Measuring What Really Matters:  
*The Personal Outcome Measures® National Database*

CQL’s 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

---

**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.
Measuring What Really Matters: 
*The Personal Outcome Measures® National Database*

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)*

<table>
<thead>
<tr>
<th>Factor</th>
<th>Outcomes</th>
<th>Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>My Self</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People Remain Connected to Natural Support Networks</td>
<td>61.7%</td>
<td>78.0%</td>
</tr>
<tr>
<td>People have Intimate Relationships</td>
<td>70.4%</td>
<td>69.6%</td>
</tr>
<tr>
<td>People are Safe</td>
<td>86.5%</td>
<td>82.7%</td>
</tr>
<tr>
<td>People have the Best Possible Health</td>
<td>74.4%</td>
<td>75.3%</td>
</tr>
<tr>
<td>People Exercise Rights</td>
<td>49.8%</td>
<td>47.1%</td>
</tr>
<tr>
<td>People are Treated Fairly</td>
<td>55.7%</td>
<td>56.5%</td>
</tr>
<tr>
<td>People are Free From Abuse and Neglect</td>
<td>84.0%</td>
<td>89.6%</td>
</tr>
<tr>
<td>People Experience Continuity and Security</td>
<td>78.5%</td>
<td>78.1%</td>
</tr>
<tr>
<td>People Decide When to Share Personal Information</td>
<td>78.2%</td>
<td>70.5%</td>
</tr>
<tr>
<td><strong>My World</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People Choose Where and With Whom they Live</td>
<td>46.2%</td>
<td>56.9%</td>
</tr>
<tr>
<td>People Choose Where they Work</td>
<td>40.6%</td>
<td>51.4%</td>
</tr>
<tr>
<td>People Use Their Environments</td>
<td>76.7%</td>
<td>79.3%</td>
</tr>
<tr>
<td>People Live in Integrated Environments</td>
<td>37.5%</td>
<td>44.3%</td>
</tr>
<tr>
<td>People Interact with Other Members of the Community</td>
<td>72.2%</td>
<td>76.0%</td>
</tr>
<tr>
<td>People Perform Different Social Roles</td>
<td>32.5%</td>
<td>33.4%</td>
</tr>
<tr>
<td>People Choose Services</td>
<td>50.3%</td>
<td>39.9%</td>
</tr>
<tr>
<td><strong>My Dreams</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People Choose Personal Goals</td>
<td>51.3%</td>
<td>39.5%</td>
</tr>
<tr>
<td>People Realize Personal Goals</td>
<td>82.7%</td>
<td>82.3%</td>
</tr>
<tr>
<td>People Participate in the Life of the Community</td>
<td>70.0%</td>
<td>79.8%</td>
</tr>
<tr>
<td>People have Friends</td>
<td>56.3%</td>
<td>60.8%</td>
</tr>
<tr>
<td>People are Respected</td>
<td>78.7%</td>
<td>83.1%</td>
</tr>
</tbody>
</table>
Measuring What Really Matters:
The Personal Outcome Measures® National Database

Percent of Personal Outcomes Present: 1993 – 2009
(n=7,879)

Most Often Present Outcomes

- People are safe: 86.5% (Present), 13.5% (Not Present)
- People are free from abuse and neglect: 84.0% (Present), 16.0% (Not Present)
- People realize personal goals: 82.7% (Present), 17.3% (Not Present)
- People are respected: 78.7% (Present), 21.3% (Not Present)
- People experience continuity and security: 78.5% (Present), 21.5% (Not Present)
- People decide when to share personal information: 78.2% (Present), 21.8% (Not Present)
- People use their environments: 76.7% (Present), 23.3% (Not Present)

In the Middle

- People have the best possible health: 74.4% (Present), 25.6% (Not Present)
- People interact with other members of the community: 72.2% (Present), 29.8% (Not Present)
- People have intimate relationships: 70.4% (Present), 29.6% (Not Present)
- People participate in the life of the community: 70.0% (Present), 30.0% (Not Present)
- People remain connected to natural supports: 61.7% (Present), 38.3% (Not Present)
- People have friends: 56.3% (Present), 42.7% (Not Present)
- People are treated fairly: 55.7% (Present), 44.3% (Not Present)

Least Often Present Outcomes

- People choose personal goals: 51.3% (Present), 48.7% (Not Present)
- People choose services: 50.3% (Present), 49.7% (Not Present)
- People choose where and with whom they live: 46.2% (Present), 53.8% (Not Present)
- People choose where they work: 40.6% (Present), 59.4% (Not Present)
- People live in integrated environments: 37.5% (Present), 62.5% (Not Present)
- People perform different social roles: 32.5% (Present), 67.5% (Not Present)
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.

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

Past Issues of the Data Quarterly

#1 – July 2007  CQL Accreditation – Setting the Bar for Quality: The Personal Outcome Measures® National Database
#2 – October 2007  Connecting to Quality: CQL’s Social Capital Index®
#3 – January 2008  Health and Safety: We Can Do Better
#4 – April 2008  How Did Rights Get so Wrong?
#5 – July 2008  It’s Not Working
#6 – October 2008  Most Wanted Outcomes
#8 – April 2009  CQL’s Quality Measures 2005® – Basic Assurances® – Part 1
#10 – October 2009  CQL’s Quality Measures 2005® – Responsive Services® and Community Life®