# Personal Outcome Measures® DATA DIGEST

2023

# PRESENTED BY:







# Introduction

We are delighted to share with you the 2023 Personal Outcome Measures® Data Digest. CQL | The Council on Quality and Leadership and MediSked have partnered to present the latest data covering personal outcomes and organizational supports – connecting the dots between the quality of services and the quality of life for people with disabilities.

CQL's Personal Outcome Measures® (POM) is a powerful tool to ensure supports and services are truly person-centered. In a POM interview, people receiving services share information about the presence, importance, and achievement of outcomes. These interviews cover quality of life topics involving choice, health, safety, social capital, relationships, rights, goals, dreams, employment, and more. Their support providers then discuss the supports that the organization has in place for those areas. The insight gained during a POM interview can then be used to inform a person-centered plan, improve individualized supports, track progress, and assess effectiveness. At an aggregate level, agencies can use the data to analyze initiatives, evaluate organizational priorities, and share results with stakeholders. The POM supports organizations to measure quality through the unique perspective of people with disabilities.

This report pulls together POM data that have been collected in 2020 and 2021 through POM interviews with more than 1,500 adults with disabilities. The information gathered during these interviews has been entered into the PORTAL Data System, powered by MediSked. The data digest presents data through an infographic format, organized under various quality of life categories.

The intent of the 2023 Personal Outcome Measures® Data Digest is to offer greater insight into the state of quality related to the disability services sector. People receiving services, families, human service providers, policy leaders, advocates, and others, can use this report to better understand the indicators that are broadly being achieved, identify services where there is opportunity for improvement, and communicate about the quality measures that truly matter in our field.

We hope that you enjoy this report and find value in sharing it with others. Thank you!

**MARY KAY RIZZOLO** 

Mary Kay Rizzolo

President and CEO

CQL | The Council on Quality and Leadership

**DOUG GOLUB** 

President

MediSked, LLC

# The Golden Rule

We all know the 'Golden Rule.' You should treat others the way you want to be treated. Far too often and for far too long, people with disabilities are not treated the same as those who do not have disabilities, and have less control over important decisions affecting their lives. The significance of this principle is not only important for topics like fair treatment, respect, and rights, but also affect other aspects of an individual's quality of life.

VOTE	66.1%			
PERSONAL DECISION-MAKING	73.09	%		of
ACCESS MONEY AS A POSSESSIO	ON <b>73.5</b>	%		10
FAIR WAGES	73.8	<b>3%</b>		W W
HAVE VISITORS AT ANY TIME		78.9%		VVC
MOVE ABOUT THE COMMUNITY		79.1%		p
NON-DISCRIMINATION AT WORK	<b>(</b>	79.5%		pres
ASSOCIATE WITH OTHERS			87.1%	hone
FILE COMPLAINTS ABOUT SERV	ICES		87.9%	proi me the
PRACTICE RELIGION			89.1%	
ACCESS FOOD			90.5%	info w
PRIVACY			91.7%	
PERSONAL POSSESSIONS			92.2%	
VOICE AN OPINION			93.29	<b>%</b>
FREEDOM FROM COERCION ANI	O RESTRA	INT		96.6%

# Percentage of people with disabilities whose rights were honored

Individuals don't have to participate in these rights to have these measures present. For example, 66.1% had their right to vote honored/recognized and not prohibited, but this does not mean that 66.1% exercised their right to vote. The POM recognizes that people should be able to make informed choices regarding which rights they exercise, and how they choose to exercise them.

# **43.5%** of people with disabilities **RECEIVED ORGANIZATIONAL SUPPORTS**

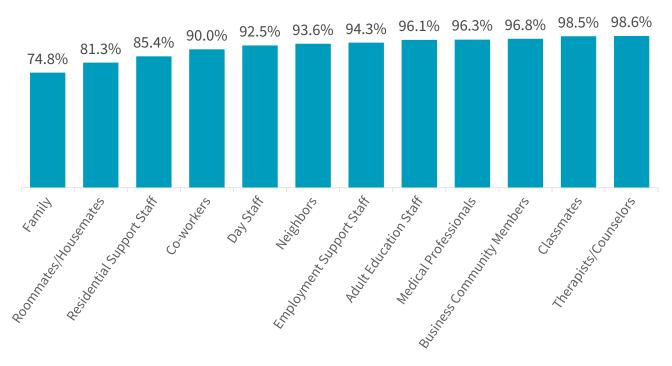
to exercise their rights

**48.8%** of people with disabilities were **RESPECTED** 

People with disabilities that are **RESPECTED** are

12.3x MORE LIKELY to exercise their rights

# People with disabilities were treated with respect by:



# People with disabilities that are **RESPECTED**

# are 12.5x MORE LIKELY

to be TREATED FAIRLY



People with disabilities who had the

#### TREATED FAIRLY

outcome present had an average of

12.6/21

total quality of life outcomes



People with disabilities who **DID NOT** have the **TREATED FAIRLY** 

outcome present had an average of

6.5/21

total quality of life outcomes



- Dignity and Respect Things That Make You Go ... Huh? (https://bit.ly/cql-dignity-respect)
- The MediSked Podcast | Episode 6: Improving Quality of Life for People with IDD, featuring THINK+change (Available on Spotify, Apple Podcasts, Google Podcasts, & MediSked.com)

# Staying Safe & Healthy

While the disability field is rooted in a medical model, and over time it has correctly shifted to a more holistic look at overall quality of life, health and safety is still vital for people. It's essential for organizations to find out what matters to people with disabilities when it comes to health and safety, and then work with the person to help attain and sustain their desires for health and safety.



### **AT HOME**

95.5% of people with disabilities knew how to respond in the event of an emergency situation

91.0% of people with disabilities' safety concerns were addressed



### **AT WORK**

83.6% of people with disabilities knew how to respond in the event of an emergency situation

80.6% of people with disabilities' safety concerns were addressed



#### IN THE COMMUNITY

94.2% of people with disabilities knew how to respond in the event of an emergency situation

92.5% of people with disabilities' safety concerns were addressed

# Organizations that provide people with disabilities with information & education about:

ABUSE NEGLECT MISTREATMENT EXPLOITATION

79.7% 78.0% 75.8% 77.9%



83.4% of organizations knew PEOPLE WITH DISABILITIES' DEFINITION of best possible health

**73.7%** of people with disabilities were supported to **SELF-MANAGE THEIR PERSONAL HEALTH** 

When people with disabilities are supported to self-manage their health, health interventions are **2.6x MORE LIKELY** to be effective



94.0% had a COMPLETE PHYSICAL EXAM within the last year



88.1% had a

DENTAL EXAM

within the last year



and health risks

The categories listed here only display data for people who are eligible to receive the healthcare, factoring in sex, age, and health risks.



**76.1**% had a **HEARING EXAM** within the last year



78.2% had an EYE EXAM or VISION SCREENING within the last year



**64.4**% had a **PAP TEST SCREENING**within the last year



71.6% had a PSA TEST FOR PROSTATE CANCER within the last year

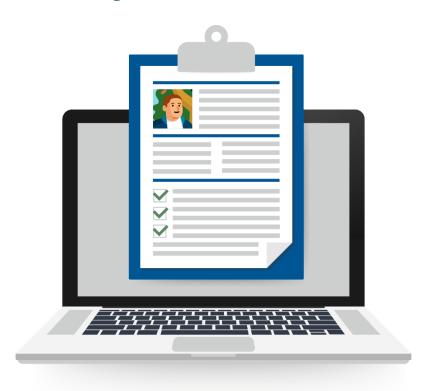


73.0% had a
MAMMOGRAM
within the last year



45.0% had a
COLORECTAL CANCER
SCREENING
within the last year

# **43.6%** of people with disabilities knew what personal information their provider organization has collected about them



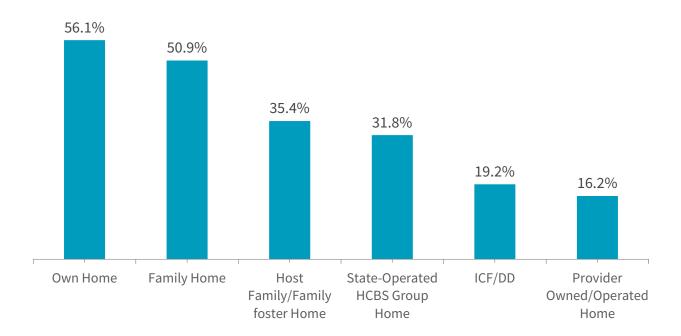
When people with disabilities were given control over deciding who their personal information is shared with, they were 4.4x MORE LIKELY to have the best possible health

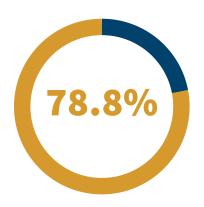
- DSP Turnover Negatively Impacts the Health and Safety of People with IDD (https://bit.ly/dsp-turnover)
- Data Outcome Stories: Supporting High Acuity Populations by Strengthening Care Management for Plans (https://bit.ly/medisked-mhpa-2022)

# It's Where the Heart Is

Home is definitely where the heart is. But for people with disabilities in the human services system, there can be some distinct differences in where people live, who they live with, and how they use and access their home. Because of this, it's especially important that support providers are aware of and responsive to people's preferences and choices involving their home.

# People with disabilities who choose where and with whom to live





of organizations **KNEW WHAT INTEGRATION MEANT TO** PEOPLE WITH DISABILITIES,

or made efforts to learn about people's preferences

- **82.4%** of people with disabilities had maximum access to their physical environment at home
- 92.0% of organizations knew if people with disabilities could access their home environment
- **82.8%** of organizations assessed people with disabilities' ability and interest for personal access and use of home environments
- **79.2%** of organizations made home modifications to promote maximum access and use for the person with disabilities



- Deinstitutionalization or Transinstitutionalization?: Residence Type, Personal Outcomes, and People with IDD (https://bit.ly/residence-outcomes-idd)
- Level Up: Using Data to Improve Social Determinants of Health Before, During, and After COVID-19 (https://bit.ly/level-up-sdoh)

# **Out & About**

Whether it's attending a festival, going to a baseball game, or checking out a concert, being an active participant in the community and all that it has to offer can have a big impact on people with disabilities' lives. And it can extend far beyond the immediate benefits like strengthening a social life or enjoying a hobby, into other quality of life areas.

# 82.8% of organizations KNEW WHAT PEOPLE WITH DISABILITIES WOULD LIKE TO DO IN THE COMMUNITY or made efforts to learn about people's preferences

27.7% of people with disabilities PARTICIPATED IN THE LIFE OF THE COMMUNITY

EMERGENCY DEPARTMENT VISITS were

**89.9% FEWER** when people with disabilities participated in the life of the community



# People with disabilities interact with other members of the community

**57.6%** of people with disabilities were satisfied with the type of interactions they had with other members of the community

36.7% of people with disabilities were satisfied with the frequency of interactions they had with other members of the community



80.2% of organizations knew people with disabilities' preferences for interaction or made efforts to learn

66.2% of organizations provided support to people with disabilities to access opportunities for interactions with others



25.3% of people with disabilities fulfilled a variety of social roles

People with disabilities are 33.0x more likely to perform different social roles when organizational supports are in place

When people with disabilities perform different social roles, they are 4.4x more likely to have friends

- HCBS Guide: Your Right To A Community Life (bit.ly/your-right-to-a-community-life)
- HCBS Guide: Supporting The Right To A Community Life (bit.ly/supporting-the-right)

# **Keeping Connected**

The friendships, relationships, and other bonds we form are a foundational part of the human experience. Support staff can play a meaningful role in helping people with disabilities develop and nurture these connections with others. The starting point involves discovery – finding out what types of connections people want, how often they want them, and the supports they desire along the way.

84.7% OF PEOPLE WITH DISABILITIES HAD FRIENDS

50.2% OF PEOPLE WITH DISABILITIES WERE SATISFIED WITH THE NUMBER OF FRIENDS THEY HAD

35.1% OF PEOPLE WITH DISABILITIES WERE SATISFIED WITH THE AMOUNT OF CONTACT WITH THEIR FRIENDS

63.3% OF ORGANIZATIONS KNEW & UNDERSTOOD PEOPLE WITH DISABILITIES' PREFERENCES FOR INTIMATE RELATIONSHIPS

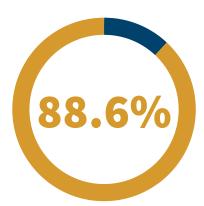
49.3% OF ORGANIZATIONS PROVIDED SUPPORT FOR PEOPLE WITH DISABILITIES TO PURSUE, FORM, & MAINTAIN INTIMATE RELATIONSHIPS

# People with disabilities are

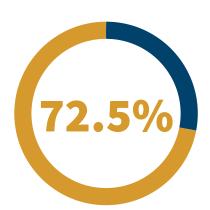
### 13.6x MORE LIKELY

to have intimate relationships when organizational supports are in place

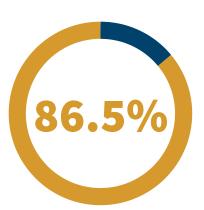




of people with disabilities' natural support networks have been identified by their organization



of organizations provided support for people with disabilities' relationships involving their natural support network



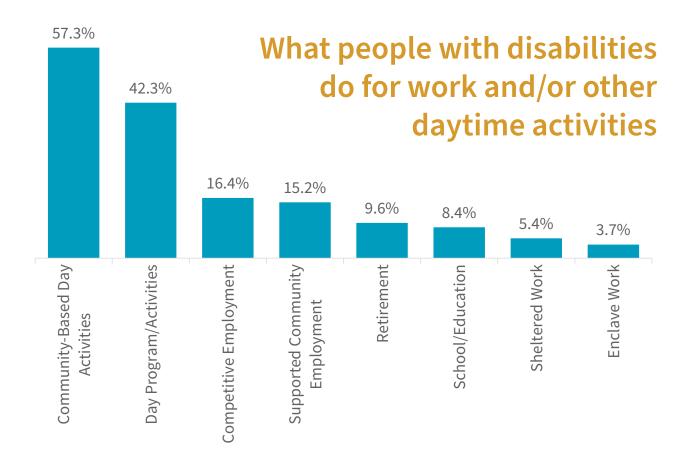
of people with disabilities had a natural support network

#### **FEATURED RESOURCE**

Sex & Relationships Conversation Cards (https://bit.ly/cql-conversation-cards)

# All In a Day's Work

"What do you do for a living?" That's a question people are regularly asked when they meet someone new. And the answer to that question can affect someone's self-worth, independence, and the control that they have over their life. Since people with disabilities face low employment rates compared to people without disabilities, employment related supports are particularly impactful.





47.7% of people with disabilities decided where to work or what to do during the day

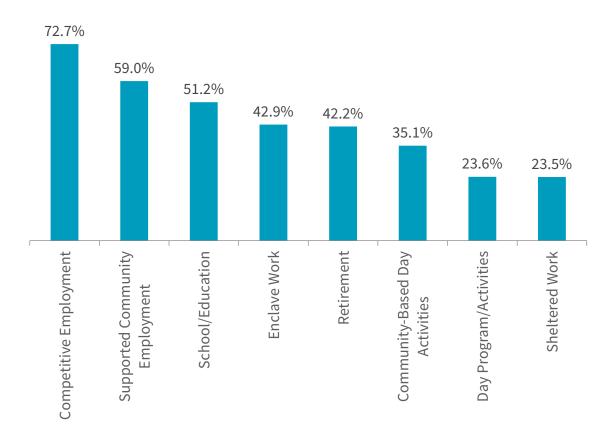


40.8% of organizations provided people with disabilities with access to varied job experiences and options



52.0% of people with disabilities had opportunities to experience different options

# People with disabilities who choose where they work



- 23.8% of people with disabilities experienced a change in employment/employer within the past 2 years
- 18.9% of people with disabilities anticipated a change in employment/employer in the next 1 to 2 years
- People with disabilities who experience continuity and security are 2.2x more likely to choose where to work

#### **FEATURED RESOURCE**

Advancing Competitive Integrated Employment for People With Disabilities (https://bit.ly/competitive-employment-disabilities)

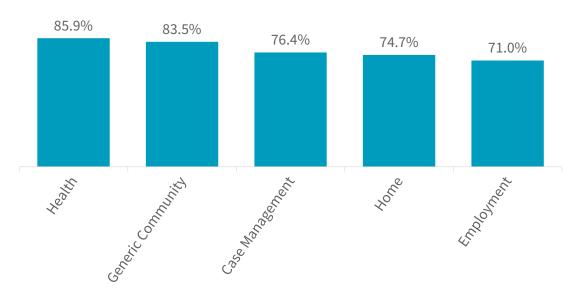
# **Supporting Dreams**

"I have a goal to volunteer in the community. We used Personal Outcome Measures® to accomplish this goal," shares Jessica Pinto, a person receiving services through A First Step LLC. From people with disabilities identifying what they want to achieve in life to assisting them making those dreams a reality, building supports to help facilitate outcomes is at the heart of service provision.



72.5% of people with disabilities choose their personal goals

# Services and/or supports that focus on the person with disabilities' goals



# **62.0%** of organizations

#### **IDENTIFIED ACCOMPLISHMENTS**

that people with disabilities saw as significant

**62.4%** of people with disabilities

**REALIZED GOALS** 

**27.9%** of people with disabilities who realized goals

**DID NOT CHOOSE THOSE GOALS** 

People with disabilities are

# 27.4x MORE LIKELY

to realize goals when organizational supports are in place

**65.9%** of people with disabilities

**ACCOMPLISHED SOMETHING** 

**SIGNIFICANT TO THEM** in the past two years

- Person-Centered Planning & The Personal Outcome Measures® (https://bit.ly/person-centered-poms)
- How Self-Direction Encourages Personal Choice (https://bit.ly/self-direction-choice)

# **About**

# CQL | The Council on Quality and Leadership

Since 1969, CQL | The Council on Quality and Leadership has been a leader in working with human service organizations and systems to continuously define, measure, and improve quality of life and quality of services for youth, adults, and older adults with intellectual and developmental disabilities, and psychiatric disabilities. CQL offers accreditation, training, certification, research, and consultation services to agencies that share our vision of dignity, opportunity, and community for all people.

## MediSked

MediSked is the leading brand in holistic solutions that improve lives, drive efficiencies, and generate innovations for health and human service (HHS) organizations that support our community. For over 19 years, MediSked has been the trusted technology partner to HHS organizations across the country, providing software and solutions to payers, government, and providers.

# The PORTAL Data System

The current PORTAL Data System was developed through a collaboration and partnership between CQL and MediSked in 2019. PORTAL, which is powered by MediSked's Connect Exchange tool, offers users a modern and intuitive platform for collecting and evaluating data to improve the quality of supports and the quality of life for people with intellectual and developmental disabilities and psychiatric disabilities. The platform includes tens of thousands of Personal Outcome Measures® surveys entered by hundreds of human services organizations spanning the United States, along with agencies internationally.

# **Recommended Citation**

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