

Participant Outcomes:  
Quality of Life in Long Term Care

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Bureau of Aging and Long Term Care Resources  
Division of Disability and Elder Services  
Wisconsin Department of Health and Family Services

## **PARTICIPANT OUTCOMES FOR COP-W/CIP II: Overview of Pilot**

Within the COP Waiver and CIP II programs, the Bureau of Aging and Long Term Care Resources (BALTCR) is planning to integrate a focus on participant outcomes. This includes:

- ✓ Incorporating participant outcomes into care planning and on-going care management.
- ✓ Integrating participant outcomes in quality assurance monitoring to provide counties with ideas for program improvement.
- ✓ Providing counties with tools to assess its own level of success in assisting participants in achieving what is important to them.

The following is a brief description of how participant outcomes are being integrated into the quality assurance monitoring process. This year, BALTCR is piloting some new tools to learn about the achievement of participant outcomes and how they are supported. In addition, we want to learn from counties what information they want to receive in relation to the impact of system delivery on achievement of participant outcomes.

### ***Outcomes in the Quality Assurance Monitoring Review:***

Until recently, the intent of the Quality Assurance Monitoring Review has been to check for technical compliance, check for participant health and safety, assuring participant needs are addressed, and receiving feedback from participants on their satisfaction with program services and workers. In addition, we want to learn about the impact of the program and services on the participant's lives. This is being accomplished through participant interviews by focusing on achievement of participant outcomes.

During participant interviews, reviewers learn how participants in the program are doing in relation to a variety of Department identified outcomes. As part of this year's review, BALTCR is assessing four specific outcome statements that reflect aspects of the RESPECT values. Eventually the outcome statements will expand to include additional elements of RESPECT.

The intent of the outcome interviews is to look at trends across a sample of the population. It is a method for providing counties with a "mirror" so to speak, to reflect on the participants' experience of being served in a community-based program. The results provide qualitative data, rather than hearsay, assumptions, or common knowledge about issues of quality. In addition, the outcome results are examined in relationship to how care plans support or facilitate the achievement of the outcomes. The results, both the outcome results and support trends, are merely a tool that counties can use to set their own benchmarks, promote areas of strength, and determine areas in which they want to focus on improvement.

### ***County Input:***

As part of this pilot, BALTCR wants input from counties so that the results from the interviews are presented in a meaningful way. The results or data should be helpful to local quality assurance and quality improvement processes and serve as a guide for care planning. Therefore, we are asking counties being monitored during this year to participate in the learning process. Please take some time to review the attached materials, participate in a discussion about the outcome results during the wrap-up meetings, and provide TMG reviewers with helpful feedback.

### ***Outcomes Decision-making Guidelines:***

The attached materials describe the four outcome statements being piloted and outline the decision-making process for determining outcome achievement. The TMG reviewers will use this tool during their interviews with participants. In this process, the reviewers learn about what is important to individual participants in relation to the four broader outcome statements. Reviewers will then summarize the results across the entire sample and discuss the larger trends as viewed from the participants' perspective.

The outcome statements are written in the first person to reflect the participant-centered focus. Each statement is categorized under one of three target areas of the RESPECT values:

- Empowerment to Make Choices
- Physical and mental health (Health and Safety)
- Community and Family Participation

### ***When Reviewing These Materials, Please Consider the Following:***

- Does it help to keep a participant-centered focus by having the outcome statements written in the first person? Does it help to keep the RESPECT values at the forefront of quality?
- Do the definitions of the outcome statements make sense? From working with people with physical disabilities and the elderly, do you and your staff feel the definitions cover what's important to these populations in general?
- Does the criteria for determining level of outcome achievement make sense? If not, what is confusing or of concern? What more would you like to learn about this process?
- Are there other "decision-making considerations" your agency feels need to be included?
- What suggestions do you have for this portion of the quality review? Is there anything else you would like to include during the wrap-up session?
- Is this a process your agency might want to use to focus on outcomes for participants?
- Would a tool like this be helpful to the care planning process?

# PARTICIPANT OUTCOMES FOR COP-W: Decision-making

## EMPOWERMENT TO MAKE CHOICES

Feeling a sense of control over one's life and being able to make your own decisions is important to most people. However, some people may choose not to make decisions and rely on someone they trust to do this for them. The opportunity to make decisions that directly affect their lives can be on a small or large scale. It is also important to have reasonable options explored so that the participant (or other decision-maker) is making an informed choice.

### Outcome #1

#### **I DECIDE WHERE AND WITH WHOM I LIVE.**

My home environment has a huge affect on my quality of life. It influences how I feel about myself, my day-to-day life, and my sense of comfort and security. One of the most important and personally meaningful choices I can make is deciding where to live, how to live, and with whom to live.

***Decision-making considerations:*** *These criteria must be present for the outcome to be achieved. If some of the criteria apply but not others, then the outcome is considered "in progress." If none of the criteria apply, then the outcome is not achieved.*

- Person is choosing to live in current arrangement OR chose current arrangement. *If person did not make the choice*, the participant feels satisfied with how the decision was made.
- Person is content with/pleased/satisfied with decision and feels it meets their needs and expectations.
- *If applicable*, person was provided information about available options and assisted to explore options they preferred. If not, did they want more options?
- *If applicable*, the person who made the decision regarding living situation (i.e. guardian or POA) based decisions on participant's preferences and needs.

Additional Information/Context to outcome achievement:

- What supports and/or services are involved to assist with this outcome? How effective are they?
- How important is the outcome for the person? Is it a high priority, not a priority, or somewhere in between?

What to learn about (*Prompts for interview*)

- ✓ How does person feel about current living situation? How did they come to live in current situation (how was it determined and by whom)? What do they like or dislike?
- ✓ Does the place feel like home to the person? Are they comfortable? Does it meet their needs and expectations? Is this their preference?
- ✓ Does the person feel the need to change their current living arrangement? If so, why? Where else would they want to live, what have they looked into? Has anyone provided them with information or helped them explore alternatives?
- ✓ If applicable, how do they feel about the people they live with? Did they decide who they were sharing living space with? Is the situation working out for them?

## Outcome #2

### **I MAKE DECISIONS REGARDING MY SUPPORTS AND SERVICES**

Services and supports are provided to assist me in my daily life in a way that meets my needs and reflects my preferences and schedule. I need to be informed and involved in the decision-making process about the services and supports I receive to the extent that I am able. In doing so, I need options and to be empowered to make informed choices.

***Decision-making considerations:*** *These criteria must be present for the outcome to be achieved. If some of the criteria apply but not others, then the outcome is considered “in progress.” If none of the criteria apply, then the outcome is not achieved.*

- Person is involved at the level desired, or extent possible, for making decisions about the services and supports that they receive.
- Person has been provided with a variety of (reasonable) options to effectively meet their needs.
- Person feels their requests and preferences about what, how, and when services are provided are honored to the extent possible.
- Person knows how to make changes regarding services, supports, and their care plan.

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Additional Information/Context to outcome achievement:

- What supports and/or services are involved to assist with this outcome? How effective are they?
- What level of priority is the outcome for the person?

What to learn about: *(Prompts for interview)*

- ✓ How involved is the person in the decision-making process regarding what services and supports will be part of the care plan? Is this satisfactory to the person or do they desire more or less involvement?
- ✓ If the person has someone else involved in the decision-making (i.e., guardian, POA, family member), does it appear that this other person is making the voice of the participant known or is there difference between the two?
- ✓ In the care planning process, does the person feel they were presented with a variety of options that will meet their needs? Was the participant or other team members able to offer some ideas for options or make requests? Or were the options very limited and/or did not seem to address the issue or concern they have?
- ✓ Does the participant feel their preferences and opinions are considered/incorporated when deciding what, how, and when services or supports are delivered? Is this done to a satisfactory or reasonable level for the person? Are there any significant conflicts?

## COMMUNITY AND FAMILY PARTICIPATION

Most people have some kind of connection to family, friends, and community. The kind of involvement they desire and in what capacity will depend on the person's situation, preferences, and opportunities available. Some people may not have had the opportunity to experience participation in their community or in the workforce and will need exposure or education to help them decide. Supporting people to maintain or reach desired levels of connection is critical to outcome achievement.

### Outcome #3

#### **I AM INVOLVED IN MY COMMUNITY.**

Community can be defined at many levels, from a small internal community like church or a residential setting, or it can be broader to include the larger community such as civic organizations or just getting out and participating in pleasurable activities. Each person has their own way of being involved in the community. This outcome takes into account the level of connection I desire to have with my community (however I define it) and my ability to access it.

***Decision-making considerations:*** *These criteria must be present for the outcome to be achieved. If some of the criteria apply but not others, then the outcome is considered "in progress." If none of the criteria apply, then the outcome is not achieved.*

- The person is involved in their community to the extent they desire.
- The person is involved in activities within the community that are important to them.
- The person is able to access their community to attend activities and go places they wish to go.

Additional Information/Context to outcome achievement:

- What supports and/or services are involved to assist with this outcome? How effective are they?
- What level of priority is the outcome for the person?

What to learn about: *(Prompts for interview)*

- ✓ What does the person consider to be their community (i.e., social group, neighborhood, residential setting, church, larger community)? Do they feel they are as involved in their community as they would like? If not, why?
- ✓ Where does the person like to go or what do they like to do in their community? What social, recreational and organization activities are important to the person? Is there anything else the person would like to be doing?
- ✓ Is the person able to access these important activities as much as he/she would like? Are they able to access their community? Does the person get out as much as he/she would like? If not, why? Is this by choice? What are the barriers? What has been tried in the past and present to overcome these barriers? Does the person have some other ideas?

## HEALTH AND SAFETY

Health and safety have been the primary tenets of human services. Because these areas often affect other areas of life (i.e., ability to be independent, to access community, make decisions, etc.) they continue to be vital areas of concern. Addressing a person's health, level of functioning, and safety issues may influence the level of achievement of other desired outcomes. However, it is essential to take into account issues of risk and work toward a balance.

### Outcome #4

#### **I FEEL SAFE.**

Feeling safe in the home environment or in the community is important to everyone. Some people may feel comfortable living with certain risks while others don't. It is important to understand what safety concerns I have and assist me to address them. In some circumstances, I may not be aware of the safety risks or am apprehensive about sharing them. In these types of situations it is important to find some way of addressing these issues whether it be education, information, reassurance or referrals. Part of feeling safe may include knowing what to do in case of emergency. To address this, I and/or my caregivers may need some type of plan for emergencies (personal, weather, and medical). This outcome is about how I feel regarding my safety and the risks I am willing to take. This is **not** an assessment of whether or not I am safe or at risk.

***Decision-making considerations:*** *These criteria must be present for the outcome to be achieved. If some of the criteria apply but not others, then the outcome is considered "in progress." If none of the criteria apply, then the outcome is not achieved.*

- Person feels they can safely live in and move about their home, neighborhood, and community.
- Person feels safe with care providers. Personal cares and services are provided in a safe manner.
- Person feels prepared for emergencies.

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Additional Information/Context to outcome achievement:

- What supports and/or services are involved to assist with this outcome? How effective are they?
- What level of priority is the outcome for the person?

What to learn about: *(Prompts for interview)*

- ✓ Does the person feel safe in their immediate environment? Are they safe outside when in the community, crossing the street, in the grocery store, etc.? Are there any times when the person does not feel safe? What is it that causes them to feel this way? What helps them to feel safe?
- ✓ Does person feel safe with care providers? Do they feel that caregivers provide personal cares in a safe manner? Does the person ever feel afraid? If so, when?
- ✓ Is the person able to safely access the areas of their home or living arrangement? Are there any potential dangers? If so, how have these been addressed? What equipment or supports are helping the person to be safe?

- ✓ Does the person feel it is important to have an emergency plan in the event of a fire, tornado, flood? Does the person have smoke detectors, carbon monoxide detectors and do they work? Is there anything the person can think of that would make them feel more safe?
- ✓ Does the person have any cognitive or physical limitations that limit their ability to understand the risks associated with their decisions? In carrying out an emergency plan?
- ✓ Has the person ever been abused in the past or in present situation? Are there any signs or symptoms? Is this an issue the person would like addressed if it's not already?