

PERSONAL EXPERIENCE OUTCOMES IN LONG-TERM CARE

Assisting people to achieve their desired individual quality-of-life outcomes is one of the primary goals of our long-term care system. The following statements and definitions demonstrate the areas of life that people in long-term care programs have identified as being important to their quality of life. They are stated in the first person to emphasize the importance of the personal voice and experience of the individual. These statements provide a framework for learning about and understanding the individual's needs, values, preferences, and priorities in the assessment and care planning process and in monitoring the quality of our long-term care programs.

Choice

When people participate in human service systems, they often feel a loss of control over their lives as professionals or others in authority get involved. In our long-term care system we strive to empower program participants (members/consumers) to have choices—to have a "voice" or say about things that affect their quality of life and to make decisions as they are able. People with cognitive disabilities are supported to actively participate in the ways they are able, and their decision-makers (guardians or POA) keep their perspectives in mind for making decisions. The following statements reflect some of the ways in which the system can help support people to maintain control over their lives.

I decide where and with whom I live.

One of the most important and personally meaningful choices I can make is deciding where and with whom to live. This decision must acknowledge and support my individual needs and preferred lifestyle. My home environment has a significant effect on how I feel about myself and my sense of comfort and security.

I make decisions regarding my supports and services.

Services and supports are provided to assist me in my daily life. Addressing my needs and preferences in regard to who is providing the services or supports and how and when they are delivered allows me to maintain dignity and control. To the extent that I desire and am able, I am informed and involved in the decision-making process about the services and supports I receive. I am aware that I have options and can make informed choices.

I decide how I spend my day.

Making choices about activities of daily life, such as sleeping, eating, bathing, and recreation enhances my sense of personal control, regardless of where I live. Within the boundaries of the other choices I have made (such as employment or living with other people), I am able to decide when and how to do these daily activities. It gives me a sense of comfort and stability knowing what to expect in my daily routine. It is important to me that my preferences for when certain activities occur are respected and honored to the extent possible.

Personal Experience

A person's day-to-day experience should meet his or her expectations a high quality life. People who participate in a long-term care programs need to feel they are 'citizens', not parts of a 'program' and that they are treated with respect. The focus of supports and services is to assist people in their daily lives, not to take them over or get in the way of the experience.

I have relationships with family and friends I care about.

People for whom I feel love, friendship, and intimacy are involved in my life. These relationships allow me to share my life with others in meaningful ways and helps affirm my identity. To the extent that I desire, people who care about me and my well-being provide on-going support and watch out for my best interests.

I do things that are important to me.

My days include activities such as employment or volunteer opportunities, education, religious activities, involvement with my friends and family, hobbies, or other personal interests. I find these activities enjoyable, rewarding, and they give me a sense of purpose.

I am involved in my community.

Engaging in the community in ways that I enjoy provides me with a sense of belonging and connection to others. Having a presence in my community enhances my reputation as a contributing member. Being able to participate in community activities gives me opportunities for socialization and recreation.

My life is stable.

My life is not disrupted by unexpected changes for which I am not prepared. The amount of turnover among the people who help me (paid and unpaid) is not too much for me. My home life is stable, and I am able to live within my means. I do not worry about changes that may occur in the future because I think I am reasonably well prepared.

I am respected and treated fairly.

I feel that those who play a continuing role in my life respect me. I am treated fairly as a person, program participant, and citizen. This is important to me because it can affect how I view myself in relation to others and my sense of self-worth.

I have privacy.

Privacy means that I have time and space to be by myself or with others I choose. I am able to communicate with others in private as needed. Personal information about me is shared to the extent that I am comfortable. Privacy allows me to be free from intrusion by others and gives me a sense of dignity.

Health and Safety

Health and safety is an essential and critical part of life that can affect many other areas of a person's life. The following outcome statements represent the person's right to determine what is important to him or her in these areas, and what risks he or she is comfortable with. It's about what the person feels he or she needs to meet personal priorities. It is **not** an assessment of whether or not the person's circumstances meet others' standards for good health, risk, or safety.

I have the best possible health.

I am comfortable with (or accepting of) my current physical, mental, and emotional health situation. My health concerns are addressed to the extent I desire. I feel I have enough information available to me to make informed decisions about my health.

I feel safe.

I feel comfortable with the level of safety and security I experience where I live, work, and in my community. I am informed and have the opportunity to judge for myself what is safe. People understand what I consider to be an acceptable level of risk and respect my decisions. If I am unable to judge risk for myself due to my level of functioning, I have access to those that can support me in making those determinations.

I am free from abuse and neglect.

I am not experiencing abuse or neglect of my person, property, or finances. I do not feel threatened or mistreated. Any past occurrences have been adequately dealt with or are being addressed.