhs.wisconsin.gov —Wisconsin Department of Health Services
- Your state's Department of Health Services
- www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm —Wisconsin's regional centers for Children and Youth with Special Healthcare Needs
- Your regional center for Children and Youth with Special Healthcare Needs
- Your county's ADRC (Aging and Disability Resource Center)
- Your local high school

This guide can help serve as a starting point to be familiar with programs that may help you and your child/young adult as they transition into adulthood. Use the included resources and those available in your area to check for updates and for the programs that apply in your situation.