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How Did Rights Get So Wrong?

For decades, advocates fought legal, political and personal battles to ensure the legal and civil rights of people with disabilities. We have achieved many successes over the years, including rights to inclusive education, fair housing, accessible environments, least restrictive/most integrated settings, and equal opportunity. Today the constitution, courts, laws, governmental policies, and many advocacy organizations provide the foundation for the protection and promotion of rights for people with disabilities.

How well have these successes been put into practice at the individual level?

Do people with disabilities define and exercise their priority rights?

How well do service and support organizations recognize underlying issues of rights restrictions in every day practice?

Are systems of due process and fair treatment working at the individual level?

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 are learning that gaps still exist in bringing about the full exercise of rights for people with disabilities.

How Did Rights Get So Wrong?

The Council on Quality and Leadership (CQL) believes that we have the responsibility to promote and protect people's rights. Knowledge about rights, laws, and supports is an important first step. We then put this knowledge into practice by promoting rights through proactive strategies, such as:

- respecting individual preferences and choices
- encouraging individual decision making
- offering people multiple opportunities and experiences

Organizations build internal systems for ensuring that people's rights are protected. These typically include policies, training, support for self-advocacy, and oversight committees. These proven practices are well documented and they do make a difference.

Our experience has shown that just as important – if not more so – is the attention to every day opportunities and experiences in promoting rights. Greater awareness of underlying rights issues can shed new light on organizational practices (however well-intentioned) that impact people's freedoms and choices – such as set waking/sleeping times, standard/limited menu choices, locked doors and alarms, sharing personal information, limited privacy, "program slots", low expectations, and limited opportunities.

Supporting people with disabilities to exercise the same rights and responsibilities as all citizens can be challenging. Organizations are encouraged to start by establishing a philosophy and culture where all people are seen as equal and all decisions are made with great thoughtfulness.

Some practical and effective strategies include:

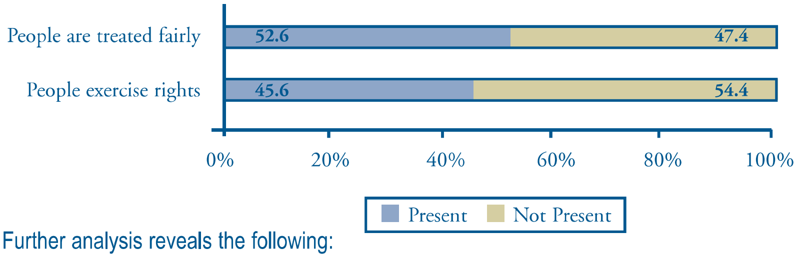
- Take a proactive approach to determining what rights and personal freedoms are most important to people and then supporting them to exercise those rights and personal freedoms. Go beyond the basic level of making sure that rights are not limited. Seek ways to support people to actively exercise rights.
- Assure that all organization members understand that the concept of "rights" goes far beyond the initial training and annual review that is required in most state systems. Rights are all encompassing and are not restricted to "service" or "treatment" rights.
- Host ongoing conversations about rights and responsibilities with staff members and people supported to improve people's understanding of these issues.
- Assure that whenever a person expresses dissatisfaction (verbally or behaviorally) with anything (where they live, where they work, how they socialize, who they live with, what progress they have made toward reaching their dreams) the people supporting that person raise questions about rights. For example: Are any rights being violated at this time? If the person did not have a disability, how would we handle the dissatisfaction? What supports might be available to them in this situation? How can the organization support this person to use those supports?
- Sustaining a Human Rights Committee that is active about ensuring that people have full access to their rights as citizens.
- Assure that people have access to legal counsel or advocacy at every court hearing, at every Human Rights Committee meeting, and at any other legal proceeding.

As organizations continue to implement person-directed supports and services – listening to and learning from each person – outcomes related to choice and rights will increase in people's lives. Decades of advocacy in promoting rights for people with disabilities have laid the cornerstone for quality in practice. What remains to be done is seeing the possibilities in each and every person.

Findings from the CQL Personal Outcome Measures® database indicate that rights issues remain a challenge for organizations. Fewer than half of the people we interviewed are exercising their personally defined priority rights. CQL Accredited organizations do demonstrate the fundamental assurances for protecting people's rights – policies, practices, and systems. Many continue to be challenged to apply those organizational systems in an individually meaningful way for each person supported.

Rights Outcomes 1993-2006

(n=6,424)



Further analysis reveals the following:

Living situations and rights:

- People living in supervised (24-hour) settings report significantly fewer outcomes in the area of rights than people in other settings
- This finding holds regardless of the level or type of disability experienced by the person
- People living independently or with family have the highest level of rights outcomes present

Source of funding and rights:

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

Top five outcomes that predict the presence of the rights outcomes:

- People choose personal goals
- People choose where and with whom they live
- People are respected
- People choose services
- People have intimate relationships

Percent of Outcomes Present

(1993 – 2006)

		Living Situation				Funding Source	
	National Data	Supervised (24-hour)	Supported	Family	Independent	ICF	HCBS
People exercise rights	45.6%	32.3%	51.7%	52.8%	61.7%	31.7%	41.4%
People are treated fairly	52.6%	41.7%	60.3%	68.4%	73.2%	44.1%	49.8%

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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