

# 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](https://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](https://PACER.org/housing/gettingstarted))
- “One Page Profile” template ([PACER.org/housing/pdf/housing-one-page-profile.pdf](https://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](https://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](mailto: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](http://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](http://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](http://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](http://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.”*



8161 Normandale Boulevard | Minneapolis, MN 55437  
[PACER@PACER.org](mailto:PACER@PACER.org) | [PACER.org](http://PACER.org)