

HELP YOURSELF

a regular person's guide to advocacy in Wisconsin's Family Care, IRIS, Partnership and PACE Adult Long Term Care Programs

If you or a loved one has a disability, you have probably been involved with advocacy for a long time. You have likely been focusing on what is needed and doing everything you can to make sure that happens. In that case, we hope these ideas enhance what you are already doing. Whether you are new to publicly funded services or have been a recipient for years, being an advocate can be quite daunting, and it's usually not something you intended to set out to do. If that is your situation, we hope these ideas will help you get started.

Yourself as an advocate

If you have ever acted in anticipation of your need for something, you have been an advocate. If you have ever called or emailed someone with decision making power and asked why certain decisions were made, you have been an advocate. If you have made a request for something you consider extremely important, you have been an advocate.

It doesn't matter if you speak or write well or if you get flustered in meetings. If you have taken on this challenging role, you have been an advocate. You are the most important person to yourself or someone you love because you understand best of all what is needed, and you probably have some pretty good ideas of how to fill those needs.

Document, document, document

It is very important to keep documentation of all communications and decisions. You may need to look back for the date you made a request, or how you worded a request. It is crucial that you keep track of dates. There are deadlines related to when you can appeal a decision or how much time it should take for others to get back to you. Here are some ideas. Use the ones that work best for you.

Keep very simple files. If they are too complicated, it will be difficult to keep up with them. Some people use these file tabs:

- **Communications** (for printed emails, letters, a call log, and meeting summaries [in your own words])
- **Decisions** (for Notices of Action [NOAs], appeal or fair hearing decisions, etc.)
- **Assessments and Medical Documentation** (relevant medical, school, employment, residential provider, and other records); if there are many of these it might be wise to split into separate files
- **Member Centered Plan (Family Care MCP) or Individualized Supports and Services Plan (IRIS ISSP)** (keep most recent plan at the top)
- **Program Information** (Family Care or IRIS handbook, care team or IRIS Consultant names and roles, program updates, blank time sheets or other reporting forms, etc.)
- **Calendar** (track appointments, deadlines, dates of requests, etc.)

You will want to adapt these suggestions to suit your needs. For example, if you are providing care for a loved one yourself, you may want an additional folder for your timesheets and care notes. If you are employing others, you may want folders relative to that.

A few additional points:

- NEVER THROW AWAY ANY LETTER FROM AN ADRC, INCOME MAINTENANCE (IM), AN MCO, an IRIS AGENCY or the STATE OF WISCONSIN.
- Whenever you receive a letter from an ADRC, IM, an MCO, an IRIS agency or the state read it immediately, or ask someone to help you understand what it says. Notices from government agencies, MCOs and IRIS agencies can be confusing. Important dates and explanations of appeal rights may be hard to find and hard to understand. Look for any dates or deadlines for responses, reporting, or payment. Write any important dates on your calendar and decide if you need to take action. Staple the postmarked envelope to the letter and file it in your communications file. NEVER treat anything you receive from an ADRC, IM, MCO, IRIS agency or the state as “junk mail.”
- Whenever possible, make requests in writing. If you ask for something verbally, follow it up with an email or dated letter restating your request. Print emails and keep them in the communications file. Keep a copy of any letter you send.
- Keep a notebook and write down EVERY call between you and your IRIS Consultant or MCO care team. Enter each time you leave or receive a voicemail. Each “encounter” should include:
 - Date/Time
 - Name of caller or name of person you called
 - Summary of call
 - Next steps, if any (who said they were going to do what)
- Write brief meeting summaries after each meeting. Each summary should include:
 - Date/Time/Location
 - Names and titles of everyone at the meeting, including people attending by phone
 - Summary of the main points
 - Next steps, if any (who said they were going to do what)

Working effectively with “the system”

View your care team or IRIS Consultant as partners.

Interactions with MCO care teams or IRIS Consultants can become adversarial, given the nature of the setup. You make a request and the care team or IC may deny it, wholly or in part. Instantly the care team or IC is perceived as an adversary, there to block what you need. First, take a breath and hear out the decision. It’s possible that your request does not fit within allowable rule definitions. Or it’s possible that the team or IRIS may be offering a reasonable alternative. Or it’s possible that the team or IRIS believes you or your loved one can get by with less (hours, lower wages, less outings, etc.). Before you fire up, listen to what they say. If you believe they are wrong are being too restrictive, and you believe your request is reasonable, try to negotiate in good faith.

Take care to honor the individual

Keep your needs or the person being served as the primary focus of the discussion. It is easy to lose sight of yourself or the person you care about and instead get caught up in right and wrong, past hurts, lack of trust, or other issues. If the person being served is unable to attend meetings, find ways to bring his or her personality and preferences into the discussion. If you are advocating for someone who can attend, find ways to make sure the individual can provide input and have a role in decision making to the degree possible throughout the meeting.

Remember—it's all about the outcomes

The services are tied to individuals' outcomes. These are personal goals that are discussed early on. Services and supports are intended to address those goals. If you ask for something, you need to be able to tie it back to which outcome is being addressed by your request. For this reason, outcomes take on a heightened importance. Make sure the outcomes listed in your MCP or ISSP are really what you or your loved one want. Outcomes can be adjusted over time. At minimum, at each annual review, it's a good idea to consider if they need to be updated or changed.

Focus your message

When you feel you must advocate for something, it can sometimes be difficult to stick to your points. It is common for advocates to bring into the discussion complaints about other things—communication problems, feelings about how they were treated or feelings of unfairness, past problems in working with the care team or IC, etc. While all these may be valid, they may not help get you to what you want. If you are having a hard time staying focused on your request, you might want to write down no more than 2-3 top things you are asking for or ways you want to phrase your request. Some people write these on an index card and keep the card in front of them while on the phone or during meetings to help them stick to the point when they find themselves straying from the main issues. Others talk out their frustrations to others before meetings or calls. Make sure at the end of every meeting or call you know what the next steps are and who is responsible for what. Write those things down in your meeting summary or call log.

Bring in experts and cheerleaders

Being an advocate takes a lot of effort and steam. Make sure you have support around you. Find people with either good knowledge of the system or people who know you or your loved one very well. You can invite them to meetings or let the care team or IC know you want them invited. It helps if you are clear about what you expect from them. You could say, "I just want you to help listen," or, "please take notes", or "jump in and help me when we're talking about the number of supportive home care hours".

Sometimes it's just *not* what you want to hear—then what?

When a care team or IC makes a decision contrary to what you are asking, that does not necessarily mean they dislike you or your loved one, or that they are just wrong. It could mean that they are following program guidelines and their decision meets those guidelines. On the other hand, they certainly could be wrong. They may be misapplying a rule, or they might not be taking important information into account, or they may be too restrictive in their interpretation of your request. Make sure you understand their reasoning. If you have unsuccessfully tried to negotiate a reasonable resolution with your care team or IRIS, it might be time to start an appeal. Your program handbook will give you information about how to appeal a decision. You can do it yourself and program staff will help you in getting your appeal started (Member Rights Specialist in Family Care or your IC or IC's supervisor at your IRIS agency). The MRS or IC/Sup, however, will **not** be advocating for you after the appeal is started. They represent the program. You can also contact an ombudsman program for assistance with an appeal or negotiation. Keep in mind that there are very strict timelines for filing an appeal, especially if you want to continue benefits while you are trying to find a resolution. **Look carefully at any documentation like the Notice of Action to see what the deadlines are.** You may want to request a formal appeal even while you are trying to negotiate a resolution. You can always withdraw the appeal if you are successful in reaching an agreement you are satisfied with.

Self-Evaluation

Being an advocate can get pretty intense, especially when going over rough patches. It's a good idea to periodically ask yourself some questions:

- Am I or my loved one getting what is really needed?
- Am I being reasonable in my request and in my approach?
- Are there any other options that might fill this need or can I think of a creative way to solve this problem?
- Do I need additional support to continue to advocate?

Bring in the support you need, take care of yourself and best wishes to you!

Resources for Information

Publicly funded long term care programs are pretty complicated, and the rules and regulations that support them are even more complex. But you do not have to feel as though you need to know everything about them in order to advocate for yourself or a loved one. Keep your program handbook handy or know where to find it online. It will contain much of the information you need.

Sometimes, you just want to get some answers or understand something a little more thoroughly. You can find information on the Department of Health Services website.

Family Care: <https://www.dhs.wisconsin.gov/familycare/index.htm>

IRIS: <https://www.dhs.wisconsin.gov/iris/index.htm>

If you are looking for an answer to a question, you have a number of options:

- ask your Family Care team or IRIS Consultant
- go to the website of your Family Care MCO or IRIS agency
- call an ombudsman program (see below)
- check the website of Disability Rights Wisconsin

DRW: <http://www.disabilityrightswi.org>

Ombudsman Programs for Family Care and IRIS

All ombudsman program services are free.

Disability Rights Wisconsin

Through a state contract with the Department of Health Services, DRW provides the **Family Care and IRIS Ombudsman Program** for Family Care members and IRIS participants aged 18-59.

800-928-8778

Board on Aging and Long Term Care

Family Care Members age 60 and older

800-815-0015

Individuals aged 60+ in IRIS can contact the Dept. of Health Services for assistance at DHSIRIS@wisconsin.gov or 608-261-6749.