

Most Wanted Outcomes:

People live in integrated environments

People perform different social roles

Fifteen years of data analysis demonstrates again and again that two personal outcomes remain out of reach for most people with intellectual disabilities – *People live in integrated environments* and *People perform different social roles*.

Over the years, we've seen gains for people in many other outcomes.

Organizational practice, individualized supports, and greater choice have improved the status of personal outcomes related to health, safety, employment, respect, and community participation. Yet, barriers still remain for achieving a fully-realized life.

Do people with disabilities have the opportunity to play a variety of social roles?

What happens to other quality of life outcomes when social roles are limited?

Can social roles be enhanced through greater community integration?

The Council on Quality and Leadership (CQL) reports the latest findings from the National Personal Outcome Measures® database. Based on over 6,400 interviews, we see the continuing challenges experienced by people with disabilities.

Most Wanted Outcomes

The roles we fill in life express what is important to us. At various times in our lives or days, we may be: child, parent, sister, niece, spouse, friend, worker, student, teacher, volunteer, athlete, coach, artist, neighbor, gardener, advocate, voter, activist, congregation member, and so on. These roles define the expectations we have for ourselves and that others have for us. The opportunity to play a number of different roles enriches our lives and the lives of others. Playing a variety of roles helps people express their unique qualities. Social roles offer people an opportunity to contribute and give back to a larger community.

For many people, the opportunity to fill a variety of valued social roles is limited only by their time, interests, and resources. We have access to information about what might be available; we have past experiences to guide us; we are free to choose and set priorities.

People with disabilities have those same desires and they can benefit even more from the opportunity to expand their social roles. Rather than living with labels and limits, people who fill a variety of social roles are more likely to be treated as valued members of the larger community. With expanded social roles, people are more likely to build ties and relationships and live healthier and happier lives.

Our data found that the greatest challenges among all of the Personal Outcome Measures® – the outcomes that remain “most wanted” are:

- People perform different social roles
- People live in integrated environments

Even for CQL Accredited organizations, there is still a long way to go in supporting people to be recognized in multi-dimensional roles in community settings. Barriers remain to full community integration – including:

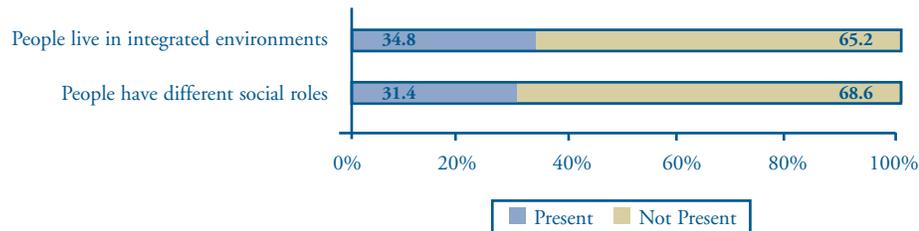
- fears about safety
- limited perceptions about ability (both for the person and for the community)
- perceived or real lack of support from community members, regulators, or families

CQL recognized these barriers (and the need to move beyond them) when we developed the Community Life® measures. We stress the importance of “bridging organizations”. In addition to providing services/supports for people, these organizations facilitate the inclusion of people into society beyond the boundaries of the organization itself. Bridging organizations connect the needs and desires of people with disabilities with the community as a whole. They seek and establish partnerships, relationships, and connections with like-minded community leaders. They find common ground across all sectors of the community. As organizations redefine their roles and leadership within their communities, so too are people with disabilities building new and powerful connections to enrich their lives and the lives of the people they meet.

We believe that the kind of change needed to address the barriers to the “most wanted outcomes” will need to come not just from individual efforts or organizational/systems improvements. We must look to our communities for the partners, resources, and inspiration to make this most critical of all changes.

Social Roles and Integrated Living Outcomes 1993-2006

(n=6,424)



Further analysis reveals the following:

Living situations:

- People living in supervised (24-hour) settings report fewer outcomes in the area of social roles/integrated living than people in other settings
- People living Independently or with their family have the highest level of social roles/integrated living outcomes present

Source of funding:

- People whose services are funded through the ICF/MR program reported significantly fewer social roles/integrated living outcomes as compared with other funding sources (such as Home and Community Based Services-HCBS)

Top five outcomes that predict the presence of the social roles/integrated living outcomes:

- People choose services
- People interact with other members of the community
- People choose where they work
- People realize personal goals
- People choose where and with whom they live

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 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 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 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 with disabilities.



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