

Navigating the Maze of Housing and Services: *Advocacy Tips*

When your young adult with a disability graduates from high school, a transition program, or college, many aspects of their life will change. Outside the education system, your young adult will need to find new ways to receive services to support living, working, and playing in the “most integrated setting.” The most integrated setting is one in which individuals with disabilities spend time with those without disabilities as much as possible.

There is limited availability of housing options and supports for adults with disabilities, and many services involve complicated timelines and long waiting lists. Your young adult’s disability alone does not entitle them to access housing and services — first, they must meet eligibility criteria.



Parents have a legal right to advocate for their children and young adults with disabilities. Here are some helpful tips to help educate you on how to advocate for appropriate services for your young adult in the most integrated setting.

Tip #1: Organization is key

When your young adult begins the journey to access housing and other services, you will be working with multiple agencies that will need the same information. It is helpful to gather and organize your young adult’s documents and make additional copies for your files.

Tip #2: Create a filing system

Your filing system, on paper or on your computer, should include:

- **Services timeline:** Create a timeline of services and supports your son or daughter has received from birth to present.
- **School records:** Include your young adult’s Individualized Education Program (IEP) and supporting documents, such as Functional Behavior Assessment and Behavior Intervention Plan, Section 504 Plan, and Summary of Performance. If your daughter or son has a Work-Based Learning Plan or related employment information, add that to your file.

- **County services:** If your young adult is receiving services through Children’s Mental Health, Home Health Care/ Personal Care Attendant (PCA), Home and Community Based Waivers: Consumer Directed, Community Directed Community Supports (CDCS), or traditional waivers for Developmental Disabilities (DD), Community Access for Disability Inclusion (CADI), Community Alternative Care (CAC), or Brain Injury (BI), gather those plans and documents associated with those services.



- **Medical records:** Include your young adult’s recent medical evaluation, diagnostic assessment, and records from related service providers (occupational therapy, physical therapy, speech/language, alternative augmentative communication [AAC]). If there have been any recent hospitalizations or services received in any residential or treatment facilities, include copies of the discharge summaries.
- **Legal guardianship documentation or Letter of Intent:** Have updated documentation (dated within the year) or a signed letter from your young adult stating that they want you to be involved with helping them navigate the process. Include a signed Healthcare Release for Information for individual providers.
- **Contact information:** For all medical providers, close family and friends, and others who are important to your young adult, include their name, professional title, relation to your young adult, mailing address, phone number, and email address.

For more information, see the following PACER fact sheets at PACER.org/publications:

- Documents to Keep for Youth Transitioning to Adult Life (NPC-33)
- Keeping & Organizing Medical Records (HIAC-h17)
- Resolving Special Education Issues: Keeping special education records (PHP-c94)
- What if My Child is Not Capable of Representing Him or Herself? Guardianship May be Needed (NPC-14)

Tip # 3: Make a one-page profile

Create a one-page profile that introduces your young adult to those who do not yet know them. Add a description of what is important to them and how to best support them. Include photos and language from their point of view to show your young adult’s strengths, needs, and hopes better than school records or medical diagnoses can.

For more information, see PACER’s Housing Projects page:

- “Getting Started” tab (PACER.org/housing/gettingstarted)
- “One Page Profile” template (PACER.org/housing/pdf/housing-one-page-profile.pdf)

Tip #4: Plan for and keep track of all communications

Prior to calling to apply for services, make a list of your concerns and questions, and keep that list in the paper or electronic file you created.

- Write down the name and job title of the person you speak with, date and time, contact information (phone number and email), and their response to your questions, including when they will get back to you.
- Request that any information you receive be given to you in writing.
- Ask that they document that you called so you can refer the next representative to the “notes on file” and don’t have to start from the beginning on every call.
- Let them know you will be following up with them.
- No matter the outcome, be respectful.

Here are some specific questions you may want to ask:

- “What is the process for this service I am requesting?”
- “What are the timelines associated with this process?”
- If you need clarification, use statements such as:
 - “I think I understand what you are saying. [Repeat what was said.] Is this correct?”
 - “Tell me more about what that might look like, so I understand it clearly.”
 - It is okay to say, “I’m sorry I just don’t understand that. Please explain it again.”
- If you are told that your young adult probably won’t qualify, follow up with:
 - “Please tell me what information you are basing your determination on.”
 - “I understand there is a process for this. Can you please explain that to me?”
 - “Thank you. I am still requesting that a certified assessor come out to assess my son/daughter for eligibility for services so we can have ‘informed choice.’”

For more information, see these PACER fact sheet at [PACER.org/publications/health/](https://www.pacer.org/publications/health/):

- Waivers Made Simple (HIAC-h31)
- Steps to Getting CDCS (HIAC-h32)

Tip #5: Use all necessary resources

If you are not able to reach a resolution with the agencies you have contacted, PACER suggests these additional resources:

- **PACER Center’s Housing Project:** The goal of PACER’s Housing Project is to develop information and resources to help parents of children and young adults with disabilities understand their options for independent living and housing. This project helps parents understand why it is important to consider housing options during their son/daughter’s high school and transition-age years, what supports and services exist, and what information and referral resources are available to meet their needs. [PACER.org/housing](https://www.pacer.org/housing)
- **County Social Services Agencies:** Call the Human Social Services Intake Line for your county listed in the MN Dept of Human Services County Information Directory. edocs.dhs.state.mn.us/lfsrserver/Public/DHS-0005-ENG

- **Regional Resource Specialists** from the Minnesota Department of Human Services can assist the public and counties with technical and policy issues. (866) 267-7655 or (651) 431-4300
- **Minnesota Department of Human Services Disability Services Division Response Center:** You may email specific questions to the MN DHS policy team. Your request will be routed to the appropriate team to provide a response. DSD.responsecenter@state.mn.us
- **Ombudsman:** An ombudsman is an advocate, free to consumers, who can assist with issues concerning the health, safety, welfare, and rights of individuals receiving health care and supportive services at home, in hospitals, nursing homes, and other community settings. mn.gov/omhdd/contact, (651) 757-1800 or (800) 657-3506
- **Disability HUB MN:** This free statewide resource network helps consumers solve problems, navigate the disability services system, and plan for the future. disabilityhubmn.org/about-the-hub, (866) 333-2466
- **Housing Benefits 101 (HB101):** This resource helps people who need affordable housing and supports to maintain it understand the range of housing options and support services available. HB101 can help young adults make choices about where they want to live. It can also help them make a long-term housing plan and take the steps necessary to meet their housing goals. mn.hb101.org
- **Disability Benefits 101 (DB101):** This resource provides tools and information on health coverage, benefits, and employment, which will help you plan and learn how work and benefits go together. mn.db101.org

Navigating the adult services world can be challenging. While your young adult is now in the driver's seat, you are there to support them on this lifelong journey. By becoming knowledgeable about what services are available and how to access them, you are modelling essential self-advocacy skills for your young adult with a disability and helping them express their needs and opinions. These skills will be key to accessing and receiving appropriate services, now and in the future.

This tip sheet is part of a housing fact sheet series. See companion sheet “Navigating the Maze of Housing and Services: Terminology You Need to Know.”



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Navigating the Maze of Housing and Services: *Terminology You Need to Know*

As you and your young adult enter the adult services system, you will encounter an array of new terms, acronyms, and processes. Using and understanding key terminology like the following will help you advocate for what your son or daughter needs and clarify what you are asking for.



- **Advocate:** An individual designated by a person or their legal representative to speak on the person's behalf and help them understand and make informed choices in matters related to identification of needs and choices of supports and services.
- **Informed choice:** A voluntary decision made by a person with a disability (and/or their legal representative) after they are informed of all available options for case management, services, and providers. Information is delivered using the person's primary method of communication, at a level they can understand.
- **Olmstead:** The U.S. Supreme Court decision that interpreted the Title II of the American with Disabilities Act (ADA) to include supporting people with disabilities in the most integrated setting possible. The decision applies to people of any age who have a disability. In Minnesota, professionals and/or other individuals in the disability field may refer to "Olmstead" when referring to "Minnesota's Olmstead Plan." The vision of this plan is, "Minnesota will be a place where people with disabilities are living, learning, working, and enjoying life in the most integrated setting."
- **Most integrated setting:** Defined by Olmstead as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."
- **245D Licensing:** Housing support services that are directly licensed under the Minnesota Department of Human Services (DHS) must follow enforced state standards that protect the health, safety, rights, and well-being of children and vulnerable adults. Services licensed under Minnesota Statutes Chapter 245D are the standard for Home and Community-Based Services (HCBS) waivers.

- **MnCHOICES:** A web-based application tool for conducting and creating person-centered assessments and support plans to determine eligibility for long-term services and supports. MNCHOICES includes two electronic tools, assessment, and support plans. An assessor should perform the assessment and complete it within 20 calendar days of a requested assessment.
- **MnCHOICES certified assessors:** Individuals who complete assessments and planning services for people who need long-term services and supports. Assessors must meet training and qualifications set out by the State of Minnesota.
- **Community Support Plan (CSP):** A written summary of information by the certified assessor that was completed through the MnCHOICES assessment. The summary identifies next steps based on the person's needs and is provided no later than 40 calendar days after the MnCHOICES Assessment.
- **Coordinated Services and Support Plan (CSSP):** A summary that identifies the person's needs and preferences for services, including long and short-range goals that ensures their health and welfare. The CSSP is developed and signed by the recipient within 10 working days after the case manager receives the assessment information and the Community Support Plan (CSP) by the certified assessor. A CSSP is only completed if the person is eligible for and chooses to receive publicly-funded home and community-based services and/or state plan services.
- **Person-centered practices:** A way of ensuring people who receive supports and services have the same rights and responsibilities as other people. This includes having control over their lives, making their own choices, and contributing to the community. Person-centered practices include:
 - Tools everyone can use to learn more about a person
 - Person-centered planning
 - Person-centered changes made in schools and human services settings
- **Support planning:** A person-centered process that helps people identify and access social, health, educational, vocational, and other community and natural supports and services based on the person's values, strengths, goals, and needs. The process encourages the use of formal and informal supports. The support planning process might involve:
 - Person who receives services and/or their legal representative
 - Case manager
 - Managed care organization (MCO) care coordinator (when applicable)
 - Certified assessor
 - Providers
 - Other people as designated by the person (e.g., relatives and friends)
- **Case management/care coordinator:** MN Department of Human Services uses the terms "case management," "service coordination," and "care coordination" interchangeably. These terms include activities that help people access, coordinate, and monitor needed services as they relate to the person's assessed needs and preferences. Needed services include: educational, medical, social, and vocational. Case management activities may be provided to or arranged for a person. Activities may include, but are not limited to:
 - Coordinating services
 - Developing a service plan based on a person's assessed needs and preferences

- Evaluating and monitoring services identified in the service plan
- Helping people access needed services
- Identifying potential service providers
- Informing people or their legal representative of service options
- **“A Person’s Own Home”**: Housing is evolving to provide individuals with disabilities an informed choice and appropriate funding and to allow them to choose where, with whom, and in what type of housing situation they live.

When a setting is “A Person’s Own Home,” the lease is in their name. If a person has a legal guardian, it may be the responsibility of the legal guardian to sign a lease on behalf of the person, depending on what the court identifies as the guardian’s responsibilities. The person or their legal guardian:

- Decides who lives in the home with the person (under the restrictions of the lease agreement)
- Decides who provides services to people who live in the home
- Decides who is responsible for the maintenance of the home

For more information on these terms and processes, see PACER’s Housing Project page at PACER.org/housing.

Additional resources can be found at:

- The Minnesota Department of Human Services website at mn.gov/dhs/people-we-serve/people-with-disabilities
- Minnesota Department of Human Services, Community-Based Services Manual at <https://tinyurl.com/yx7grmu7>

Content in this tip sheet sourced from the Minnesota Department of Human Services “Community-Based Standards Manual.”

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Tips When Considering Housing and Services

When you consider your young adult's future life, where they live is important. It's crucial that you talk with your young adult about their vision for housing and independent living, so you can support their needs and desires.

Every young adult has different abilities and needs, and some parents will need to be more involved in this process than others. Many housing options and supports involve eligibility criteria, timelines, waiting lists, and limited availability to obtain services. Planning early for housing leads to better outcomes.



Tip #1: Shift your thinking and put your young adult in the driver's seat

Parents are usually the primary decision makers for their children. Now is a good time to see your young adult as part of the larger community and put them in the driver's seat so they are at the center of the planning process. This is called "person-centered" thinking and planning, which is a process driven by the unique likes and dislikes of the person involved and their family.

Person-centered planning uses a set of written and visual tools to assist your young adult's team to define a vision for how they want to live a meaningful, self-directed life. The following questions encourage person-centered thinking:

- What are your young adult's unique hopes and dreams?
- What are their favorite places, activities, and people?
- What rituals and routines provide them with consistency, comfort, and happiness?
- What is necessary for their health and safety?
- What do people need to know and do to best support them?

Tip #2: Assess your young adult's support needs

You will need to help determine your young adult's ability to live in a home of his or her own. This information is key when you work with outside agencies to determine the level of support services that will be required for your child to live as independently as possible outside the family home. Consider the following:

- How much daily assistance does your young adult require? Can they dress, bathe, cook, and organize their day on their own, with some assistance, or with complete assistance? For example, do they need assistance with shopping, managing their finances, or medication management?
- Does your young adult need help with behavior, communication, or to stay on task?



Tip #3: Talk to your young adult about where they want to live

Does your young adult prefer to live close to family and friends in familiar surroundings? For some, the relationships they have in their communities are very important and those close to your young adult may serve as “natural” (unpaid) supports. Family, friends, neighbors, acquaintances, teachers, and members of your faith or cultural community, have shared experiences and memories for your son or daughter and may provide a sense of “home.” This isn't true for everyone. Some young adults thrive on change, and moving away from the family home and community is important for them to foster a sense of independence. They may prioritize living near favorite places, activities, friends, and transportation.

Tip #4: Explore housing options with your young adult

Discuss the differences between available types of housing, and ask your young adult what options appeal to them. At the same time, be realistic about housing costs. Can your young adult or your family afford to purchase a home? Is there an option to rent from a family member? Will your young adult need to have a roommate to share expenses?

Other things to consider are your young adult's physical space needs, accessibility, and the availability of housing in their preferred location.

Tip #5: Consider how your young adult will pay for housing and services

How will your young adult personal needs, food, and rent or a mortgage? Are they currently working, or do they have job experiences through school programs or volunteering that can lead to employment? Having a disability does not automatically qualify your young adult for funding for housing and services; they must meet eligibility criteria set by federal and state government. There are two categories of funding assistance for housing and services: Funding for the “shelter” or “housing option,” and funding for “supports” or “services.” Funding sources include government benefit programs such as Supplemental Security Income (SSI), Medical Assistance (MA), and state and county social services programs.



Tip #6: Talk to your young adult about considering a roommate

Due to rising rental costs and the limited availability of affordable housing, your young adult may need to consider sharing expenses with a roommate. Some young adults prefer to have a roommate; others would like to live alone. If your young adult is considering a roommate, they should think about whether they have a friend or acquaintance who might be compatible. Talk to your young adult about what is important to them when considering a roommate: The potential roommate’s interests and hobbies, sensory and environmental issues such as noise or allergies, daily sleeping habits, and cleanliness are important discussion topics.

Tip #7: Network to expand your young adult’s community connections

Community connections are important and can build natural supports your young adult will need. When you think about how to connect them to the community, consider their hobbies and interests, places they enjoy visiting, and volunteer activities they are involved in.

Tip #8: Assess your young adult’s need for direct support staff

Direct Support Professionals (DSPs) play a vital role in your young adult’s life by helping with a wide range of daily activities and interactions with friends, employment, healthcare and physical care, skill development, and more. DSPs also help facilitate connections to people, resources, and experiences. In considering a DSP, identify personal compatibility and the supports your young adult wants and needs. Key skills, personality traits, culture, and language ability may be important considerations.

Tip #9: Explore your young adult's transportation needs

Reliable, cost-effective, accessible transportation that provides your young adult with the freedom to go where they want, when they want, is important. It allows them to participate in the community and have access to employment, housing, education, and social connections. For some young adults, this means convenient public transportation. If your young adult is able to drive, consider whether or not they can afford to purchase and maintain a car.

Tip #10: Begin to research housing and services resources, attend workshops and events

To learn about housing and services in your area, you can research online resources available from state and local human services departments, advocacy organizations, and disability resource and referral organizations. A great way to start is by visiting PACER's Housing Project at PACER.org/housing. Attend relevant workshops and events, and network with other parents and young adults exploring housing options and services. Once you have identified important person-centered needs for your young adult, you'll be able to create a one-page profile that can serve as a guide when you speak to housing professionals.

By planning and learning as much as possible about housing and services, resources, and options ahead of time, you will have a greater chance of achieving your young adult's vision for independent living.

For more information, visit PACER's Housing Project at: PACER.org/housing.

