



Data Brief

Trends in Outcomes Achieved for Individuals with Intellectual and Developmental Disabilities: *Findings from 20 years of Personal Outcome Measures® Data*

By:

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For the past 20 years, the Council on Quality and Leadership (CQL) has worked with State human service agencies, service provider agencies, individuals with intellectual and developmental disabilities (IDD) and their families to measure the quality of services in long-term services and supports. The development of the *Personal Outcome Measures®* (POM) in 1993 changed the way quality and outcomes were considered, and measured, into a more holistic person-centered approach. As service systems, service populations, and quality expectations have changed over the past 20 years, the POM have maintained a strong structural measurement of the outcomes individuals achieve, and the supports available to achieve each outcome at the individual level.

This data brief provides an initial national view of changes in achieved outcomes over time – during the past 20 years (1993 to 2013) while POM data was collected. Future analyses will delve even deeper into these data, to assess correlations between these trends and systemic changes, and correlations between variables. What follows here is: (a) the methodology for data collection and analysis; (b) findings; and, (c) concluding remarks.

METHODOLOGY

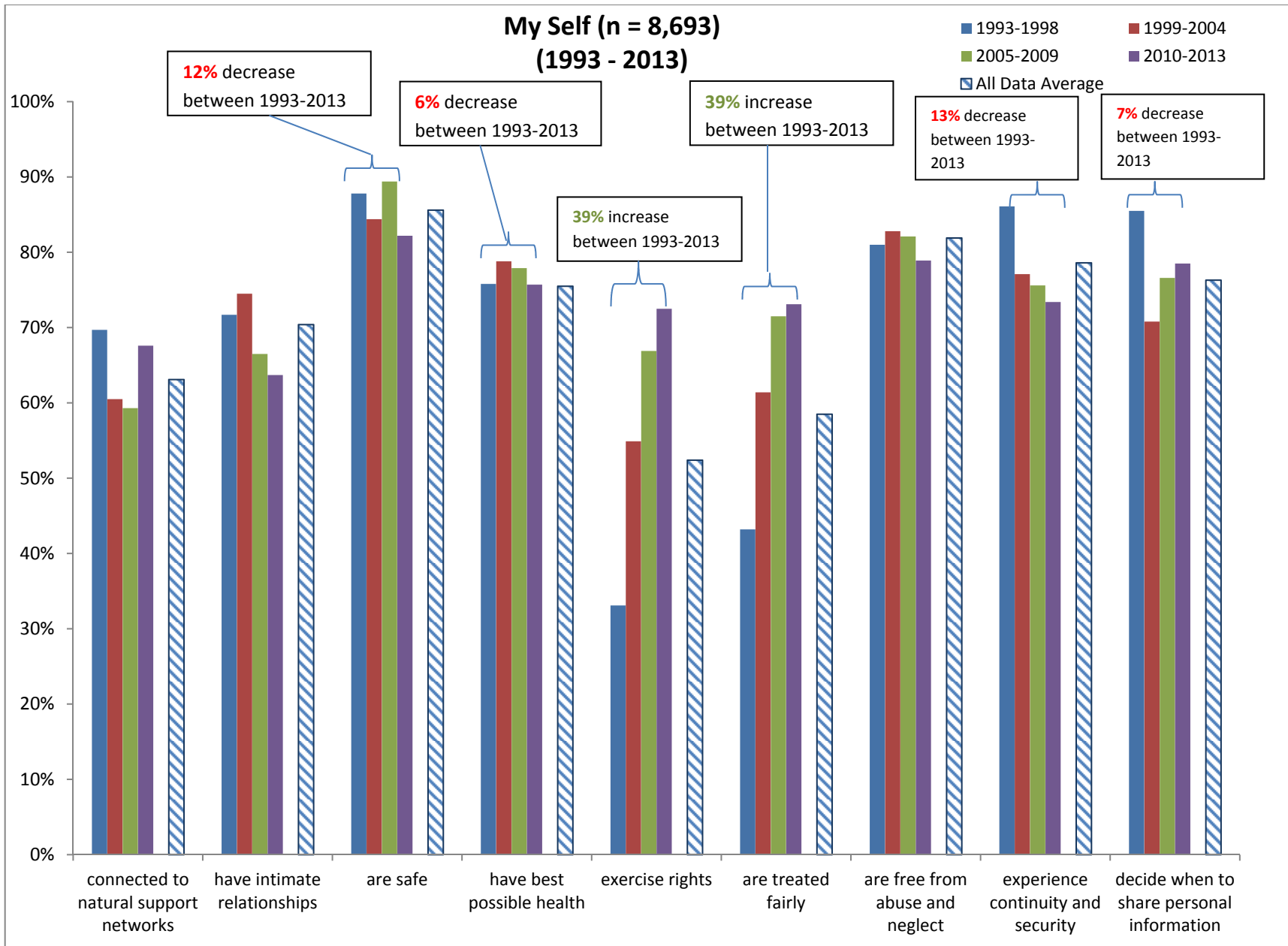
Data for this report has been aggregated to include *Personal Outcome Measures®* data from the past 20 years. The data in this report comes from reliable interviewers who are either: (a) CQL staff or (b) CQL certified interviewers. All available data was aggregated in SPSS Statistics (v. 22). Once the dataset was compiled, groupings were reviewed in five year increments: 1993-1998; 1999-2004; 2005-2009; and 2010-2013. Data was then analyzed by year-span increments for trending purposes. Importantly, prior to 2005, the POM consisted of 25 indicators for measuring individual outcomes. In 2005, the POM was restructured and reduced to include 21 of the original 25 indicators. These 21 indicators are presented in three categories: My Self, My World, and My Dreams. This analysis focuses on the current 21 POM indicators.

Due to differences in degree of completion, the population (n) associated with each of the three main categories changes slightly. In each chart (below), the n is noted. The n ranges from 8,689– 8,697. However, there is not an equal distribution across time periods. The population size for a given time period ranges from 930 (2010-2013) to 3,834 (1999-2004). The table below identifies the number of interviews analyzed in each of the five year time periods. This range may account for some of the trending changes over time, but was not analyzed for this brief. Additionally, 523 cases did not have a date associated with the interview. In these instances, results were not included in the five year increments, but were included in the “all data” total – showing the average across all 20 years by indicator.

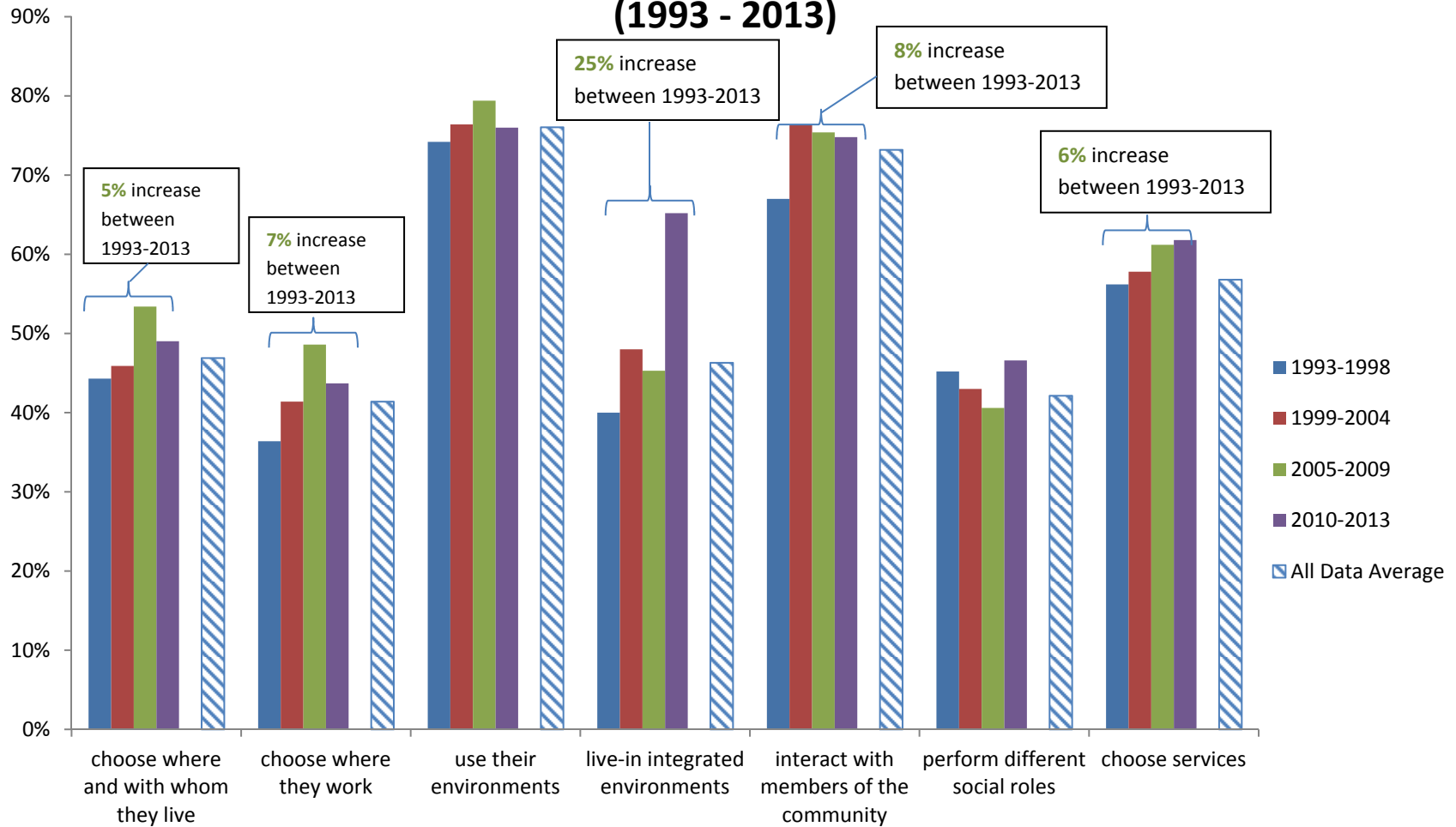
Average n Per Period	
1993-1998	1,809
1999-2004	3,834
2005-2009	1,658
2010-2013	930

FINDINGS

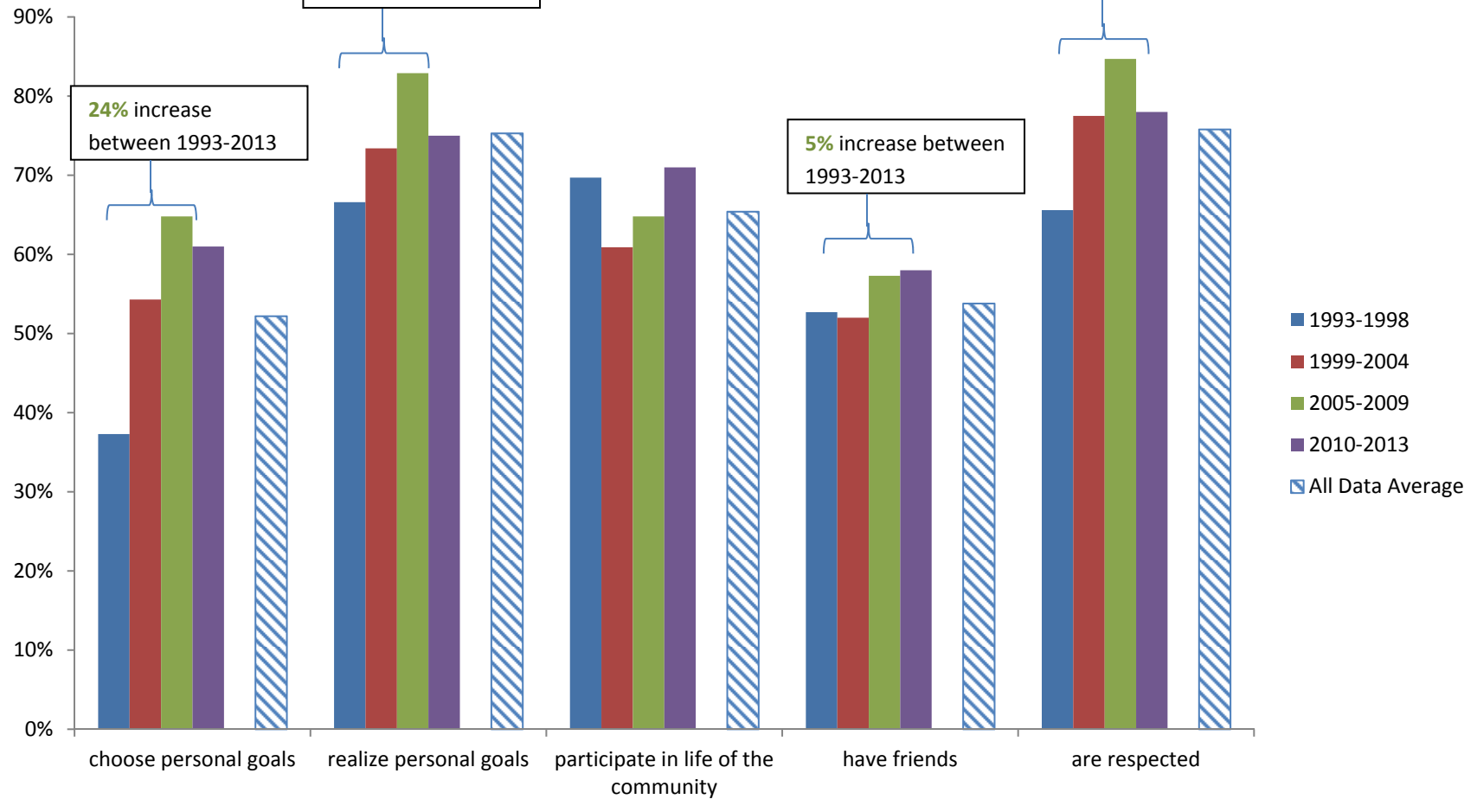
The charts below illustrate the findings from the 20 year trend data; where applicable, significant changes (+/- 5% point change) from 1993 -2013 are highlighted.



My World (n = 8,694) (1993 - 2013)



My Dreams (n = 8,696) (1993 - 2013)



Percentage of Individuals Achieving Outcomes by Indicator Across Time Intervals

		1993-1998	1999-2004	2005-2009	2010-2013	All Data Average
My Self	connected to natural support networks	70%	61%	59%	68%	63%
	have intimate relationships	72%	75%	67%	64%	70%
	are safe	88%	84%	89%	82%	86%
	have best possible health	76%	79%	78%	76%	76%
	exercise rights	33%	55%	67%	73%	52%
	are treated fairly	43%	61%	72%	73%	59%
	are free from abuse and neglect	81%	83%	82%	79%	82%
	experience continuity and security	86%	77%	76%	73%	79%
	decide when to share personal information	86%	71%	77%	79%	76%
My World	choose where and with whom they live	44%	46%	53%	49%	47%
	choose where they work	36%	41%	49%	44%	41%
	use their environments	74%	76%	79%	76%	76%
	live-in integrated environments	40%	48%	45%	65%	46%
	interact with members of the community	67%	76%	75%	75%	73%
	perform different social roles	45%	43%	41%	47%	42%
	choose services	56%	58%	61%	62%	57%
My Dreams	choose personal goals	37%	54%	65%	61%	52%
	realize personal goals	67%	73%	83%	75%	75%
	participate in life of the community	70%	61%	65%	71%	65%
	have friends	53%	52%	57%	58%	54%
	are respected	66%	78%	85%	78%	76%

CONCLUDING REMARKS

The data presented above highlight some thought-provoking findings. As shown, in many areas, the percentage of individuals achieving outcomes has been relatively constant (e.g., the areas of relationships, health, freedom from abuse and neglect, social roles and community participation). In other areas, however, greater changes have occurred over the years. In each of the three primary categories (My Self, My World, and My Dreams), increases of 5% points or more in individual outcome indicators can be observed, and under My Self decreases of 5% points or more can be observed as well. Primarily, data indicates that larger changes in achieved outcomes have been positive, with 11 of the 15 highlighted areas illustrating increases in the achievement of outcomes for individuals (e.g., exercising rights, being treated fairly, choosing services and where to work and live, living in integrated environments, interacting in the community, choosing and realizing personal goals, and being respected). The remaining four highlighted areas, though, identify net decreases of 5% points or more. These include: Individuals have intimate relationships (-8%); Individuals are safe (-6%); Individuals

experience continuity and security (-13%); and Individuals decide when to share personal information (-7%).

These finds also bring to light challenges still facing the human services field when looking to how services will be provided into the future. For example:

- Although significant changes have occurred in residential settings and day activities for individuals with intellectual and developmental disabilities over the past 20 years, data presented above indicates relatively little change (5% and 7% respectively) in people's choice in where and with whom they live and where they work. Changes in Federal Medicaid policy under revisions to the home and community based waiver residential setting regulations indicate that a lot of work is still needed in increasing individual choice.
- There has been a 25% increase in people living in integrated environments, yet only a small change in the percentage of individuals interacting with the community (8%), and marginal change in the percentage of people participating in their communities (1%) or developing friendships (5%). This data challenges the system to move beyond settings simply integrated into the community, and strive for increase the interactions and roles individuals hold within their communities.
- Lastly, over the past 20 years, the service system has stayed relatively constant with a high percentage of individuals indicating that they are free from abuse and neglect (average 82%), however, nearly 20% of interview respondents still note that there are issues or concerns regarding abuse and neglect in their services and the outcome is not present. This data indicates that although individuals accessing service are free from abuse and neglect overall, work is still needed to increase awareness, prevention and monitoring of abuse and neglect to increase the degree to which this outcome is present.

As described earlier, this initial brief is limited in scope, yet clearly raises issues for further consideration. Here, we see growth, consistency or decline in specific areas of personal outcome achievement. In fact, over half of the indicators (14 of 21) have seen great changes nationally (plus or minus 5%) over time. These changes require further study to better understand the influences of change. As an example, further analysis can measure the degree to which supports are in place for achieving individual outcomes. Further, although the category "My World" has seen increases of 5% or more over the past 20 years, 4 of 7 indicators in the category still show that fewer than 50% of respondents are achieving any of the included outcomes. Look for this analysis and more in future CQL data briefs, where we intend to correlate these 20 years of individual outcome data - with both supports in place, and systemic structural and policy changes over time.

To access resources, articles and videos about the Personal Outcome Measures®, visit

<http://www.c-q-l.org/pomindex.aspx>



To learn more, contact:

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CQL's Mission:

CQL is dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.