

CONSUMER PERSPECTIVES ABOUT QUALITY



*“... everyone grows in their own way and time.
They grow better at some seasons and not at others.
If they are nourished and strengthened they can grow into something useful.”
—PhotoVoice participant*

June 30, 2010

**This is a product of the Massachusetts Systems Transformation Grant.
It is still a work in progress. The core consumer outcomes were
developed by the Quality Subcommittee and illustrated with photos
taken by consumers as part of the PhotoVoice project.**

Comprehensive Quality Management Across Long Term Services & Supports

The Quality Subcommittee of the Massachusetts Systems Transformation Grant developed the following Vision and Mission Statements which were adopted by the Executive Leadership of the Executive Office of Health and Human Services in August 2009.

Vision and Mission Statements

Vision for Quality Management in Long Term Services and Supports

Citizens participate in and benefit from a quality management and improvement system for long term services and supports.

Mission for Quality Management in Long Term Services and Supports

To design and implement a comprehensive, continuous, consumer-focused quality management system that supports individuals, including but not limited to elders and persons with disabilities to live in communities first.

The quality management system will be responsive, accountable and sustainable, supporting consumer quality of life and informed choices, and optimal efficiency and effectiveness in service delivery and consumer satisfaction.

Core Consumer Outcomes:

The Quality Subcommittee Core Outcomes Workgroup identified five domains of quality that are important to each of the State agencies across EOHHHS and reflect important areas of consumers' lives related to quality of life. The five domains are:

- Respect and Dignity
- Access
- Health and Safety
- Person-Centeredness
- Community Integration and Inclusion

As part of a project called "PhotoVoice," consumers with a variety of disabilities of all ages took photos that illustrated these five areas of quality. They met to discuss their photos and developed brief statements explaining what the photos meant to them. The Quality Subcommittee Core Outcomes Workgroup next developed a series of outcome statements to illustrate the desired outcomes of each of these areas. These outcomes were developed after an analysis of the photos and narratives to identify common themes of importance to the consumers. The photos in this booklet illustrate what it is like for people with disabilities when the various quality outcomes are met or not met.

Respect and Dignity

Outcome Statements

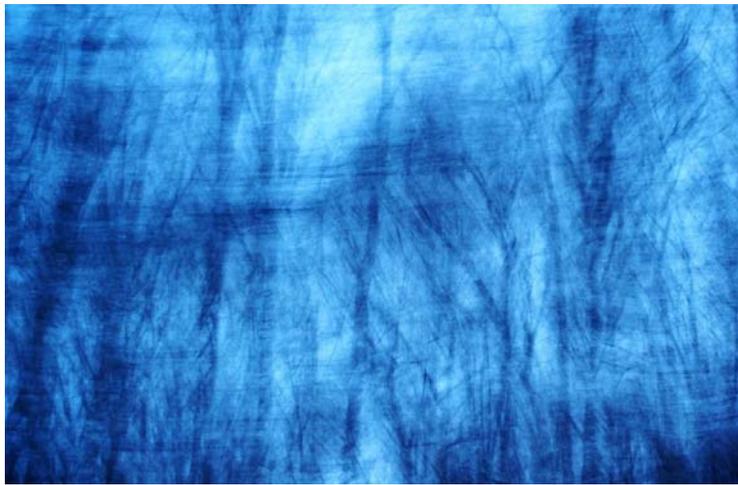
People respect me as equal and value my strengths.

I have the supports I need to live the life I choose.

I make the choices in my life without fear of others.

When this outcome is met:

"I am more than my disabilities. It may take me longer to complete a task, my education, and life goals. But I can still learn and do the things that you can do. I am a computer tech, a photographer, a videographer, a leader, and an artist. I also have a passion for advocating for myself and others. I believe we are more than the labels we are given."



When this outcome is not met:

"These dumpsters flank the entrance to this unmarked door... This is the route to my therapist office... There are three dumpsters in this parking lot. The summer brings on an unimaginable odor. The liquid drainage from the dumpsters (stain seen) runs right into the path of the walkway. This is the only entrance to the building. This access is unacceptable and degrading to think we, as mental health clients do not deserve better."



Access

Outcome Statements

My environment is barrier-free.

I am able to live where and how I choose.

I have the economic resources to support my life.

I have transportation to support my daily needs.

When this outcome is met:

“This photo is of the deck in my home. It reminds me of when I get to hang out on it with my friends and caretakers during the warm weather. I also have cookouts out on the deck. The deck also helps me get in and out of my home with my wheelchair because it has an accessible ramp.”



When this outcome is not met:

“As you can see there is a hill that separates me from my son’s game. I cannot get down the hill to sit with the other parents and families to watch the game and support my son because I cannot walk down the hill. So I sit in my car to watch the game and yell my heart out in hopes that he can hear my voice or excitement. When actually there are times when I cannot make out which player is my son. I am so proud of my son and I wish I could sit closer to the game to feel involved and be part of it all; instead, I feel segregated.”



Health & Safety

Outcome Statements

I feel good about my health and my life.

I have access to health services that support my specific abilities and needs.

I feel safe in my home and community.

When this outcome is met:

“This yoga pose requires a lot of physical balance, which can seem counterintuitive finding balance when I look decidedly unbalanced. Yet, this echoes my own recovery. In the chaos of my daily environment, and even within my own body and mind, I am always able to find some kind of balance. The more I take those changes, large and small, the stronger I am for myself and my peers. This cycle of balance and imbalance is integral to the peer/recovery movement.”



When this outcome is not met:

“This is the exam table at my doctor’s office. Due to my limitations, I cannot get up on the table to be examined. If I absolutely need to be fully examined my doctor does offer me assistance; I do accept help sometimes but not always because I have injured myself trying to get up on the table. I often wonder if I am putting my health in jeopardy by not using this table. However, I don’t have many options and I trust the doctor I have now.”



Person-Centeredness

Outcome Statements

I feel supported to develop my own capacities and strengths.

I have control over my life and personal choices.

The relationships I have fulfill me.

When this outcome is met:

“Little in life is assured to stay, yet I pray that all is not taken away. The flag displayed proudly and not turned aside keeps reminding and fulfilling as a remaining pride. People, places and things may pass from being part of my life but the flag and all it means continues to fill, thrill and sustain me.”



When this outcome is not met:

“A life of depression can be so bleak and desolate. Sometimes, when I go outside with my camera all I can see is sadness, emptiness, and aloneness. Depression seems to block my vision, making me unable to see brightness, beauty, and happiness. In a depressed mood, this picture would show how I feel, alone in an empty world, a dead tree in the murky slime of life while healthy trees in the back ground look on.”



Community Integration & Inclusion

Outcome Statements

I am happy with the friendships and community support around me.

My family, friends, and peers are there to support me when I need them.

I have access to participate fully in my community.

I feel good about myself and the things I offer the world around me.

One photo illustrates both met and unmet needs for this outcome:

“For many years I sang with different choirs including the choir at my local church and a traveling choir. After becoming disabled I can no longer climb the stairs to the choir loft, so this sets me apart. I no longer feel a part of something I once loved to do. Having a physical disability leaves me sitting at the bottom. Maybe when the new choir is built they will think about those with disabilities and seniors.”



Quality means something different to each of us ...



*Giving up is not a choice even with or without a disability.
Life goes on and there's always a way to pursue your dreams.
I went from not having access to an education to having my Bachelor's and Master's degrees.*

Do not give up!



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