



**MAKING CARE PLANS  
PERSON-CENTERED:**  
*Policy and Practice Recommendations*

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Care plans are an important tool for ensuring that people get the services that they need to live and thrive while remaining independent and in the community. Care planning helps ensure person-centered care coordination, a key feature of integrated care. For people with marginalized identities, care planning can also be an invaluable tool in addressing social and economic drivers of health. When executed well, care plans can ensure better supports for people with disabilities and people of color and promote health equity and racial justice.

Person-centered planning is a component of care coordination that is required of health plans and home and community-based providers that serve people enrolled in Medicaid. Care plans, the written plan for supporting the person, are the output of the care planning process. In order to meet the objectives of the care planning benefit, health plans and other service providers employ nurses, social workers, or other health professionals to complete the care planning process with beneficiaries. These employees fill the “care coordinator” role and are the go-to contacts for people needing support with managing or coordinating their care. Managed care plans are regulated by federal requirements, but states do have some limited flexibilities, including where in the state they offer managed care and what services are included in the care plan. States can require Medicaid beneficiaries to enroll in managed care in order to receive services. Particularly as more people are navigating services under a managed care plan, policymakers and health care organization leaders must pay close attention to the care planning process to ensure that people with complex needs receive truly person-centered care.

## THE BASICS: WRITING A CARE PLAN

A care plan should thoroughly capture a person’s full life, needs and preferences. It should outline everything a provider needs to know about a person before interacting with them. When done collaboratively, thoroughly and intentionally, a care plan can be an indispensable resource for people with disabilities to self-advocate and address inequities they face when interacting with the health care system. Each person must have the option to meet with their care coordinator outside of a clinical setting, such as in their home, to develop their care plan, which should include the following:

- **Articulation of Goals**

- Led by the person and put into their own words
- Comprehensive, with attention to the following: functional status; health care, including sexual and reproductive health; behavioral health; social needs; interpersonal relationships; lifestyle and general preferences; community integration/wellness goals (e.g., hobbies, life goals, who’s important to them, education and career goals)
- Potential barriers to accomplishing goals, including systemic barriers such as [medical racism](#), [inadequate preventative care](#) for women with disabilities, or [ableism in reproductive health care](#)
- Linguistic and cultural preferences and preferred means of communication

- **Action Plan**

- Each goal should be accompanied with an action, a responsible party for completing it, a timeline, and a contingency plan if issues or barriers arise<sup>1</sup>
- Must include a plan for addressing health inequities the person is disproportionately likely to experience due to factors such as race, ethnicity, gender, geographic location, and sexual orientation

<sup>1</sup> One Care Implementation Council. Next up in ongoing conversation to strengthen integrated care coordination model. December 2020. Available at: <https://www.mass.gov/doc/implementation-council-care-coordination-discussion-12-8-20-0/download>

- **Medication and Supplies**
  - List of medications
  - Durable medical equipment
  - Other supplies
- **Social and Economic Drivers of Health**
  - Physical and social living situation; key relationships in the person’s life
  - Caregivers and other supports and the details of their roles
  - Emergency preparedness
- **Contact Information**
  - Care coordinator and other members of care team
  - Caregivers and/or other supports identified by the consumer
  - Emergency contact
- **Review**
  - Established plan for reviewing on a regular basis<sup>2</sup> – with more frequency if there are changes to a person’s health status, needs, or circumstances – with the care coordinator

### EXAMPLE OF AN ACTION PLAN:<sup>3</sup>

Jasmine is a 35-year-old Black woman with cerebral palsy, which limits her physical mobility. As a result, over time, Jasmine has started to experience frequent joint pain. When Jasmine started having pain flares, she was initially denied pain relief and had her concerns dismissed. This is an example of an action plan in a care plan that could help support Jasmine when she experiences systemic racism and ableism while seeking care:

<b>Goal: What is action contributing to?</b>	<b>Action: What needs to be completed?</b>	<b>Who: Who is responsible for completing action?</b>	<b>When: What is the timeline that the action needs to be completed?</b>	<b>Contingency: If there is an issue or barrier, what are next steps?</b>
Manage moderate joint pain	Medicate pain episodes with NSAIDs/muscle relaxants/SSRIs as needed, complete mild exercise three times a week	Patient, with guidance from rheumatologist	Daily, beginning immediately and to continue until reassessed at next Rheumatology appointment	Any major pain flares should be immediately reported to Dr. Smith’s office (123-456-7890).  If the patient is experiencing barriers to accessing pharmaceuticals for pain management, they should contact their care coordinator.

For an in-depth guide on writing a person-centered care plan, see our [“Person-Centered Planning and Disaster Preparedness Guide.”](#)

<sup>2</sup> At a minimum, the care plan should be reviewed annually.

<sup>3</sup> Post-Encounter Action Grid, Boston Children’s Hospital. Available at: [http://www.childrenshospital.org/-/media/Centers-and-Services/Programs/F\\_N/Integrative-Therapies-Team/Action-Grid.ashx?la=en&hash=D156813DDB83061530E2BD35F58E850E17F4A30F](http://www.childrenshospital.org/-/media/Centers-and-Services/Programs/F_N/Integrative-Therapies-Team/Action-Grid.ashx?la=en&hash=D156813DDB83061530E2BD35F58E850E17F4A30F)

## ***Policy and Practice Recommendations:***

Too often, people are not aware of who their care coordinator is, nor have they had an opportunity to meet with them to develop a care plan. When a meeting with a care coordinator occurs, these meetings can be limited in quality, timeliness and scope. People often lack the ability to access their own care plan, especially without the involvement of their care coordinator. Policymakers and health care organization leaders can improve the care experience by requiring the following care planning policies:

- The person should be leading, or be supported by loved ones and/or care team members to actively participate in the development of the care plan; their perspective, needs, and preferences always come first.
- The person must have the option to identify who they would like to participate in the care planning process, including members of the interdisciplinary team, friends and/or family.
- People must be made aware of their right to a care coordinator, know who their care coordinator is, and have their contact information.
- People must be able to reach their care coordinator in a timely manner.
- People must be meeting regularly with their care coordinator and their stated needs must be reflected in an updated care plan.
- People must be fully aware of their options for [self-directed care](#).
- People must be able to review and approve their care plan before any changes are finalized.
- Care coordinators should be connecting people to, and collaborating with, community partners and resources that fit their needs.
- People should have access to their care plan at all times, ideally through a centralized portal.

These care planning requirements must be integrated into health care organization reporting and evaluation, and adherence must be regularly monitored. Data must be collected and disaggregated by key factors, including by race and gender.

In order to ensure widespread participation in care planning, policymakers and health plan leaders must ensure that care coordinators, and the people they serve have the necessary supports to engage in person-centered care planning. Requirements should include:

- Care coordinators, primary care providers and other members of the care team must be [educated](#) on how to develop a care plan, [core competencies](#) for person-centered care planning, and [best practices](#) for working with care plan enrollees.
- Caseload sizes must take into consideration the practice setting, care coordination services, clinical (physical, behavioral and psychosocial) factors, interpersonal situation, the care plan and desired outcomes.
- A diverse set of providers should be included in the care planning process to address the holistic needs of the consumer in a culturally responsive way. Beyond primary care and clinical providers, long-term service and supports providers, peer recovery counselors and/or community health workers could be included.
- A portal that care plan enrollees can access and use to request changes, and/or appeal changes that may take place in their care plan.
- These infrastructure requirements must be integrated into health care organization reporting and evaluations, and adherence must be regularly monitored. Data must be collected and disaggregated by key factors, including by race and gender.

## HEALTH EQUITY

Certain populations are disproportionately impacted by the harms of our existing inequitable health system and other systems of oppression. Specifically, these populations include people who are Black, indigenous, and/or people of color, those living in urban and rural settings, those who have disabilities and health conditions that put them at higher risk, and those with a history of substance use and/or addiction. These inequities are especially [stark](#) for people who use home and community-based services, where people of color have [lower utilization rates](#) than white individuals. Policymakers and health system leaders can begin to address these disparities by making health equity a core requirement.

### ***Policy and Practice Recommendations:***

- Care plans must include identifiable goals for achieving health equity.
- Care plans should name important factors that influence health inequities, including factors such as racial identity, substance use, geographic context, gender identity, and sexual orientation.
- Holistic physical and emotional well-being should be considered, and sexual health and relationship goals must be addressed with a clear plan as to how they will be met.

These health equity requirements must be integrated into health organizations' reporting and evaluations, and adherence must be regularly monitored. Data must be collected and disaggregated by key factors, including by race, ethnicity, gender, disability, age, language and care setting.

## EMERGENCY PREPAREDNESS

The COVID-19 pandemic has revealed weaknesses in care and service plans and has had a [disproportionate impact](#) on people with disability and/or complex care needs. While all emergencies are not as widespread and catastrophic as a pandemic, even a temporary power outage could put many at significant risk for hospitalization or even death. Emergency and disaster preparedness should be part of any care plan review and should happen on a regular basis.

### ***Policy and Practice Recommendations:***

Policymakers and health care organization leaders can improve emergency preparedness by requiring the following:

- Coverage for additional amounts of medications, supplies and equipment needed for emergency preparedness.
- Care coordinators must review emergency preparedness as part of the care planning process and health care organizations must identify resources needed for emergency preparedness.
  - Support people with disabilities during emergencies (e.g., pandemics, natural/manmade disasters) by including detailed instructions in the care plan (e.g., who to contact and what resources are available) for emergencies.
- Policymakers can further support people with disabilities during emergencies in these ways:
  - Ensure local, county, and state aging and disability departments have online repositories of disaster resources – local governments, plans, and advocacy organizations should also have this information readily available.
  - Ensure local emergency systems offer information for people with disabilities and have disability accommodations integrated into their planning.

## ADDRESSING CAREGIVER SHORTAGES

One major barrier for people who rely on long-term services and supports (LTSS) is caregiver access and availability. As anyone who relies on caregivers knows, there are structural reasons that can make it incredibly difficult for people to access the LTSS they are entitled to. These challenges have only been [magnified during the COVID-19 pandemic](#).

### *Policy and Practice Recommendations:*

- Fund and promote direct care workforce development programs that recruit and train direct care workers
- Support the development of direct care workforce apprenticeships and [curriculum](#) at state and local educational institutions
- Increase wages and improve benefits for caregivers at the state and local level
- Increase the Medicaid reimbursement rate for LTSS providers that employ direct care workers
- Remove barriers for family members and guardians to serve as paid caregivers
- Promote infrastructure that supports the professional development of direct care workers, such as associations and advisory boards
- Support programming that develops a diverse direct care workforce; caregiving hiring should reflect the population of consumers being served and a person's care team should reflect their own lived experiences

## OVERSIGHT

There is often limited information about equity, ombudsman activities, and how frequently people's needs are fully met through the care planning process. In addition to the specifics of the care planning process, broader steps should be taken to ensure care plans are equitable and high quality and that health care organizations are held accountable to these standards.

### *Policy and Practice Recommendations:*

#### **Consumer Rights Under Care Plans**

- State policymakers, specifically state ombudsmen, must do outreach and education to ensure enrollees [know their rights](#) as a central member of their care planning team. This includes filing grievances and appealing the care decisions made by care plans.
- States must ensure that managed care plans are subject to existing Medicaid due process rights.

#### **Equitable Data Collection and Accountability**

- States must consistently collect and make publicly available oversight data, including appeals and grievance data that includes the number of appeals and denials by plan, services that were the subject of the appeal, and which grievances and appeals come out in favor of plan members compared to plans. This data should be regularly publicly reported, annually at minimum.
- States should track data on plan "churn," opt outs, and disenrollment, including tracking if individuals go back to the fee-for-service system or switch to a different plan.
- States should track grievances and appeals specific to HCBS and use the data to make HCBS access equitable.
- All data should be disaggregated by relevant equity factors in order to identify specific populations impacted by inequities, with race and ethnicity as a major priority.
- States and health care organizations should actively monitor caregiver shortages, such as measuring the numbers of caregiving hours consumers are eligible for compared to how many

caregiving hours they are able to fill; this data should be distinguished between agency care and consumer-directed care.

- States should require uniformity in how managed care plans collect data.
- The data points being collected must be integrated into plan quality measures.

### **Care Coordination Quality**

- States should require health care organizations to analyze outcomes for care plan enrollees, including level of services provided, community tenure, and consumer satisfaction.
- States should require health care organizations to directly engage their enrollees to seek feedback on their care coordination, and they should be required to regularly report how recommendations from directly impacted people are being implemented.
- States should require health plans to report care coordinator caseloads and turnover.





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