



PERSON-CENTERED PLANNING AND DISASTER PREPAREDNESS GUIDE

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As someone who works with older adults and people with disabilities to develop care and service plans, you play an important role in supporting people to live their lives to the fullest. We've heard from people about how important a care plan can be, and the challenges that they face in working with their care team to develop and implement a plan that meets their needs. The care plan becomes even more important when life brings unexpected challenges, such as the COVID-19 pandemic or natural disasters, like floods and fires.

Whether you're new to care planning, or already a pro, we hope these tips will give you some practical ideas for improving the planning process for you and the individuals you are working with. Thank you for taking the time to read this and for your interest in person-centered care.

WHAT IS PERSON-CENTERED PLANNING?

Person-centered planning is a process for selecting and organizing the services and supports that an older adult or person with a disability needs to live in the community. Person-centered planning is frequently required of health plans and agencies providing home and community-based services to people through Medicaid.

Health plans and agencies often employ nurses, social workers, or other health professionals to complete person-centered planning for beneficiaries. The output of the process is a **care plan**, a written plan for supporting the person.

A note about terminology:

Many different terms are used to describe this process, depending on the state or program involved. The written plan for supports can be referred to as a "care plan" or a "service plan," and we use both terms. The person facilitating the plan could be a "care manager" or a "service coordinator." We tend to use the term "individual," "enrollee," "person" or "people" to refer to the person(s) receiving the services. Some states might use the term "consumer," "member," or "patient" but not all. We hope that the guidance in this document will be generally applicable and useful, regardless of the specific terminology used.

WHAT GOES INTO A CARE PLAN?

A person-centered care plan is a collection of attainable health and quality of life outcomes, steps needed to achieve the desired outcomes, and a detailed illustration of supports needed to help the individual in achieving these outcomes.

Emergency planning is part of this process. Your efforts can help proactively address people's needs and reduce the impact of unexpected crises.

WHAT DOES IT MEAN TO BE "PERSON-CENTERED"?

The individual should be considered the **team leader**, while the person writing the plan is the **facilitator**. All other participating parties are members of the individual's care team. It is up to the team leader to choose who is permitted to be on their care team, though the facilitator may make suggestions. Your role as a professional in this process is to enable and assist people to identify and access the services they need and to provide support during planning.

Your goal should be to involve the individuals receiving services and supports as much as possible, even if the person has a legal representative.

SET YOURSELF UP FOR SUCCESS

Preparation is the key to success. This starts with scheduling your appointment. Be sure to arrange enough time to complete a comprehensive assessment and develop the care plan in a collaborative way. Schedule the appointment at a time and place that works for the individual, when they can be at their best. Not everyone likes to meet at 7am!

Some individuals may prefer several shorter visits, rather than a multi-hour marathon, depending on their stamina and their service and care schedule. A home visit, if the person is open to it, can be invaluable for helping you to understand their unique living situation and to identify opportunities to provide additional supports.

Recognize that once you've booked the appointment, it can be difficult for the individual to reschedule on the fly, especially if they have coordinated with others to be present for the appointment.

Make sure that the people the individual chooses are able to be at the appointment, including the members of the interdisciplinary team the person would like to be present. Additionally, make sure you know whether a legal representative will need to be there, and arrange for any necessary accommodations, such as for people who communicate in a language other than English, who have hearing impairment, or who have vision impairment.

If you are visiting in person, know where you are going, where you are going to park or what public transit stop you'll use, and any considerations about the specific location (e.g., is it down a long unpaved road? are there pets in the home that you might be allergic to?). Similarly, avoid fragrances and be aware of any allergies the individual might have that could be an issue (latex, food allergies, etc.) Be familiar with their previous plans and come prepared with an understanding of the services that are available to them in their area.

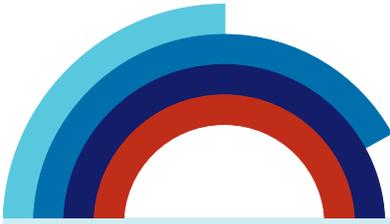
Be aware of your organization's safety plan, including prepping your car with a full tank of gas (if applicable), leaving your travel plans with a member of your team, having emergency contact numbers, and understanding procedures for preventing the spread of pests or pathogens.



"You don't live this life, the individual does. It's their life. It's their plan. It's their care. Ultimately, they are in charge." (Enrollee)

"[He] knows exactly what he wants in his care. He's very good at expressing his needs. I prefer that they don't always defer to me... because I think he's really capable of answering most of what they want to know." (Support Person)

If you've written a person-centered care plan that only describes the person you are working with then you've done a great job! Each plan should be as unique as the individual it was written for...like their fingerprint. When the goal of creating a care plan is to replicate the same degree of individuality as a fingerprint, it will be more successful in meeting an individual's care needs than if you are simply filling in blanks on a template.



DEPARTURE CHECKLIST

Have everything you need prior to your departure for the appointment? The checklist below will make sure you are well-prepared prior to meeting with an individual to develop a care and service plan.

People:

- Are all of the people who are needed going to be present?
- Have I arranged for any needed accommodations (such as an interpreter)?
- Am I aware of any allergies and have I planned to avoid triggers?

Place:

- Do I know where I am going?
- Where can I park?
- What are the public transit stops and what's the schedule?
- Any specifics about the location (which entrance to use, how to contact the individual when I arrive, is it accessible)?

Time:

- Have I arranged enough time?
- Do I have my calendar if we need to schedule another time?
- Have I cleared my schedule as much as possible so that I can be fully present?

Safety:

- Have I left my travel plans with someone?
- Did I review my organization's safety checklist?

Resources:

- Review previous care plans
- Have available any forms/templates needed for comprehensive assessment and care plan
- Know information about resources available to the person in their area
- Bring a charged phone and computer with internet connectivity, with chargers and extra batteries (and the phone number for your IT helpdesk)
- Bring business cards, identification, information to leave behind, pen, shoe coverings
- Prepare PPE: masks, gloves, hand sanitizer, wipes to clean any equipment used, trash bag and any other personal protective equipment required by your employer

GETTING STARTED: BREAKING THE ICE

Each individual has their own set of goals, strengths, and challenges. *Never begin this process with assumptions.* Relaxed conversation with the person and their care team is a great way to learn what their goals, strengths, and challenges are. If they have trouble articulating what their goals, strengths, and challenges are, think about reframing your questions and give them time to answer — the questions may be worded in a way that is confusing or the person may just feel put on the spot. Be mindful that you are not the first case worker/advocate/service coordinator the individual has been assessed by, and the process can be tedious and tiring. Steering the conversation in the direction of their hobbies and personal interests can be a great ice-breaker and may reveal the answers you’re looking for.

ASK, DON'T ASSUME

In taking the person-centered approach, it is important to acknowledge that people who have the same disability or health condition do not necessarily have the same symptoms, preferences, or priorities. You are writing a care plan for a specific person. You are not writing a general commentary about a specific disease or chronic illness. For example, some individuals with Osteogenesis Imperfecta (OI) can walk or at least bear weight, while others cannot. The care plan should reflect whether or not the person is ambulatory and what supports the individual needs to complete ADLs, for instance.

Similarly, in your work, you will have the chance to meet individuals from different backgrounds and different perspectives. Be aware of your own biases, and do not make assumptions about a person based on their race, ethnicity, sexual orientation, or gender identity. Demonstrate a commitment to inclusiveness by practices such as arranging for language interpretation (examples of best practices here: [American Family Physician: Appropriate Use of Medical Interpreters.](#)) and asking all people for their pronouns and preferred name. And remember that you are a guest in someone’s home. Ask where you should sit and put your belongings, and ask about whether you should remove your shoes/use shoe covers. Be prepared with what you plan to say if you are offered food or beverage.

PEOPLE ARE NOT PLANTS

The focus should be on the person and life as a whole. Thus, care plans should reflect the individual’s personal characteristics and needs and aspirations beyond purely medical conditions. This can help ensure that people who are providing care to the individual understand their preferences. This could include things like their favorite foods, preferences



"Get to know the person. It's very important that the supports coordinator gets to know the person." (Enrollee)



"We're just always seemingly trying to meet these very basic needs, when we have to remember these are human beings, and very complex people, and everyone has needs that go beyond that. Whatever those are, I think they should be somehow addressed. Our goal should be to enrich people's life to the maximum amount possible." (Support Person)

"[A]s human beings, we need more than just to be fed and watered. There is a lot that goes into each and every person. To be able to express some of that, I think, really makes people happier, and makes their life more complete." (Support Person)

for scheduling (whether they like to get up early or late, for example), and if they don't like to be touched without permission. Beyond specific care needs, the care plan should address people's needs that are beyond "feeding and watering." This includes consideration of social and cultural needs; a desire for play, exercise, and sport in some form; and the human need for purpose and meaning, which can be expressed in a myriad of ways, including through art, learning, employment, community engagement and spiritual and religious activities.

RECOGNIZE THAT CARE PLANNING CAN BE HARD FOR INDIVIDUALS TOO!

While these are important conversations that you need to have with the individual and their care team, don't take it personally if they seem annoyed or disinterested. You may be one of many providers to whom they must divulge their personal information. Care planning is best done within a relationship of trust, and building trust takes time. Particularly in a system where structural racism and ableism have significantly eroded trust.

It may be helpful to briefly explain to the individual how having a detailed care plan can help protect them in case of a health crisis or natural disaster because it will illustrate their needs and abilities to those in charge/on call who may not be familiar with the person's situation. Most importantly, despite any disinterest, do not shift your focus from the individual to someone else. Always speak directly to the person whose plan is being developed, even if they use an interpreter or electronic speech device.

BE INTENTIONAL WITH WHY YOU ARE ASKING EACH QUESTION

To write a good care plan, you will need to understand a lot about the day-to-day life of the individual, including personal topics like how they go to the bathroom, get dressed, and do other activities. Not everyone will want to share information with you, particularly if they don't know you or if it feels that you are being nosy. It is important to be clear and focused about your questions and explain why you are asking certain questions. We like the phrase "respectful curiosity." It can be helpful to think about focusing your questions on the goal of getting enough information so that someone could read the care plan and step in to assist the individual with care or services, even if they don't know the person directly.

ADDRESS RESOURCE NEEDS

The care and service planning process presents an opportunity to proactively address resource needs, such as access to food, transportation, personal care, and housing. These needs, and the disparate access many people of color and individuals with disabilities have had to resources to meet those needs, have been magnified during the COVID-19 pandemic. When identifying resources for people, make sure that they can address the specific needs (medical and cultural) of the individuals you are working with. For example, a contact at a food pantry that can deliver to individuals with transportation/mobility difficulties is more useful than a long list of food pantries in the area. When appropriate, timelines for attaining specific goals/steps should be included. For example, if it is known that a person will be moving out of a long term-care facility and into the community by a specified date, then housing needs to be acquired before that date.

If you are able to observe the individual's living environment, think about safety and accessibility and proactively suggest services for their consideration that might be beneficial. They may not be aware of all of the services and equipment available to them, such as for home mobility and safety.

STRENGTHEN DISASTER PREPAREDNESS

Structural racism and ableism have left many individuals with disabilities and people of color more vulnerable to injury and death following disasters. With climate change increasing the frequency and severity of natural disasters, it is more important now than ever to make sure individuals have the resources they need to deal with the immediate and long-term impacts of all kinds of disasters. As a care planning professional, you can help them to be as prepared as possible for emergencies.

Help individuals plan by reviewing preparedness checklists, such as those developed by the [Ready Campaign](#). It is important to help work with individuals to prepare extra medications, supplies (gloves, wipes, diapers, catheters, dressing supplies, food/special feeds—anything the person uses on a regular basis), back-up equipment (a manual wheelchair, for example), and extra batteries/power sources. Asking about personal protective equipment for them and their caregivers is also vitally important.

Pay special attention to transfers (how will someone get in or out of bed if the power is out, or if they need to evacuate) and transportation needs. Remember that service animals need to be provided for. Think about options for back-up personal care assistance if the regularly scheduled staff are unable to come.

Recognize that it can be difficult for individuals to acquire extra supplies for items subject to quantity limits and other restrictions. We recommend that you work with your plan or agency to expand people's ability to access needed emergency supplies.

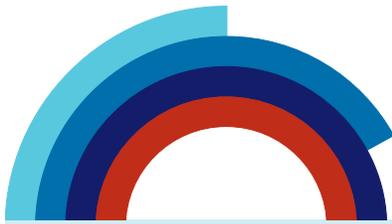
In addition, encourage your plan or agency to form relationships with organizations in your service area that are part of emergency response. Identify specific contacts at organizations and agencies that are available to assist people during an emergency.



“What we've seen ... is difficulty for people to get their medicines and their groceries. I was shocked by how many months it took for the managed care organizations to offer rides to people to get what they need at the store. People can't go through food banks with their wheelchairs.”

We had an incident where there was a planned power outage for our neighborhood.. So I did contact the case manager, and they basically told us there was nothing that they could do to help us, that we could go to the local emergency room, and wait it out there. ... When you're dealing with someone who is medically fragile, the emergency room is the last place that they want to hang out in. So I started reaching out to people in our city that I knew. Someone pointed us to an organization that rents out tools to people living in our city. Sometimes they have generators. But not often. The gentleman that ran the organization was so incredible. He said, "We're going to make sure that you have power to run oxygen and all of that." They went and rented one for us. We were so grateful, but also really frustrated that there is no provisions for any of this.

My personal feeling was it was a lot less expensive to rent a generator than to go check in at an emergency room for the day and get your needs met there. ...We don't have anything in the care plan listing where we can get services, who can provide those services. That was a huge disappointment.”



DISASTER PREPAREDNESS CHECKLIST:

A person-centered care plan should include a section on disaster preparedness. To help individuals plan for emergencies, review preparedness checklists such as <https://www.ready.gov/disability>. The items below will help you organize your conversations with individuals to make sure they have considered all of their needs and are prepared for an emergency.

- **Does the person have back-up medication and supplies?**
 - Extra medications
 - Sufficient PPE
 - Diapers, catheters, dressing supplies
 - Food/Special feeds

- **Does the person have back-up equipment and power sources?**
 - Wheelchair
 - Extra batteries for things like hearing aids or assistive devices
 - Back up plan for ventilators, oxygen concentrators, lifts and other powered devices

- **Does the person have an evacuation plan?**
 - Where will they go?
 - How will pets or service animals be cared for?
 - If the power is out or personal support can't get there, do they have a means of getting out of bed and out of the house/apartment?
 - What transportation is available?

- **Does the person have a list of people/local agencies who can be called on to help during an emergency?**

- **Has the person (and caregivers, if appropriate) practiced how to locate and use emergency equipment and how to evacuate, if needed?**

As the care manager, it is important for you to work with your health plan to ensure that the individual can access backup medications and other supplies to have them on-hand for an emergency.

WRITE THE CARE PLAN SO IT IS UNDERSTANDABLE TO A NON-HEALTH CARE PROFESSIONAL

Even though you are a health care professional, the care plan will be used by people who do not have a medical background. Therefore, the care plan should describe the individual's health condition or disability in detail, in the most basic language possible. Breaking this section down into two parts is helpful because all conditions do not affect all people in the same fashion.

1. Define the chronic illness/disability and provide resources for further education on the subject.
2. Describe how the individual's chronic/illness affects him/her/them.

Remember to write in plain language and avoid medical jargon.

LEAVE SOME BLANK PAGES

If you're using a template, be sure it has some blank pages. If you have ever written a care plan before, you have very likely had to cram important notes in the margins. If you're an individual that has had a care plan written on your behalf, you have likely been left feeling like everything important to you regarding your health care was not included. Make sure you have the space to capture all of this valuable information.

FOLLOW THROUGH TO MAKE THE PLAN A REALITY

After you've had the chance to meet with the individual and their chosen care team, keep up your good work by paying attention to some key follow-ups. Make sure they know how to get in touch with you. Be clear about when and how you will be sharing a draft of the care plan, what the process is for them to edit/revise the care plan, and make sure they get a copy of their care plan.

Follow through to make sure that the individual actually gets the services that they need. Finally, recognize that a care plan is only valuable if it is accurate and up to date. The care plan should be updated on a regular basis, as well as with changes in health status, and also with other events, such as a move, that can dramatically affect a person's services. Proactively identify changes that can impact emergency preparedness, such as the addition of new powered equipment, loss of family supports such as when a family member moves away, or turnover of personal care attendants. People should also have the opportunity to update the care plan as needed, and it's important to make this process clear for them.

YOU play a vital role in ensuring that the individual you are working with has access to the services they need to thrive. Advocate for the member, knowing that the care plan is critical to their well-being.



"We have not had any real ability to provide input. I don't know if it's that way by design here, or if it's an oversight, or if these agencies just got used to doing it this way, and maybe they don't realize the value of having the families and the patient have input into the plan of care." (Support Person)

When I need to make changes to the care plan and reach out to the case manager, generally you can do it through the portal for the managed care organization, though ours has not been working. ...We don't tend to...get a reply right away. It takes a lot of work to try to communicate with case management to get things changed in the care plan." (Support Person)

A SPECIAL NOTE ABOUT MAKING CARE PLANS A REALITY

In speaking with people about care planning, we gained insight into best (and not-so-good) practices, which we are sharing here. But above all, we heard about many challenges that individuals and caregivers are facing when it comes to actually receiving the services they need. We want to recognize that the act of developing the care plan is only one piece of person-centered care. It is critically important to address the barriers to receiving services, including shortages of paid caregivers, the long time it can take to get caregivers approved, and the low wages paid to caregivers. We have developed a set of policy recommendations around these and other topics, and also want to recognize the important work being done in this area by many individuals who receive care and advocates.

GO FORTH AND PLAN!

Thank you for reading our care planning guide. Please see these following sources of information:

National Center on Advancing Person-Centered Practices and Systems

<https://ncapps.acl.gov>

Disaster Preparedness for Individuals with Disabilities:

(<https://www.ready.gov/disability>)



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