

Measuring What Really Matters:

The Personal Outcome Measures® National Database

CQL|The Council on Quality and Leadership reports the latest findings from the National *Personal Outcome Measures®* Database. The introduction of the *Personal Outcome Measures®* in 1991 flowed from our tradition of defining quality and organizational improvement from the perspective of the person receiving the supports.

The *Personal Outcome Measures®* contains 21 items that define quality from the individual's perspective. These are the key factors and experiences that people with disabilities and their families have said are most important to them. CQL's *Personal Outcome Measures®* explore whether or not, and how, an indicator is meaningful and important to the individual. Linking the question of personal relevance to support planning and outcome measurement is particularly important for people with disabilities.

Based on over 7,800 people interviews conducted during CQL Accreditation visits, our findings reveal:

- Safety, security and health are well supported in these organizations
 - Exercising meaningful choice in important life decisions remains a challenge for most people
 - Community integration and enhanced social roles are the least likely to be present in people's lives
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What Really Matters

CQL's approach to quality is about focusing on the real meaning of things – personal choice and person-directed services. We believe that organizations need to focus on what really matters to people. Organizations and service systems need to be about excellence in facilitating personal control and person-directed services.

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CQL's approach to measurement looks at personal quality of life and addresses questions of priority and relevance for the person. The identification, planning, and provision of supports that facilitate personally defined life outcomes require a uniquely individualized and customized approach. This means individually designed and customized supports – for everyone – all the time.

Personal Outcome Measures® 1993 – 2009

The following charts present the findings from over 7,800 interviews.

Some key findings:

- Four outcomes look at matters of Choice – where to live, where to work, where to receive services, and what goals to pursue
 - Less than half of the people we interviewed were exercising these choices in a way that was meaningful to them
 - Organizational supports for choosing where to live and work were more likely to be present, even when the outcome for the individual was not present – indicating that organizations are supporting people in these areas to make the outcome a reality
- Four outcomes address community involvement, integration and relationships – participation (presence) in the life of the community, interaction with other community members, friendships, and being in integrated settings
 - We found that participation and interaction in community were present for about 70% of the people
 - When it comes to friendships, 56% reported this outcome as present in their lives
 - Only about 1 in 3 people are fully integrated in the community
- Many outcomes focus on matters of health, safety and security
 - More than 8 of 10 people report being safe and free from abuse and neglect
 - Over 70% are experiencing continuity and security, privacy, respect, accessible environments, and best possible health
 - Exercise of rights and fair treatment are reported by 50% and 55% (respectively) of people interviewed

Percent of Personal Outcomes and Supports Present: 1993 – 2009

(n=7,879)

Factor	Outcomes	Supports
My Self		
People Remain Connected to Natural Support Networks	61.7%	78.0%
People have Intimate Relationships	70.4%	69.6%
People are Safe	86.5%	82.7%
People have the Best Possible Health	74.4%	75.3%
People Exercise Rights	49.8%	47.1%
People are Treated Fairly	55.7%	56.5%
People are Free From Abuse and Neglect	84.0%	89.6%
People Experience Continuity and Security	78.5%	78.1%
People Decide When to Share Personal Information	78.2%	70.5%
My World		
People Choose Where and With Whom they Live	46.2%	56.9%
People Choose Where they Work	40.6%	51.4%
People Use Their Environments	76.7%	79.3%
People Live in Integrated Environments	37.5%	44.3%
People Interact with Other Members of the Community	72.2%	76.0%
People Perform Different Social Roles	32.5%	33.4%
People Choose Services	50.3%	39.9%
My Dreams		
People Choose Personal Goals	51.3%	39.5%
People Realize Personal Goals	82.7%	82.3%
People Participate in the Life of the Community	70.0%	79.8%
People have Friends	56.3%	60.6%
People are Respected	78.7%	83.1%

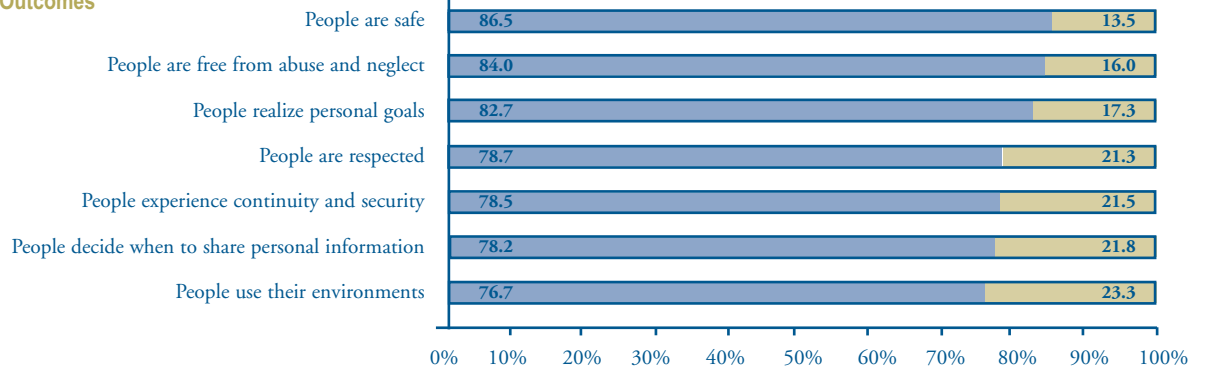
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Percent of Personal Outcomes Present: 1993 – 2009

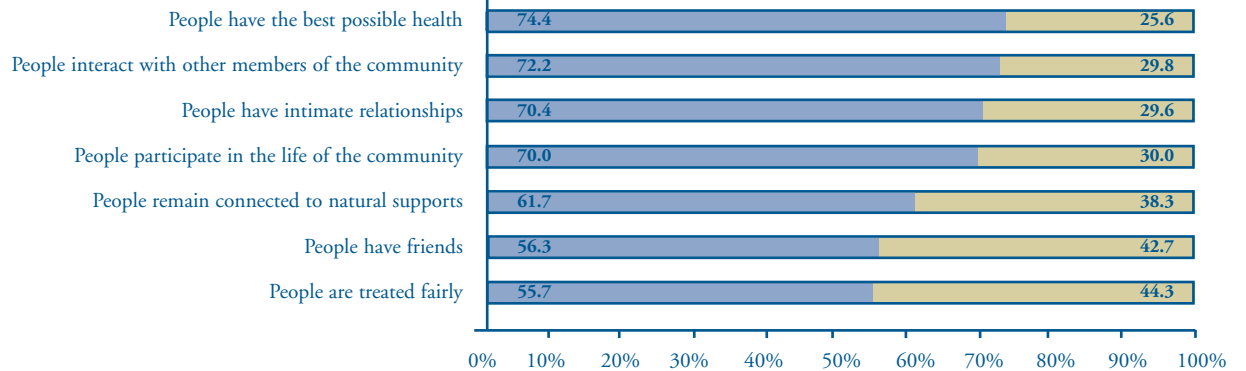
(n=7,879)

■ Present ■ Not Present

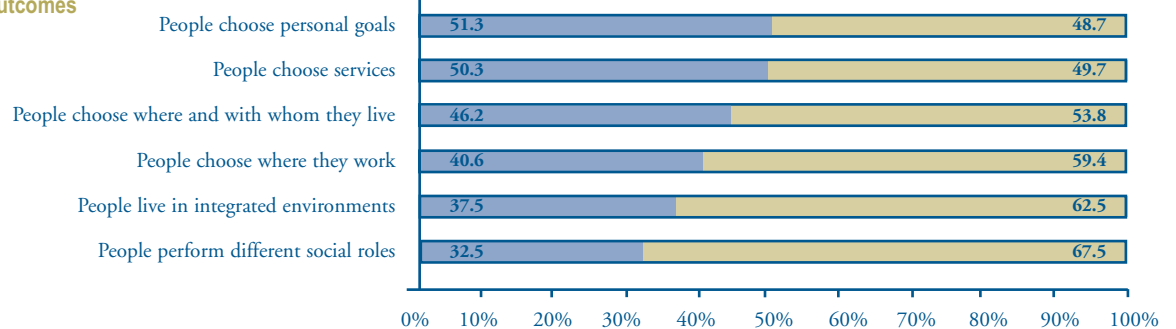
Most Often Present Outcomes



In the Middle



Least Often Present Outcomes



CQL – The National Database on *Personal Outcome Measures*®

Inspired by a vision of a world of dignity, opportunity, and community inclusion for all people, CQL | The Council on Quality and Leadership is an

international leader in the definition, measurement, and improvement of quality of life for people with disabilities. CQL has demonstrated that valid and reliable quality of life measurement can be incorporated in community-based human services.

In the 1990s, CQL redefined quality as responsiveness to people rather than compliance with standards. After conducting focus groups throughout North America, CQL published the *Personal Outcome Measures*® offering people with disabilities an opportunity to define their own quality of life outcomes and exert choice and self-determination. In 1993, CQL published the *Personal Outcome Measures*® as an alternative to both its traditional quality indicators and assessment methodology. CQL signaled a new era in quality measurement with a re-definition of quality from organizational compliance to responsiveness to people. The Personal Outcomes focus on the items and issues that matter most to people. Organizations committed to Personal Outcomes recognize the connections between the service and intervention and the whole person. Learning about Personal Outcomes results from talking to people and discovering what is important to them and why.

In 2005, CQL introduced the *Quality Measures 2005*®, including the 2005 edition of *Personal Outcome Measures*®. This new edition contains 21 Personal Outcomes, organized into the following factors:

- My Self:** Who I am as a result of my unique heredity, life experiences and decisions.
- My World:** Where I work, live, socialize, belong or connect.
- My Dreams:** How I want my life (self and world) to be.

CQL recognizes that large-scale adaptation of a person-centered approach to quality of life assessment is strengthened by an evidence-based quality model. To that end, we established the *Personal Outcome Measures*® Database in 1993. The database now contains data collected during interviews with over 7,800 individuals receiving services from organizations pursuing CQL Accreditation, between 1993 and 2009. These organizations are not a random sample of the human service system. They are instead a group of highly motivated service/support providers who have adopted the principles and practices of the *Personal Outcome Measures*®. They represent a range of community service providers delivering residential, vocational, service coordination, case management and other supports, and are found across the United States in small rural communities, as well as suburban and metropolitan areas.

CQL has studied and published findings from the data in peer-reviewed journals. We have demonstrated and reported on the validity of the *Personal Outcome Measures*® as an instrument and the reliability of the review and interview methodology.

This is one of a series that reports key findings from the CQL National *Personal Outcome Measures*® Database. We encourage readers to consider the lessons learned from our data in the movement toward a meaningful quality of life for people in the community.

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