
Questions about Family Care for People with Developmental Disabilities

Responses to Questions from Consumers,
Guardians and Families

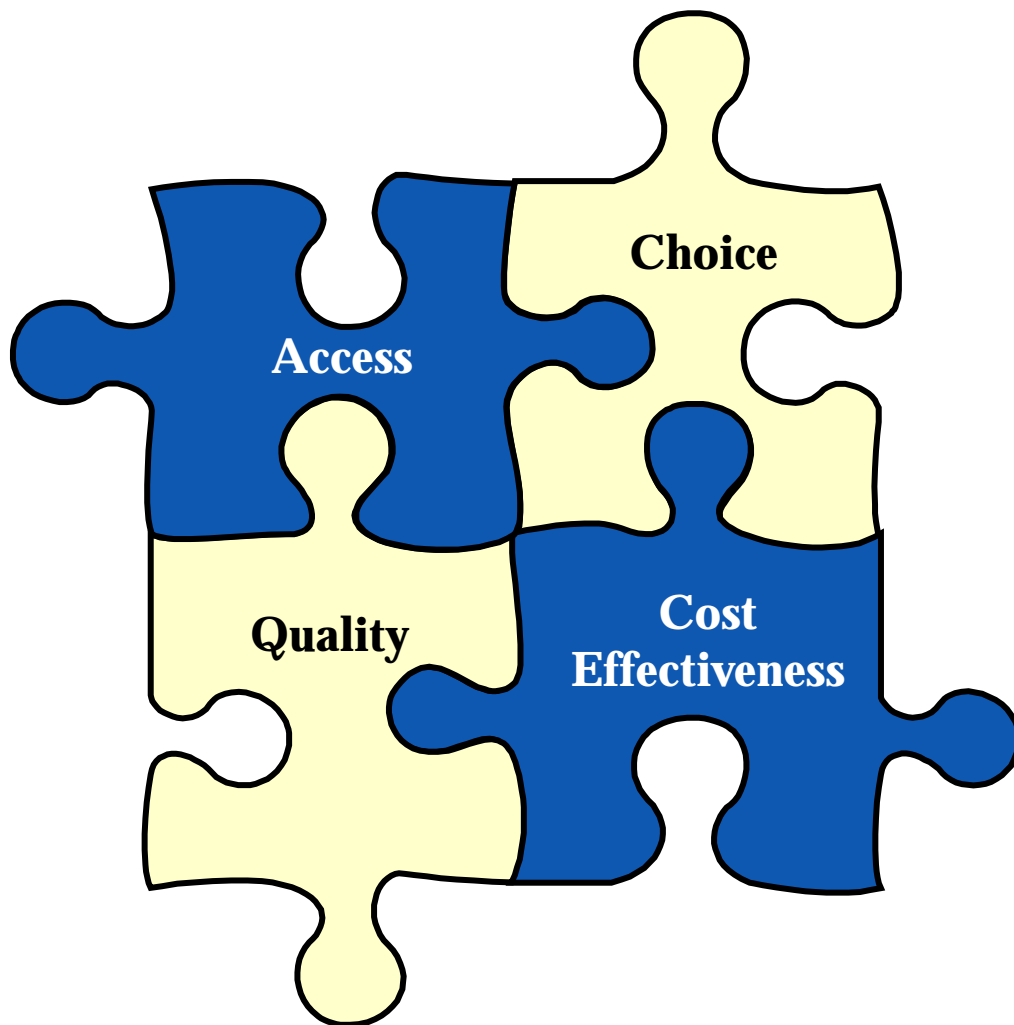


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Family Care Program Design

1. What is Family Care and where did it come from?

In the mid-1990s, people began to agree that Wisconsin's long-term support system needed to be redesigned. People were concerned about:

- waiting lists for services;
- the cost of the current system and its complicated rules;
- uneven availability of services; and
- our aging population's growing demand for long-term support.

During the next few years, consumers, advocates, providers, State and local officials, and others worked together to design a new approach to long-term support in Wisconsin. This new approach, named "Family Care," was approved by the Governor and Legislature in 1998. Family Care began serving adults with developmental disabilities, adults with physical disabilities, and frail elders with a long-term support need in 2000. Family Care has two major parts:

- Aging and Disability Resource Centers (ADRCs), which are a single place where anyone can get information and advice about a wide range of resources available in their local communities; and
- Care Management Organizations (CMOs), which manage and deliver the new Family Care benefit, which combines funding and services from a variety of existing programs into one flexible long-term care benefit, tailored to each individual's needs, situation and preferences.

ADRCs are currently operating in 23 counties – Barron, Brown, Calumet, Fond du Lac, Forest, Green, Green Lake, Jackson, Kenosha, La Crosse, Manitowoc, Marathon, Marquette, Milwaukee (serves elders only), Outagamie, Portage, Racine, Richland, Sheboygan, Trempealeau, Waupaca, Waushara, and Wood.



Family Care CMOs are currently operating in seven counties - Richland, La Crosse, Fond du Lac, Milwaukee, Portage, Racine, and Kenosha.

2. What are Aging and Disability Resource Centers (ADRCs)?

Aging and Disability Resource Centers (ADRCs) are the first place to go with your disability and aging questions. ADRCs are service centers that provide a place for the public to get accurate, unbiased information on all aspects of life related to living with a disability or aging. These centers are friendly, welcoming places anyone can contact to receive information and assistance regarding not only the public benefits that may be available, but all of the programs and services available throughout the area. Individuals, guardians, concerned families or friends, or professionals working with issues related to aging, physical disabilities, developmental disabilities, mental health issues, or substance use disorders, can receive information specifically tailored to each person's situation. ADRC services can be provided at the ADRC, or via telephone or through a home visit, whichever is more convenient to the person seeking help.

3. What services are offered by ADRCs?

ADRCs provide the following services for all consumers, regardless of their condition or their income:

- Information and assistance to the general public about help that is available;
- Long-term care options counseling to help people make the best choices;
- Short-term care management if someone needs help right away;
- Elderly and disability benefits counseling to help people apply for or keep their Medicare, Social Security, or other benefits; and
- Access to the Family Care program. For people who request it, ADRCs will conduct the long-term care functional screen to determine the person's level of need for services and determine if they are eligible for the Family Care program. ADRCs also help people enroll in Family Care.

Family Care Terms

ADRC - Aging and Disability Resource Center

CMO - Care Management Organization

IDT - Interdisciplinary Care Management Team

MCO - Managed Care Organization

RAD - Resource Allocation Decision Method

SDS - Self-Directed Supports



4. How does Family Care make the system better for people with developmental disabilities?

Family Care builds on the strengths of Wisconsin's rich history of providing services that meet the unique needs of people with developmental disabilities in their homes and communities. Family Care makes the system work better for people with developmental disabilities by improving access, choice, quality, and cost-effectiveness.

Access - Access is improved by assuring people get all the services they need, when they need them. Family Care is an entitlement which means that there are no waiting lists for services.

In addition, Family Care coordinates both long-term supports and health care services. Long-term supports include assistance with activities such as eating, bathing, or using the telephone; transportation; and respite for your caregivers. Depending on a person's needs, Family Care can help people find health care providers and get the health care services, such as doctor visits, immunizations, and medications, they need.

Choice - Choice is improved by giving people better choices about where they live and what kinds of services and supports they get to meet their needs. Family Care offers choices among a wide range of services provided in individual's homes and communities. Family Care provides a choice of at least two providers of each service and also allows people to self-direct their supports.

Quality - Quality is improved by Family Care's focus on health and quality of life outcomes for each consumer. Outcomes are what is important to a person and helping people achieve their individual outcomes is the goal of the Family Care program. Quality in Family Care means assuring safety and much more — improving health and quality of life.

Cost-Effectiveness - Cost-effectiveness means getting the best results possible for the money spent. Cost-effectiveness is improved by making sure that everyone with a long-term support need gets the right service, in the right amount, at the right time. Our experience operating Family Care during the past six years has demonstrated that this approach to long-term support is cost-effective and therefore sustainable into the future. Family Care focuses on providing the most effective services to meet individual's outcomes. The most effective service is often not the cheapest, but is cost-effective.

The right service, in the right amount, at the right time.

5. What are outcomes and how are they identified?

Quality of life outcomes represent what is important to a person, what is valued by the person, and often are things the person wishes were different in his or her life. Some outcomes may be very simple and others may be more complex.

Helping people achieve their individual outcomes is the goal of Family Care. The Family Care outcome statements on the following page are general statements that guide the Family Care program overall. The examples of individual outcomes show how the general Family Care program outcomes might be stated by an individual person. Family Care helps people reach all of their individual outcomes, including employment outcomes.



The first step in planning Family Care services is for you to discuss with your interdisciplinary care management team (IDT):

- What kind of life you want to live;
- Whether you want to live where you live now or in a different living situation; and
- What kind of support you need to live the kind of life you want.

This step is called the assessment. The assessment helps you identify the real-life personal outcomes that matter to you and the services you need to reach your outcomes.

For years, John went to the same sheltered workshop, but he always wanted to work in a restaurant. With Family Care, he is able to work in a restaurant as a dish washer with supported employment services and is taking cooking classes at the technical college so that he can be promoted and work as a cook in the future.

Family Care Outcome Statements

Example Individual Outcomes

I decide where and with whom I live	<ul style="list-style-type: none">· <i>I want to live by myself in my own apartment</i>· <i>I would like to live with my friend, but I don't want to share a room</i>
I make decisions regarding my supports and services	<ul style="list-style-type: none">· <i>I want my baths in the evening</i>· <i>I want my sister to help me with my baths</i>
I decide how I spend my day	<ul style="list-style-type: none">· <i>I want to watch the 10:00 news</i>· <i>I want to take a short walk after lunch</i>
I have relationships with family and friends	<ul style="list-style-type: none">· <i>I want to have dinner with my boyfriend on Friday nights</i>· <i>I want to go shopping with my friends</i>
I do things that are important to me	<ul style="list-style-type: none">· <i>I want to go to church</i>· <i>I want to go to concerts in the park</i>
I am involved in my community	<ul style="list-style-type: none">· <i>I want to volunteer at the humane society</i>· <i>I want to go to the farmers market and see my neighbor's flower stand</i>
My life is stable	<ul style="list-style-type: none">· <i>I like my life the way it is</i>· <i>I like my routine</i>
I am respected and treated fairly	<ul style="list-style-type: none">· <i>I want people to take the time to listen to me, even if it takes me longer than other people</i>· <i>I want delivered meals to be kosher</i>
I have privacy	<ul style="list-style-type: none">· <i>I want to dress myself in my room, even if it takes me a long time</i>· <i>I want my own bathroom</i>
I have the best possible health	<ul style="list-style-type: none">· <i>I want to manage my diabetes better</i>· <i>I want to quit smoking and need someone to help me get through the tough times</i>
I feel safe	<ul style="list-style-type: none">· <i>I want a dog who will bark if someone is at the door</i>· <i>I want to hire my own home care workers</i>
I am free from abuse and neglect	<ul style="list-style-type: none">· <i>I know that I can use the phone to talk to my care manager if someone tries to hurt me</i>· <i>I know that it is not ok to be hurt</i>

6. Who decides what services I get?

Your individual service plan is determined by your IDT. There will always be at least three people on your IDT – a social worker, a nurse, and you, the member. In Family Care participants are called members because they are a member of the IDT and the CMO. The contract between the Family Care CMO and the State requires that the social worker and nurse care managers have knowledge of community alternatives for people with developmental disabilities and the full range of long-term support resources.

Your IDT includes:

- You
- Social Worker
- Nurse

You can also include family members or others important to you.

The job of the IDT is to help you to:

- Identify your individual outcomes;
- Develop a service plan that will help you achieve your outcomes; and
- Make sure the services in the plan are actually provided.

You should have a chance to be involved in every part of the process, and should get any extra help you need in order to be involved, like someone to read or interpret for you. If you want, the other team members will help you to involve family members, friends, an advocate, or other people important to you in the planning process.

If you have a guardian or an agent under a health care power of attorney, they will be involved in planning along with you, and will give the legal consent for services. A guardian is responsible for protecting your best interests. This includes working with you and the rest of the planning team to ensure that your voice is heard and respected. The CMO should work with guardians or health care agents on how to identify and work toward the personal outcomes you want, and on ways to help you be able to make more decisions for yourself.

Your individual service plan will help you move toward the personal outcomes that you and your team identified in the assessment. The plan must be clear about what services and supports you will receive to achieve your personal outcomes, who is going to provide you with each service or support, and when each service or support will be provided. The plan will describe things you are going to do yourself or with help from family or friends.

Nothing about me without me.

The CMO is responsible for helping you achieve your personal outcomes, but also has to consider cost-effectiveness of services and providers. CMOs do this through an exercise called the Resource Allocation Decision (RAD) method. The RAD method is a series of questions that your team will answer for each of your outcomes. Answering these questions will help your team determine what services are effective at meeting your outcomes and therefore cost-effective.

The RAD Method

1. What is the need, goal, or problem?
2. Does it relate to the person's assessment, service plan and desired outcomes?
3. How could the need be met?
4. Are there policy guidelines to guide the choice of option?
5. Which option does the member (and/or family) prefer?
6. Which option is the most effective in meeting the desired outcome?

It is important to remember that the most effective service does not mean the cheapest. If you would like to read more about how the RAD method works, go to:

<http://dhfs.wisconsin.gov/LTCare/pdf/RADMethod.pdf>

You do not have to settle for a service plan that does not help you reach your outcomes, or that gets in the way of an outcome. However, a CMO may choose to provide a service in a less expensive way if the service plan is still effective in helping meet your individual outcomes. You may have to compromise on some of your personal outcomes if reaching them fully, or right away, is so difficult or so expensive that it is not reasonable. If you and the rest of the team cannot agree, you have a right to request a different IDT. Question 10 describes other options available to you if you have concerns about your care plan.

7. Why does everyone have a nurse on their care management team?

The Family Care program helps people with developmental disabilities have the best health possible by coordinating your health care and long-term supports. In many cases, health care providers do not understand the unique needs of people with developmental disabilities and, as a result, health care services are not available or effective. People with poor health are far more likely to enter a nursing facility. And, like everyone else, people with disabilities are living longer. The inclusion of a nurse on your IDT will help you get your health care needs met.



During your initial assessment the nurse on your IDT will identify any current health care issues. The nurse can also help prevent new health care issues from emerging by making sure that you get regular exams by a doctor and immunizations, for example. Even if you don't have any current medical problems, the nurse will identify any new problems that develop over time. Finding problems early, keeps you healthier. Finding and fixing problems early is often cheaper than the cost of dealing with them later. Everyone in Family Care gets this level of attention from the nurse on their team. Beyond that, involvement of the nurse will depend on your individual needs.

The nurse on your IDT will help you
achieve the best health possible.

8. What services are included in Family Care?

Family Care services include the same long-term support services included in the current Medicaid waiver programs - Community Integration Program (CIP), Community Options Program (COPW) and Brain Injury Waiver (BIW). Long-term supports provide assistance with activities such as eating, bathing, or using the telephone; transportation; and respite for your caregivers. The following long-term support services are included in the Family Care benefit:

- Adaptive aids
- Adult day care
- Adult family home
- Certified Residential Care Apartment Complex (RCAC)
- Children's foster care and treatment foster care (for people between the ages of 17 years nine months and 22)
- Communication aids/interpreter services
- Community-Based Residential Facility (CBRF)
- Consumer education and training
- Counseling and therapeutic resources
- Daily living skills training
- Day services
- Financial management services
- Home delivered meals
- Home modifications
- Housing counseling
- Personal emergency response system services
- Prevocational services
- Relocation services
- Respite care
- SDS support broker
- Skilled nursing services
- Specialized medical equipment and supplies
- Supported employment
- Supportive home care
- Transportation
- Vocational futures planning



