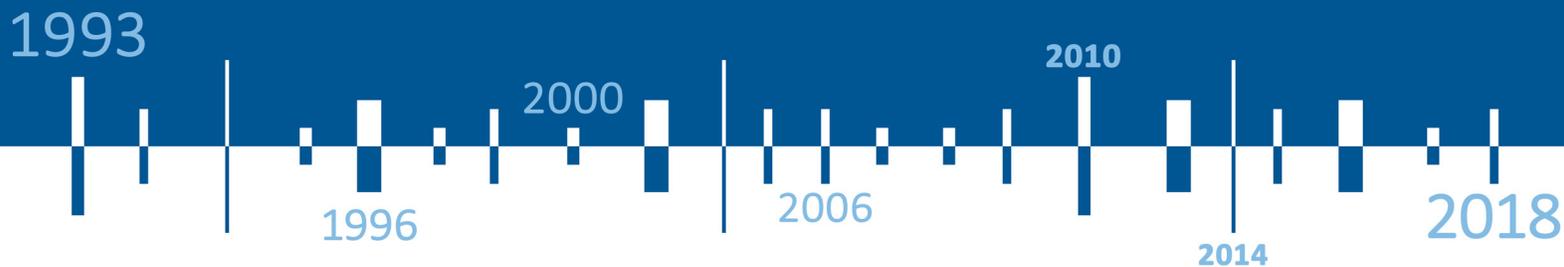




PERSONAL OUTCOME MEASURES®

25 YEARS

OF PERSON-CENTERED DISCOVERY
AND ACHIEVING OUTCOMES





For over 45 years CQL has provided international leadership in designing progressive practices in services for people with intellectual and developmental disabilities and people with psychiatric disabilities. Our work remains focused on organizations and helping them make real change.

MISSION

CQL is dedicated to the definition, measurement, and improvement of personal quality of life.

VISION

A world of dignity, opportunity, and community for all people

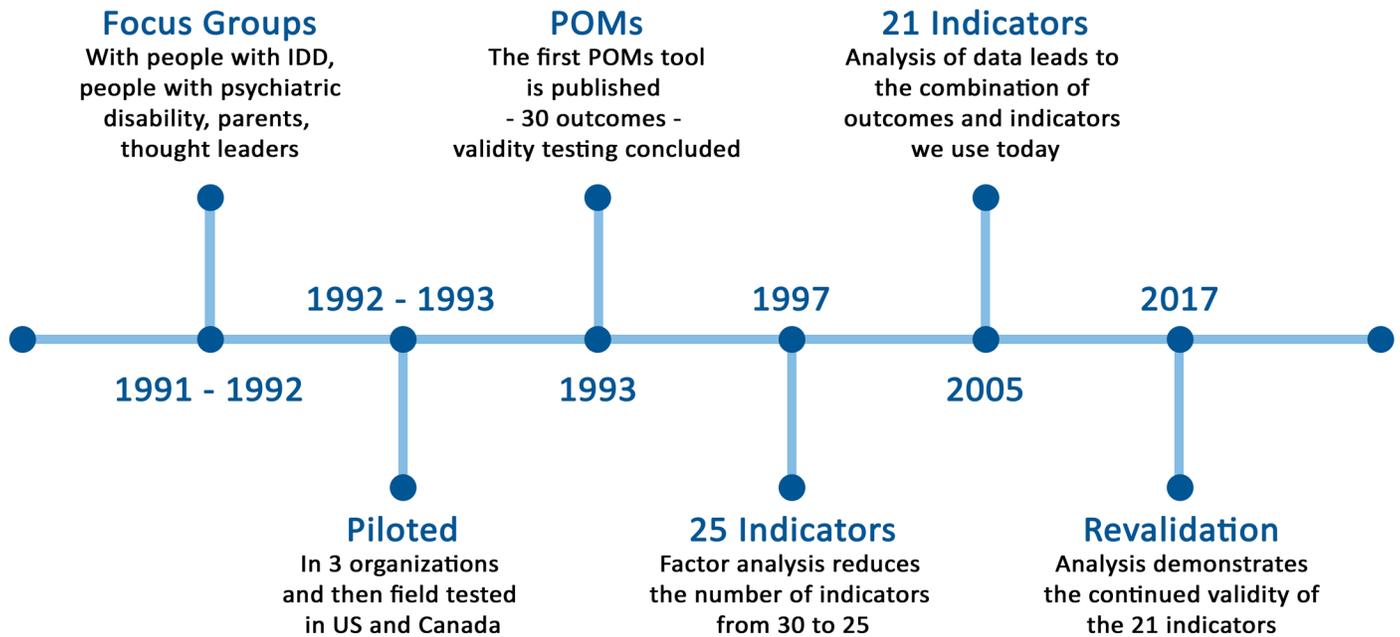
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The Personal Outcome Measures®: 25 Years in the Making

CQL | The Council on Quality and Leadership's Personal Outcome Measures® (POMs) are used to identify people's quality of life outcomes, plan supports, and gather information and data about individual outcomes. We conduct Personal Outcome Measures® interviews to demonstrate the link between personally defined quality of life and excellence in person-centered services, and the importance of data in planning and making change.



CQL first introduced personal outcomes in the 1993 Edition of the Outcome Based Performance Measures. We refined and published the revised outcomes as the Personal Outcome Measures® in 1997, 2005, and 2017.

In the 2017 revision, CQL conducted a validity analysis and reorganized the indicators into five new factors:

-  **My Human Security**
Non-negotiable human and civil rights
-  **My Community**
Access to be in, a part of, and included in the community
-  **My Relationships**
Social support, familiarity, intimacy, and belonging
-  **My Choices**
Decisions about one's life and community
-  **My Goals**
Dreams and aspirations for the future

As a data driven organization, CQL continuously re-examines the data to reflect the real-world changes in quality of life for people who receive human services and supports, as well as ever changing service systems. This report does just that by reporting key findings from 25 years of the Personal Outcome Measures®.

The Personal Outcome Measures®: International Database

In order to strengthen the evidence-base of the Personal Outcome Measures®, CQL first introduced its Personal Outcome Measures® database in 1993. Our most recent iteration of the Personal Outcome Measures® database, PORTAL, was introduced in 2017. PORTAL is a new, secure online data system developed by CQL which provides human service organizations and state agencies with reporting, tracking, analysis, and logging of personal outcomes and supports for people receiving services. This system encompasses CQL's internationally-recognized Personal Outcome Measures® and Basic Assurances® to collect and evaluate quality of life areas including health, safety, social roles, rights, relationships, community integration, employment, and so much more.

The database contains data from organizations that provide human services, including: service coordination; case management; individual and family supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); human services systems; and state and local governments. The database now contains data from over 11,500 people receiving human services in the United States collected by certified reliable interviewers alone.

CQL utilizes this data to help improve the quality of life of people with disabilities, and the services organizations provide to support them. To do so, CQL analyzes and publishes this data in peer-reviewed journals, research summaries, and practice capstones. This report aggregates data from the last 25 years about the quality of life of people with disabilities to serve as lessons to guide future directions of the field.

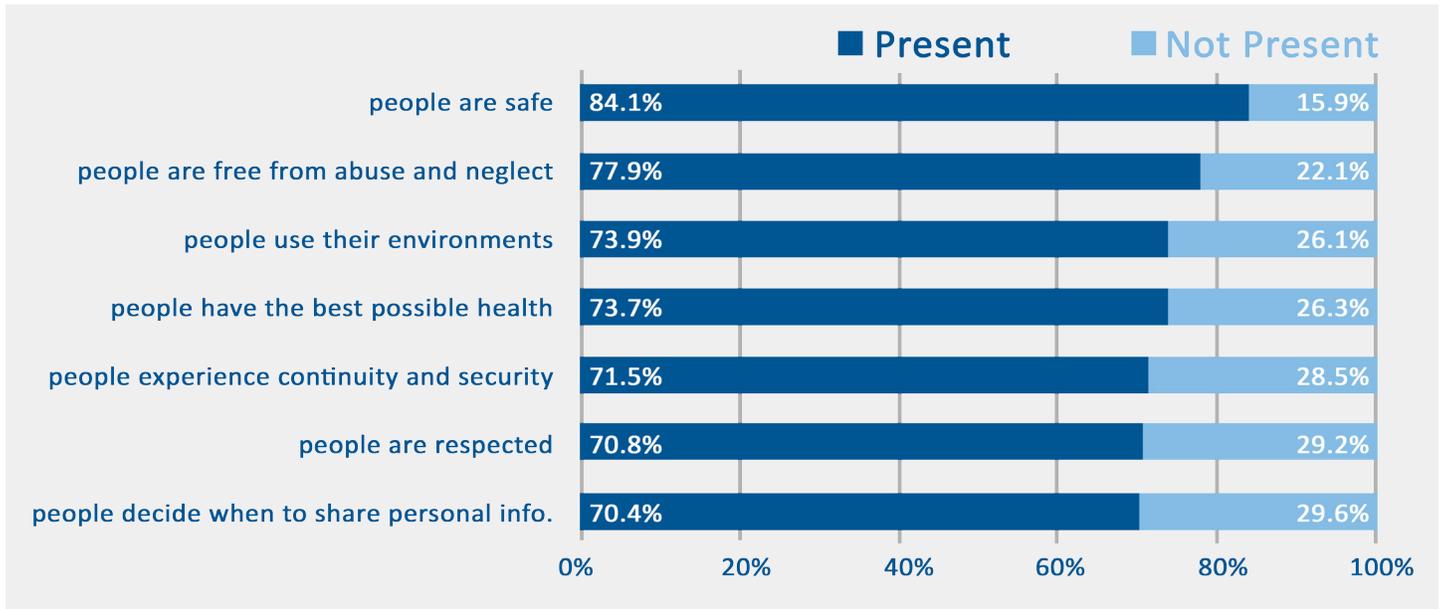


Outcomes Present & Organizational Supports In Place (1993 - 2017, n = 11,328)

	OUTCOMES	SUPPORTS
MY HUMAN SECURITY		
People are safe	84.1%	81.7%
People are free from abuse and neglect	77.9%	80.9%
People have the best possible health	73.7%	74.7%
People experience continuity and security	71.5%	73.7%
People exercise rights	50.4%	48.5%
People are treated fairly	57.7%	58.2%
People are respected	70.8%	75.2%
MY COMMUNITY		
People use their environments	73.9%	75.2%
People live in integrated environments	45.7%	50.5%
People interact with other members of the community	70.3%	72.8%
People participate in the life of the community	61.7%	70.6%
MY RELATIONSHIPS		
People are connected to natural supports	59.9%	74.6%
People have friends	51.1%	55.2%
People have intimate relationships	64.4%	63.6%
People decide when to share personal information	70.4%	66.0%
People perform different social roles	41.4%	41.5%
MY CHOICES		
People choose where and with whom to live	42.2%	51.1%
People choose where they work	39.5%	48.9%
People choose services	51.0%	52.9%
MY GOALS		
People choose personal goals	50.8%	51.6%
People realize personal goals	70.2%	69.5%

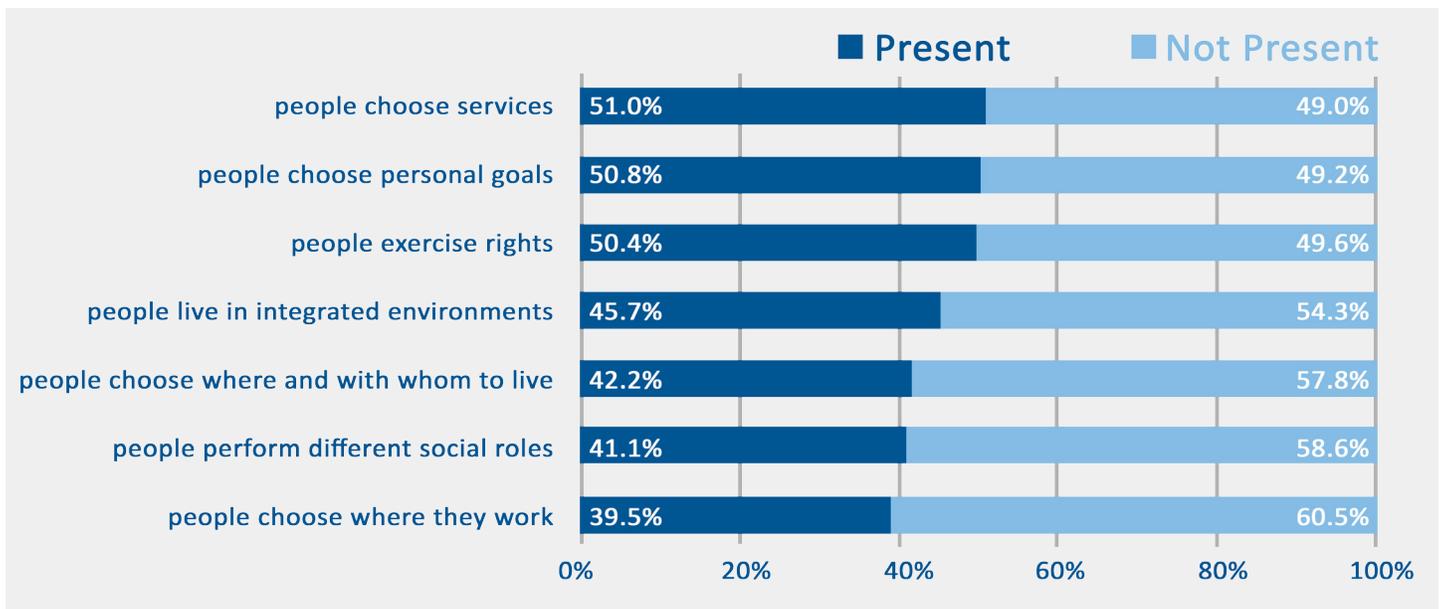
Most Present Outcomes

25 years of Personal Outcome Measures® data reveals fundamental forms of human security, such as safety, health, and respect, are some of the most frequently achieved outcomes. While these outcomes are attained more frequently than other quality of life outcomes, human security should be non-negotiable – there is still room for improvement. Moreover, legislation and litigation such as the Americans with Disabilities Act (1990) and *Olmstead v L.C.* (1999), and advocacy by people with disabilities have increased expectations of quality, beyond traditional forms of human security.



Least Present Outcomes

Based on 25 years of data from over 11,000 people, people with disabilities continue to have a lack of choices and opportunities, including not only to choose where they spend their days and where they make their homes, but also how they exercise their human and civil rights. As this lack of choice and rights mirrors historical custodial models of care, improving the quality of services people with disabilities receive requires a culture of transformation, one which moves beyond compliance, builds off what organizations are doing well, and implements person-centered practices.



The Personal Outcome Measures®: Impact

Indeed, when we calculated outcome correlations using regression analyses, findings revealed the outcomes that have the greatest impact in predicting overall quality of life for people with disabilities are: exercise rights; treated fairly; are respected; choose where and with whom to live; and, choose services. Many of these outcomes with the greatest impact, are also the ones that are least frequently achieved, and vice versa.

Outcomes Correlations (n = 11,328)

HIGHEST	
People exercise rights	0.560
People are treated fairly	0.543
People are respected	0.534
People choose where and with whom to live	0.528
People choose services	0.524
LOWEST	
People are connected to natural supports	0.412
People realize personal goals	0.382
People are free from abuse and neglect	0.362
People have the best possible health	0.359
People are safe	0.263

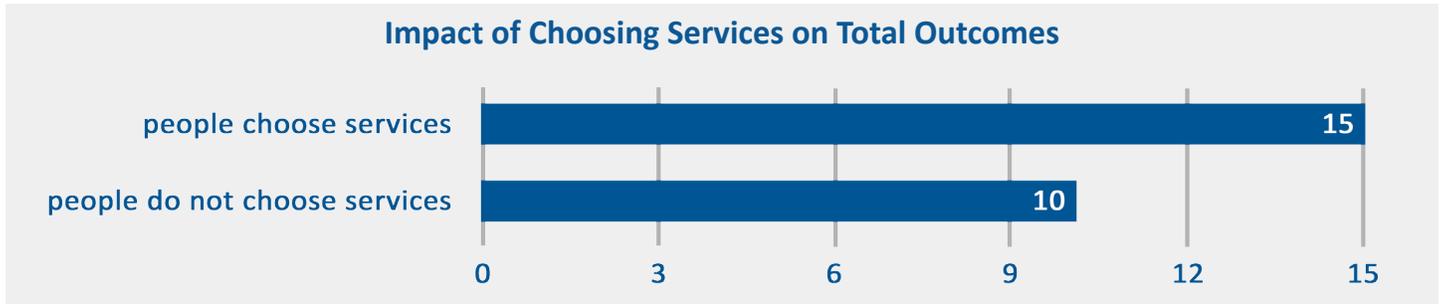


"Quality really is measured
by personal outcomes."

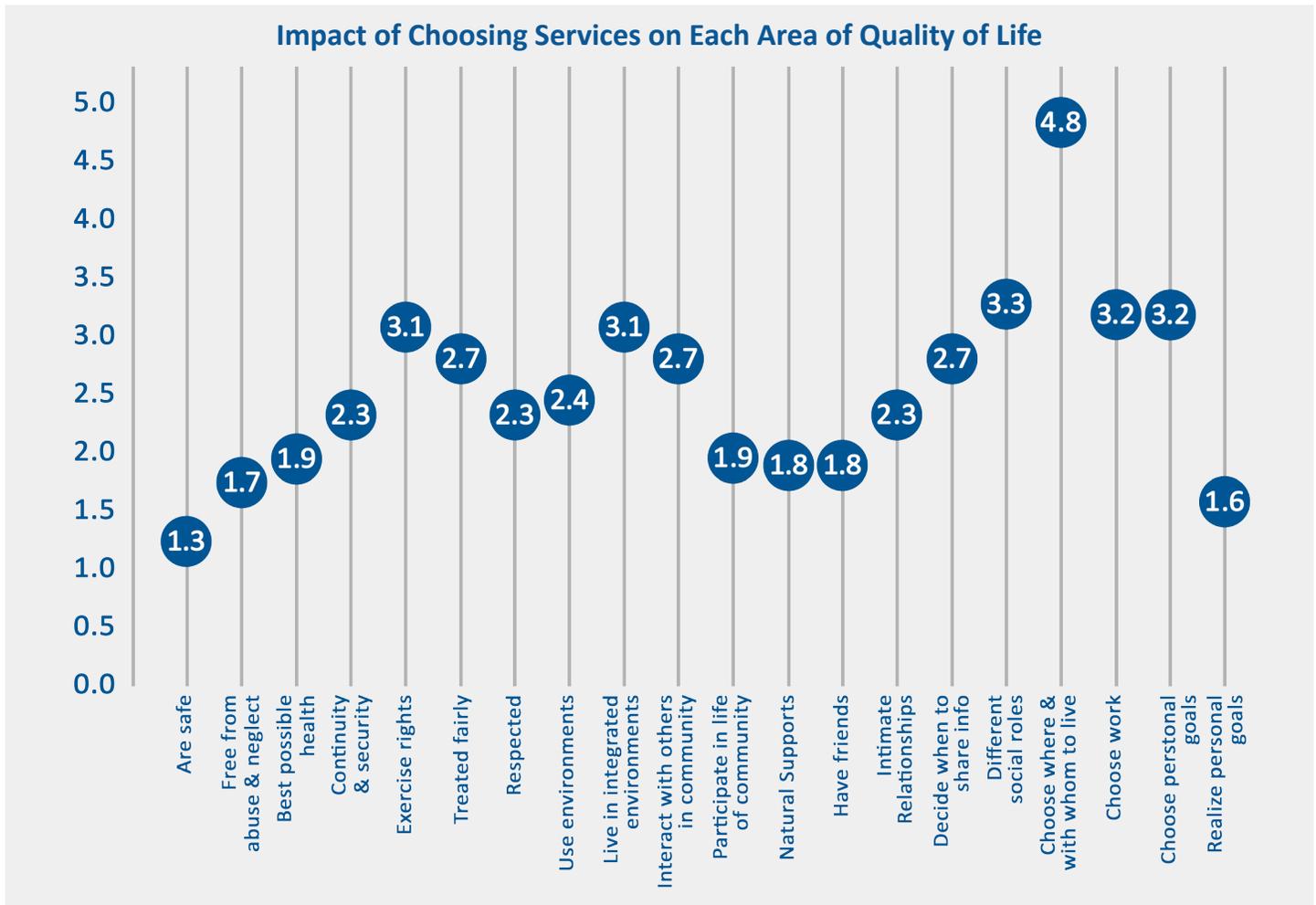
- Carmine Marchionda, ARC of Rockland

Impact of Choosing Services on Quality of Life

Because of the importance of choice for people with disabilities, and because the limited opportunities people with disabilities often have to make choices, we ran a linear regression model to examine the relationship between choosing services (outcome present), and ones' total quality of life. Findings revealed, people who choose their services have a significantly better overall quality of life compared to people who do not choose their services (15/21 versus 10/21) (see Figure).

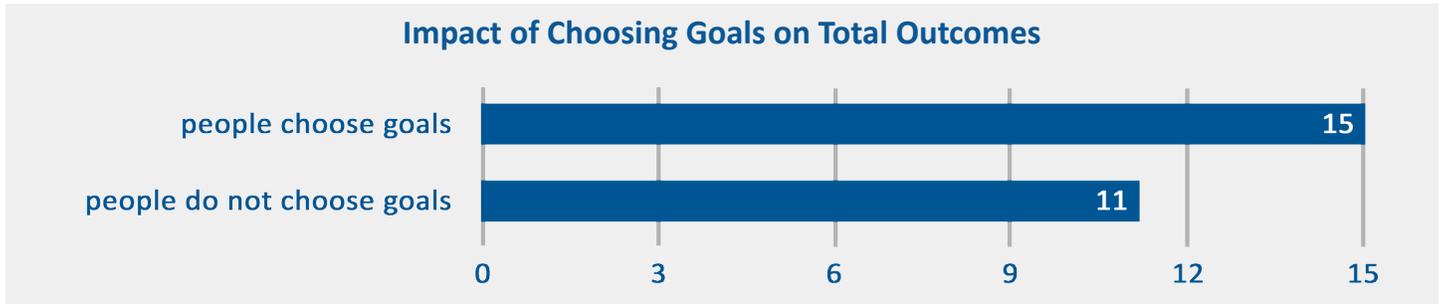


To determine the impact on specific areas of quality of life, we also ran binary logistic regression models (with Bonferroni correction) to examine the impact of people with disabilities' choosing their services on each quality of life indicator. Findings revealed when people with disabilities choose their services, every single area of their quality of life is improved (see Figure). For example, people who choose their services are 4.8 times more likely to choose where and with whom to live, 3.1 times more likely to live in integrated environments, and 1.9 times more likely to have the best possible health.

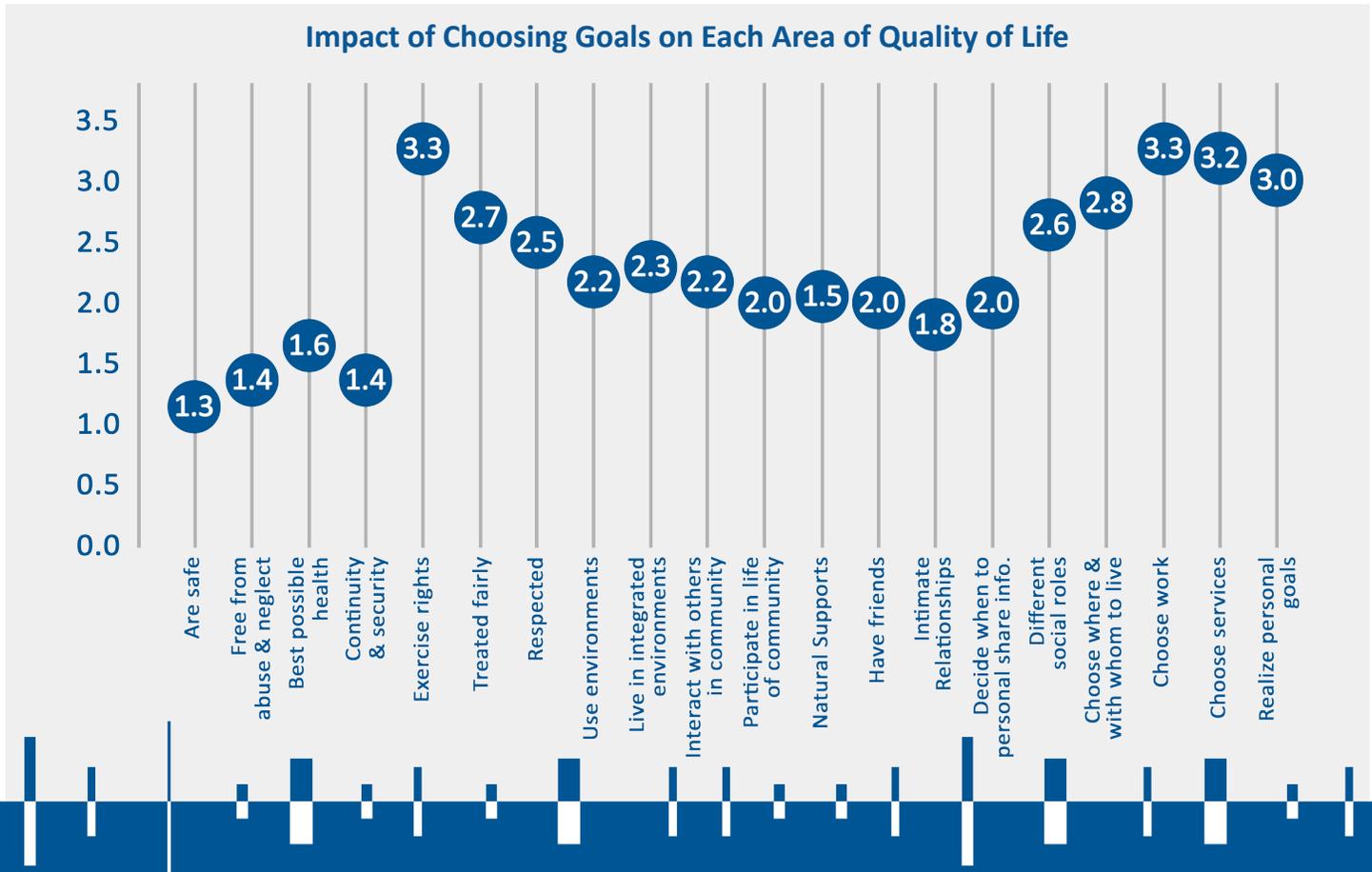


Impact of Choosing Goals on Quality of Life

In addition to examining the impact of people with disabilities choosing their services on their quality of life, we were also interested in exploring the impact of people with disabilities choosing their personal goals. To do so, we ran a linear regression model to examine the relationship between choosing personal goals (outcome present) and total quality of life. Findings revealed, people who choose their personal goals have a significantly better overall quality of life compared to people who do not choose their personal goals (15/21 versus 11/21) (see Figure).



As a follow up, we also ran binary logistic regression models (with Bonferroni correction) to examine the impact of people with disabilities' choosing their personal goals on each specific quality of life indicator. Findings revealed when people with disabilities choose their personal goals, every single area of their quality of life is improved (see Figure). For example, people who choose their personal goals are 3.3 times more likely to choose where to work, 2.6 times more likely to perform different social roles, and 2.0 times more likely to participate in the life of the community.



"Person-Centered Plans are derived from Personal Outcome Measures®"

The Personal Outcome Measures® and Person-Centered Planning

Person-Centered Planning is a discovery process focused entirely on the person, empowering them to be at the center of the planning process. It is the single most important way in which we demonstrate respect to and for the person. It takes our attention away from the system and requires that we view the person as the expert of their own life – they know who they are and what they want.

Unfortunately, as O'Brien and O'Brien detailed in *The Origins of Person Centered Planning: A Community of Practice Perspective*¹ (1999) “like other efforts for social change, person-centered planning has been used and misused, complicated and simplified, lengthened and shortened, trivialized, legalized, and lionized” (p. 4). Person-Centered Planning challenges us to be authentic – we must engage in authentic Person-Centered Planning to truly be respectful.

**We must engage
in authentic
Person-Centered Planning
to truly be respectful.**

**Person-Centered Planning
is rooted in what is
most important
to the person**

Authentic Person-Centered Planning is an art, not a science. It is practiced by people who are skilled at listening to what people want in their lives. It is fun, creative, and synergistic work. Person-Centered Planning is rooted in what is most important to the person and directly involves the person with their community, network of connections, and close personal relationships to explore and create innovative ways to live the life they choose.

The Personal Outcome Measures® have been used in authentic Person-Centered Planning to help practitioners learn about the person. Skilled interviewers ask questions about the 21 quality of life indicators to discover the person's definition of outcomes and expectations to achieve them. The interviewer learns about what is happening in the person's life regarding supports, quality of life, and what is most important to the person. Knowing what is important and what the person wants guides the person and their team to create supports.

Supporting Ben to Build Connections

For example, in planning with Ben², who lived in a small mining town, he and his team focused on developing relationships and community connections. Ben enjoys music and coffee; he and his team set out to explore and discovered a small local coffee shop where local musicians gathered frequently. The musicians entertained themselves and others with their original music. Ben enjoyed the music and started going to the coffee shop regularly with some of the other men with whom he lived. After a few weeks, the musicians gave Ben and his companions harmonicas, and invited them to play. Ben enjoyed the music and the camaraderie, so he continued to go to the coffee shop regularly, joining in with the musicians. Ben not only often played along and enjoyed his time, he also developed relationships. After a while, a group of the musicians came to Ben's home for a visit, bringing with them a variety of instruments for the housemates to play, including guitars, keyboards, and other instruments. Ben and his housemates had a great time and invited his new friends to stop by again.

¹ O'Brien, C. L., & O'Brien, J. (2000). *The origins of person-centered planning: A community of practice perspective*. Lithonia, GA: Responsive Systems Associates.

² Names have been changed.

Over the next few months Ben continued to hang out with the musicians regularly not only at the coffee shop, but at local restaurants and around town. Ben enjoyed the music, the coffee, and the connections. Although later, the musicians were no longer able to play at the coffee shop, Ben continued to go just to visit and drink coffee with his friends, the musicians, and other patrons. Ben now feels a connection to the people in the small mining town – he knows people and people know him. In fact, Ben is confident that many people will come to his neighborhood cookout this summer.

Supporting Jose and Samantha to Get Married

In using the Personal Outcome Measures®, teams learn about people's personal goals. Authentic Person-Centered Planning mandates no "dream-snuffing." Authentic Person-Centered Planning means that we accept people's goals and support them to address all barriers. Personal goals vary because they are exactly that - personal. Some goals may be easier to attain than others, such as buying a computer, while others may require more planning, such as getting married.

There is an agency that provides services to people with intellectual and developmental disabilities in a small community in New York. They support people who live with their families, people who live in licensed homes, and people who work in the community or in sheltered workshops. The staff at the agency began learning about the Personal Outcome Measures® in 2011, and goals began shifting from what staff thought was important *for people* to goals that were identified as important *to people*. One service coordinator, a real champion of the Personal Outcome Measures®, was one of the first to truly listen to Jose and take seriously his wish to get married.

The story really begins before 2011 when Jose, who lived with his family, met Samantha at work. Jose and Samantha had a lot in common – they enjoyed listening to country music, talking about NASCAR races, and spending time together. After a while, the couple started talking about getting married. Many people in the organization could only see the challenges and barriers of Jose and Samantha getting married. The agency talked about all the things Jose needed to be able to do independently, such as pay bills, take his medication, and cook, before he could get married and live on his own. However, Jose's Service Coordinator began to talk about how to make this happen and assembled a team to begin putting action steps into place. The challenges, including Jose's seizure disorder, were acknowledged, but instead of dismissing Jose's dream, the team worked to systemically break down the barriers and put supports in place. The Service Coordinator worked with Jose, Jose's family, Samantha, Samantha's service coordinator, and other supporters to figure out what supports were needed to pool their resources (e.g., money, paid supports, and natural supports). Today, Jose has been married to the love of his life since 2015. Jose and Samantha still enjoy listening to country music, watching NASCAR races, and spending time together. The organization reported the Personal Outcome Measures® caused a shift in the culture for the entire organization – there was no more dream snuffing. All goals, whether they are perceived to be achievable or not, deserve to be pursued. Truly person-centered planning takes commitment, learning, and perseverance.

Using the Personal Outcome Measures® in authentic Person-Centered Planning can help organizations successfully support change for individual people, groups of people, and even across the organization. The Personal Outcome Measures® is an efficient and effective tool in guiding the discovery, planning, and effectiveness of services in supporting people to attain goals. When there is authentic Person-Centered Planning, there is genuine respect for the person.

Personal Outcome Measures®
caused a shift
in the culture for the
entire organization

More Information about Personal Outcome Measures® Data

CQL is dedicated to the definition, measurement, and improvement of personal quality of life. However, we believe collecting data is only valuable if you do something meaningful with it. Personal Outcome Measures® data can guide individual plans, provide agencies with information to make data-based decisions, and give states the information they need to demonstrate compliance, set priorities, and focus limited resources.

PORTAL Data System

CQL's PORTAL Data System provides agencies and systems with reporting options to better understand and analyze outcomes data collected through CQL's Personal Outcome Measures®. Data can be analyzed at the individual, organizational, or national level to evaluate the presence of outcomes and the supports that are provided. This data can then be dissected across hundreds of different data elements, such as disability type, residential setting, race, gender, geographical location, decision-making authority, age, and more.

Learn more about PORTAL: www.c-q-l.org/PORTAL

PORTAL Alerts

CQL also recently launched PORTAL Alerts, which is an email distribution list to receive articles, updates, and information about CQL's data system PORTAL, along with research authored by CQL staff. These alerts go beyond just the data, sharing analysis and insight into how it can be applicable to your supports and services. (You do not need to be a PORTAL user to receive PORTAL alerts.)

Sign up to receive PORTAL Alerts: www.c-q-l.org/PORTALalerts

Personal Outcome Measures® Training

CQL's training options will equip staff and your organization with tools to deliver the highest quality of services. They cover many topics, including supported decision-making, communication, community, rights, outcomes, and more. CQL also offers a number of webinars, including ones on Personal Outcome Measures®.

Browse CQL's training menu: www.c-q-l.org/Training

View CQL's webinar recordings: www.c-q-l.org/Webinars

Personal Outcome Measures® Certification

CQL also offers certification for Personal Outcome Measures® Interviewers and Trainers. They include a process for organizations to help increase the value and reliability of internal data collection about Personal Outcomes.

Find out more about CQL Certification: www.c-q-l.org/Certification

Sign up for The Certification Network, an email list about certification: www.c-q-l.org/CertNetwork



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