

Health and Safety – We Can Do Better

How safe are people with disabilities?

Are people with disabilities achieving their best possible health?

How well are we responding to allegations and incidents of abuse and neglect?

Across the country, reports by the media, federal oversight bodies, and state regulatory agencies all point to the fact that the status of health, safety, and security for people with disabilities remains a major concern.

The Council on Quality and Leadership (CQL) reports the latest findings from the National Personal Outcome Measures® Database.

Based on over 6,400 interviews with people with disabilities, we have clear evidence that CQL Accredited organizations are delivering person-centered basic assurances and building the foundation for true quality of life. CQL believes that organizations must meet these fundamental requirements as a prerequisite to staying in business. People with disabilities deserve nothing less.

Quality – Beyond Assurances

CQL believes we must separate the term “quality” from the term “assurance” – together they pose a confusing contradiction. Assurances are one thing; quality is yet another.

“Assurances” are critical in organizational life and conduct. They are essential, fundamental and non-negotiable. We expect nothing less than complete assurances in human services – people must be safe, unharmed, treated fairly, and secure.

“Quality” on the other hand implies excellence – for CQL this means that service providers are responsive to the individuals they support. They learn about and recognize each person’s individual characteristics, needs and dreams – and they provide supports that are tailored to the person. The organization’s quality is measured by the quality of life experienced by each individual.

Too often when confronted with a public outcry regarding unacceptable conditions and actions within a service system, the first reaction is a call for more regulations, more inspections, or greater control – all under the banner of “quality assurance”. CQL believes we can do better.

Rather than turn the clock back to greater controls, fewer options, and less freedom, we can raise the level of Basic Assurances® in our service systems at the same time we promote and foster quality of life. Assurances are best understood and delivered in the context of the individual’s preferences and situation. CQL’s Basic Assurances® offer a foundation for service quality, containing requirements for systems, policies and procedures. CQL Accreditation expects organizations to demonstrate the organizational values, systems, and practices that support people to have the level of health, safety, and security they are entitled to. CQL looks at the effectiveness of systems through the personal impact of policies, procedures, and practices on people – person by person.

Our data indicate that outcomes in health, safety, and security are present to a large degree in CQL Accredited organizations:

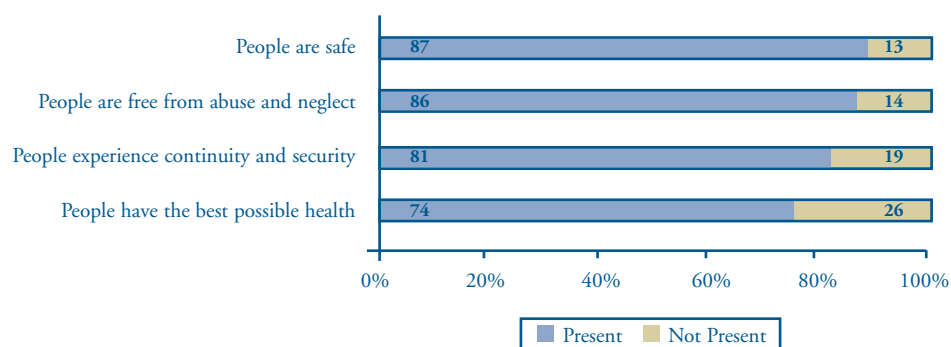
74%	People have the best possible health
81%	People experience continuity and security
86%	People are free from abuse and neglect
87%	People are safe

CQL Accredited organizations have the strong foundation of applying proven process standards and practices – and they have embraced the organizational values that guide a person-directed approach to all services and supports.

Note on CQL measurements. CQL’s measures are more comprehensive and rigorous than those typically required by, or reported to, public officials. CQL includes in all its Basic Assurance® outcomes those items identified by the individuals themselves. These self-identified outcomes pertain to the individual (and often include individual priorities for health, safety and security outcomes) and would not have application for other individuals. Thus, the percentages reported here may appear lower than similar aggregated data reported elsewhere.

Health and Safety Outcomes 1993-2006

(n=6,424)



Our data also indicate that these health and safety outcomes are more likely to be present when the outcomes of Respect, Intimate Relationships, and Natural Supports are also present. These findings point to the importance of a person-centered values base. When people are known and supported as individuals – whether by organizational staff, family, and/or close friends – they are more likely to experience personal safety, best possible health, and security. People are also less likely to be subject to abuse and neglect, when they remain connected to support networks of people who care deeply about them.

Further analysis reveals that even in small, community-based settings (accredited by CQL), people with disabilities maintain these essential outcomes for safety, health, security, and freedom from abuse and neglect. With the right values base and appropriate individualized supports, community-based services (accredited by CQL) offer a safe and secure alternative for people with intellectual disabilities.

In addition to data collection through the accreditation program, CQL has trained others as reliable certified interviewers with the Personal Outcome Measures® and we have worked with public agencies in several states to collect personal outcomes data outside of accreditation. The table below presents a comparison of some of these projects:

Health and Safety – Comparison of Data from National CQL Accredited and Two Non-Accredited States

Percent of Outcomes Present

	National Database CQL Accredited (n=6,424)	Southern State Non-accredited (n=2,594)	Eastern State Non-accredited (n=101)
People are safe	87.1	64.7	83.2
People are free from abuse and neglect	85.8	83.5	77.2
People experience continuity and security	80.8	39.7	39.6
People have the best possible health	74.5	43.1	67.3
Average	82.1	57.8	66.8

This comparison further illustrates the positive impact of CQL Accreditation on these fundamental and essential health and safety outcomes on the lives of people with intellectual disabilities.

Inspired by a vision of a world of dignity, opportunity, and community inclusion for all people,

The Council on Quality and Leadership (CQL) 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 changed human services when it 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 redefinition 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 Basic Assurances® and 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 6,400 individuals receiving services from CQL Accredited organizations, between 1993 and 2006. These organizations are not a random sample of the disability 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.

During the CQL Accreditation process, individuals with disabilities meet a CQL staff member for a personal outcomes interview and follow up is done with others who know the person best to further evaluate the presence of outcomes and supports for each person. People in the CQL database represent the range of intellectual and developmental disabilities, as well as mental illnesses.

CQL has studied and published findings from the data in peer-reviewed journals (see references below). 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 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 with disabilities in community.



To learn more, contact:

CQL – The Council on Quality and Leadership
100 West Road, Suite 406
Towson, Maryland 21204
410.583.0060
www.c-q-l.org
info@thecouncil.org

References

- Gardner, J.F. & Carran, D.T. (2005). "The Attainment of Personal Outcomes by People with Developmental Disabilities." *Mental Retardation*, 43(3), 157-173.
- Gardner, J.F., Carran, D.T., & Nudler, S. (2001). "Measuring Quality of Life and Quality of Services through Personal Outcome Measures: Implications for Public Policy." *International Review of Research in Mental Retardation*, Vol. 24, pp 75-100.
- Gardner, J.F., Nudler, S., & Chapman, M. (1997) "Personal Outcomes as Measures of Quality." *Mental Retardation*, 35:4 (August), 295-305.