

# WHAT REALLY MATTERS

A GUIDE TO PERSON-CENTERED EXCELLENCE



Application for Services for People with Disabilities



### **CQL | The Council on Quality and Leadership**

For over 40 years CQL has provided international leadership in designing progressive practices in services for people with intellectual and developmental disabilities and people with mental illness. We have provided a comprehensive approach to quality improvement and personal quality of life, with an emphasis on social capital and community inclusion.

Our work remains focused on organizations and helping them make real change. CQL engages organizations, people, their families and supporters in the development of resources and strategies that they can use to define and demand excellence in person-centered supports and services.

### **CQL VISION:**

A world of dignity, opportunity and community for all people

### **CQL MISSION:**

To provide leadership to improve the quality of life for people with disabilities, people with mental illness, and older adults

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# KEY FACTORS AND SUCCESS INDICATORS: A GUIDE TO PERSON-CENTERED EXCELLENCE

## Introduction

For over four decades CQL | The Council on Quality and Leadership has taken the leadership initiative in developing progressive measures of quality in services and supports, quality of life outcomes and community life.

Based on our data and experience, CQL embarked on the development of new definitions, metrics and improvement methods focused on person-centered services. Inspired by the words of the artist Georgia O’Keeffe – *“Only by selection, by elimination, by emphasis do we get at the real meaning of things”* – we launched the What Really Matters Initiative in 2009 to take a new look at the challenges and solutions in realizing person-centered services and supports across a range of human services.

CQL redefined quality in terms of person-centered supports and services. This revised definition resulted in the identification and development of a key set of 34 success indicators that characterize excellence in person-centered supports and promote personal quality of life outcomes.

This Guide to Person-centered Excellence is intended to promote quality improvement in services and supports for people with disabilities. These best practices and the resulting quality improvement initiatives can be applied across the full range of supports and services for people with disabilities.

These success indicators in person-centered supports acknowledge the person’s life story. Supports and services incorporate the person’s passions and priorities and provide the opportunity for the person to continue to address his or her interests, concerns and dreams. Person-centered supports recognize each person’s unique individuality. Systems and organizations promote dignity and respect when they incorporate elements of the person’s life story in the provision of services and supports.

## A Note about Language

We are committed to the principles and values of person-centered and self-directed supports across the range of service and support settings. These principles and values enhance the quality of life for all people – people receiving supports, their family, friends, support personnel and volunteers.

Across the broad range of human services, a variety of terms are used to describe services or supports offered, service providers – including employees, professionals and organizations of all types – and the people who receive or purchase those services and supports.

In this manual we strive for the broadest audience and use terms that we believe convey value and respect for all. We use “people-first” language to demonstrate that respect and value. At times, specific terms are included to add clarity.

- The terms “people” or “person” or “individual” refer to the person receiving the support or service. We also use the terms “consumer” and “peer” to represent the individual with mental illness.
- Other people are identified by their related roles to the person, such as family members, community representatives, legal representatives, volunteers, employees, friends and peers.
- “Support or service system” refers to an array of services and supports coordinated and provided within a geographical area or a political jurisdiction. These systems reflect a remarkable diversity in types of services that are planned, coordinated, financed and delivered directly or through contracts with other organizations.
- The term “organization” indicates an entity that provides services and supports. The organizational entity can be large or small, public or private, and offer resources ranging from episodic supports to long-term services. Organizations can provide minimal or infrequent supports as well as comprehensive, around the clock services.

For additional information about other terms used, please refer to the glossary in this manual.

## How This Manual is Organized

This manual has eight main sections and each section contains a key factor with its success indicators. We use the term ‘factor’ to refer to the main area: for example, Person-centered Planning. Likewise, each factor has a number of ‘success indicators’ that describe critical aspects of the factor.

For each success indicator there are three parts:

- A statement of the indicator
- A brief explanation of the meaning behind this indicator
- A description of how organizations apply this indicator in practice



## How to Use this Manual

These success indicators are not standards. They are not designed to measure compliance with regulations or even system or organizational processes.

These success indicators promote personal quality of life and we encourage organizations to use them as part of their own internal quality improvement system. We recommend that organizations prioritize the success indicators in their own setting and begin to implement those that will have the greatest impact and the most probable success for the people receiving services and supports.

CQL partners with organizations in a unique consultative experience for human service organizations – built on the principles contained in this manual. This experiential consultation – the Focus Forum – is used by organizations and leaders as a:

- strategic thinking exercise
- mission alignment exercise
- organizational transformation initiative
- organizational assessment, or
- implementation strategy for enhancing person-centered services, self-determination, or person-centered quality of life

Many organizations find that the Focus Forum can both launch and re-energize organization or culture change efforts.

# KEY FACTORS AND SUCCESS INDICATORS IN PERSON-CENTERED SUPPORTS

## **FACTOR 1** Person-centered Assessment and Discovery

- Indicators:**
- 1a People feel welcomed and heard
  - 1b People have authority to plan and pursue their own vision
  - 1c Assessment of needs is fair and accurate
  - 1d Assessment and discovery identify personally defined quality of life

## **FACTOR 2** Person-centered Planning

- Indicators:**
- 2a Planning is person-centered
  - 2b The plan identifies and integrates natural supports and paid services
  - 2c Informal community resources are used
  - 2d Planning is responsive to changing priorities, opportunities and needs
  - 2e Planning and funding are connected to outcomes and supports, not programs

## **FACTOR 3** Supports and Services

- Indicators:**
- 3a People have authority to direct supports and services
  - 3b Supports are flexible
  - 3c Support options are accessible
  - 3d People manage supports and providers
  - 3e Supports are available in an emergency or a crisis
  - 3f People can identify personal champions

## **FACTOR 4** Community Connection

- Indicators:**
- 4a Community membership facilitates personal opportunities, resources and relationships
  - 4b Peer support/mentoring is available
  - 4c People receive information and training

## **FACTOR 5** Workforce

- Indicators:**
- 5a The workforce is stable and qualified
  - 5b Practices are culturally competent
  - 5c Personnel have the flexibility and autonomy to support people
  - 5d Support for cultural/organizational change is provided
  - 5e Advocacy efforts promote fair and affordable provider rates and responsive payment systems

**FACTOR 6 Governance**

- Indicators:**
- 6<sup>a</sup> Organization mission, vision and values address person-centered supports
  - 6<sup>b</sup> Organizational practices are both person-centered and system-linked
  - 6<sup>c</sup> People and families play meaningful leadership roles

**FACTOR 7 Quality and Accountability**

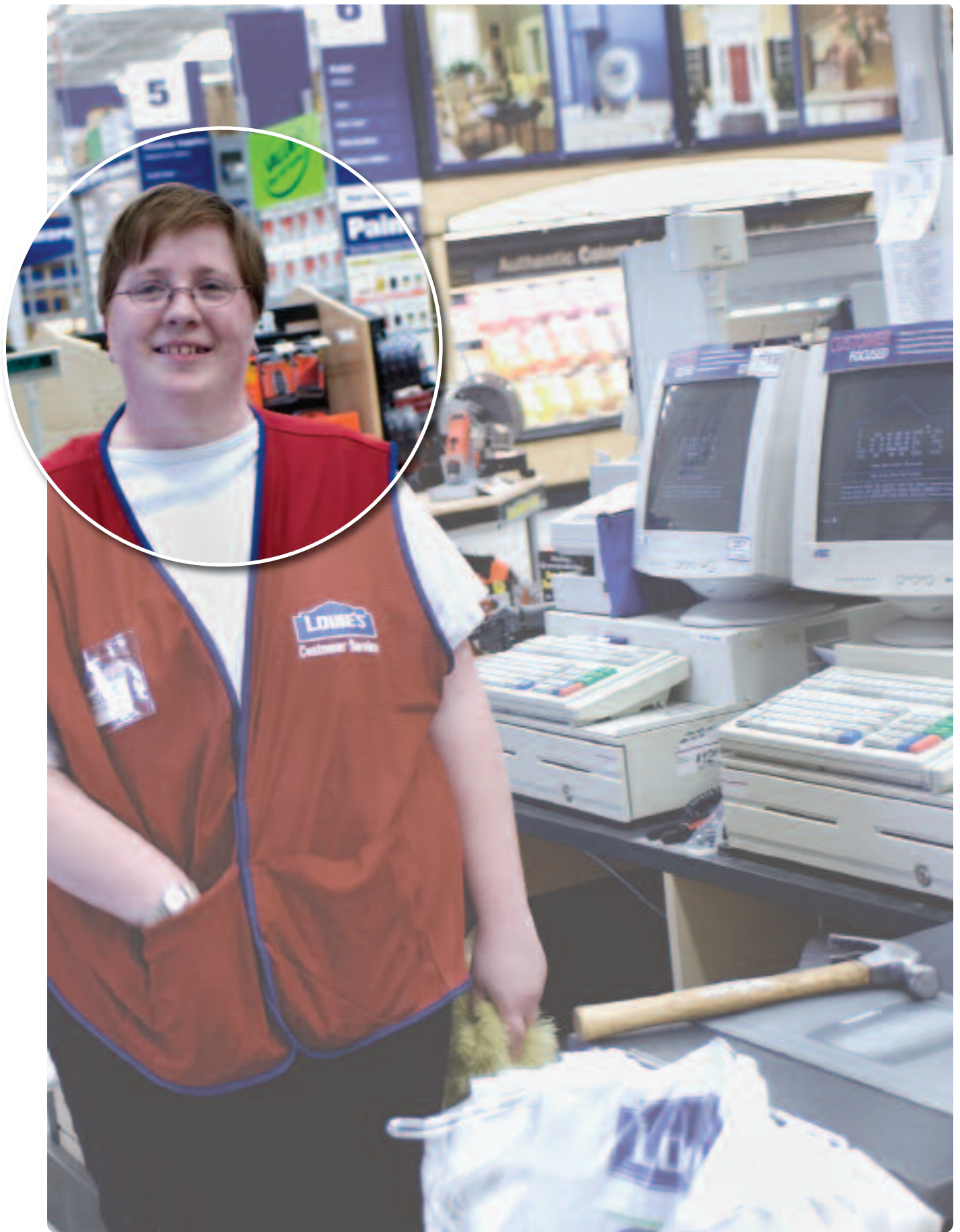
- Indicators:**
- 7<sup>a</sup> Quality management systems are integrated
  - 7<sup>b</sup> Quality of supports is measured
  - 7<sup>c</sup> Participants, families and advocates evaluate supports and providers
  - 7<sup>d</sup> The public is kept informed
  - 7<sup>e</sup> Personal information remains confidential

**FACTOR 8 Emerging Practices in Individual Budgets**

- Indicators:**
- 8<sup>a</sup> People control their budget allocations
  - 8<sup>b</sup> Individual budgets are both fair and ample
  - 8<sup>c</sup> Budget, money and services/supports are portable

**Key Factors and Success Indicators****APPLICATION FOR SERVICES FOR PEOPLE WITH DISABILITIES****Person-centered Excellence:**

Each person has a vision for what really matters that flows from a singular life history; a range of experiences and emotions; and unique dreams and goals. And, we provide each person with unconditional acceptance and the support to live his or her own life – to plan, to contribute, to participate, to choose – and to be respected and valued.





# KEY FACTOR<sup>1</sup>

## Person-centered Assessment and Discovery

Assessment and discovery initiate and guide the planning and implementation of person-centered supports. The purpose of assessment and discovery is to deepen and broaden an understanding of the person. Discovery is a continuous process. People change through experiences, learning and life events. The support or service provider keeps up with that change so that the person's supports and services can change in response. Informal discussions with people often reveal information about goals and preferences that may not surface during formal evaluations. People benefit from opportunities to experience new and unfamiliar situations before they clarify desires and the organization learns more about these desires and the person's dreams and goals.

### KEY TERMS

**individual life priorities | listening and learning | assets | strengths | dreams | change | flexibility | self-direction | respect**

### SUCCESS INDICATORS

- 1a – People feel welcomed and heard
- 1b – People have authority to plan and pursue their own vision
- 1c – Assessment of needs is fair and accurate
- 1d – Assessment and discovery identify personally defined quality of life

## FACTOR 1 INDICATORS

### 1a People feel welcomed and heard

People seeking supports and services feel welcomed, listened to and supported in their decisions – and are not pre-judged. People are the experts when it comes to their own lives. They know their strengths, preferences and needs. They expect their opinions to be heard, respected and acted upon.

### 1b People have authority to plan and pursue their own vision

The person is in the best position to know what he or she wants and needs. In addition, the person has the control and influence in the decision processes that can begin to move visions into reality. People have the authority to state what they want. Other stakeholders – organizations, families, volunteers, community representatives, friends and peers – listen to and respect each person's point of view.

### 1c Assessment of needs is fair and accurate

A person-centered system of supports and services includes a fair, valid and reliable assessment measure. The assessment system provides sufficient information to identify needed supports. This assessment process is separate from person-centered planning.

### 1d Assessment and discovery identify personally defined quality of life

Organizations that provide person-centered supports use valid and reliable methods to explore and discover each person's priorities. This discovery enables the person to provide his or her own meaning and definitions to the goals and priorities that are most important to him or her. This discovery of personally defined quality of life is different than standardized assessment described in # 1c above.

## ...AND THEIR APPLICATIONS

The assessment process begins by making the person feel welcome and comfortable. The environment accommodates the person's needs. Staff uses a speaking pace, volume and rhythm that enable the person to fully understand and gives him or her the opportunity to speak. The person shares how he or she is doing now and what his or her interests are. Individuality and uniqueness are acknowledged by listening and encouraging, without challenging.

The person has support to express his or her needs, wants, and likes or dislikes about his/her life. This comes before suggesting what services should be provided or which organization(s) or programs should provide them. People talk about their histories and lives and share what is most important to them. Assessment begins with the person's own priorities, what changes he or she would like in his or her life, if any, and what his or her plans are for the future. People feel empowered when you seek out and show that you understand their interests, hopes, dreams, and worries or fears.

Many assessment/discovery methods are available that are both valid (ensures the assessment item really measures what it is intended to measure) and reliable (correctly measures the item each time). Assessment is the beginning of the support/service experience. Assessment identifies individual assets, capabilities and needs. The assessment provides information that enables families, communities and service coordinators to identify potential providers of needed supports and services. The assessment includes the development and/or review of the person's individual budget. Each person should have meaningful participation in the assessment and discovery process.

The discovery process includes conversation and sharing, coupled with a comprehensive assessment. The discovery process integrates information concerning the person's priority quality of life outcomes with standardized assessment information about support needs and funding sources. A good discovery and assessment process helps the person, families, communities and friends understand what kind of life the person wants. A good discovery and assessment process helps people make choices that support their quality of life priorities. Assessment also helps individuals, families, communities and friends to join together to encourage and support the person.

# KEY FACTOR<sup>2</sup>

## Person-centered Planning

Person-centered planning keeps the focus on each person as the key decision-maker in his or her own life. This life planning process is rooted in what is most important to the person and involves the person directly with his or her community, network of connections, and close personal relationships in order to look at innovative ways to attain life goals and dreams.

The system used for person-centered planning and the plan that results are flexible. As people's interests and priorities change, the planning process is revisited as often as necessary to ensure that both major and day-to-day decisions also change in response.

Person-centered planning leads to transformation in a person's life when creative new directions and approaches are taken. People move towards the realization of specific life dreams and into a world of greater possibility for new goals to emerge.

### KEY TERMS

**individual life priorities | personal goals | options and opportunities | choice | flexibility | change | support | decision-making | control**

### SUCCESS INDICATORS

- 2a – Planning is person-centered
- 2b – The plan identifies and integrates natural supports and paid services
- 2c – Informal community resources are used
- 2d – Planning is responsive to changing priorities, opportunities and needs
- 2e – Planning and funding are connected to outcomes and supports, not programs

## FACTOR 2 INDICATORS

### 2a Planning is person-centered

Person-centered planning is a life-planning process that examines innovative ways to attain life goals and dreams. Person-centered planning focuses on what is most important to the person and directly involves the person with his or her community, network of connections and close personal relationships.

### 2b The plan identifies and integrates natural supports and paid services

The person-centered plan states an individual's personal vision for the future. The plan incorporates individually defined goals and priorities tied to major life areas. The plan identifies available public and community resources including financial resources, natural or unpaid supports, paid services and action steps for achieving personal outcomes, including supports needed. The plan enhances natural supports that already exist and incorporates paid services into the life of the person, which build upon, but do not replace the natural supports.

## ...AND THEIR APPLICATIONS

Person-centered planning means that a plan is developed that addresses the unique needs, preferences and choices of the person. The planning structure enables the person to choose who, if anyone at all, should be involved in helping to plan or provide supports. With the appropriate array of supports, people can, if they choose, lead their planning meetings.

The plan is more than a service or support plan. The development of a person-centered plan enables each person to express what he or she wants in life and make decisions about the supports needed to achieve his or her priorities. It enables the person to have the quality of life he or she wants. Formal services and supports are identified and authorized to address the specific needs of each person based on an individualized assessment and identified quality of life priorities.

When people are served one-by-one, each person creates his or her own life. Each person's life is different and the decision to make changes in one's life is part of a normal process of change. Planning is characterized by optimism, an assumption that each person can make his or her own decisions and contribute in a meaningful way, a willingness to embrace change and a commitment to support the person to control his or her own life.

Communities and organizations assist each person who chooses to receive support to build an active circle of support. The circle assists each person to review what is working or not working in his or her life, to make small daily changes or large life changes. The circle of support can also assure that all needed supports are available. Power and decision-making rests with the person, with the support of his or her circle.

Person-centered planning identifies the integration of natural supports and paid services to assist each person in securing valued outcomes, while also assuring basic health, safety and welfare. Person-centered planning enables each person to identify his or her own preferences in terms of support providers. People have options about receiving supports from formal systems and organizations, from informal systems and volunteers, from family, friends and neighbors, or no supports at all.

The assessment process identifies how supports can be provided by neighbors, friends and family members who can offer assistance in natural ways. In work settings, supports are provided by supervisors and co-workers. A support broker helps build a network of support for the person from paid and unpaid resources in the community.

## FACTOR 2 INDICATORS

### 2c Informal community resources are used

Person-centered supports and services incorporate supports and resources closest to the person such as friends, family, neighbors, co-workers, members of faith communities, other informal and generic community resources, as well as public service opportunities.

### 2d Planning is responsive to changing priorities, opportunities and needs

Person-centered systems are flexible and can change the array of supports to reflect the person's changing priorities and goals. Person-centered systems encourage opportunities for new partnerships and support and provide ongoing training for all participants in the person-centered planning process. Person-centered models focus on personal interests and outcomes and not specific services, supports or programs. There are alternative pathways to achieving individual priorities. The supports that work for one person may not work for another. Flexibility is demonstrated by the availability of intermittent supports – that is, supports that can be arranged when they are needed and disappear when they are no longer relevant.

### 2e Planning and funding are connected to outcomes and supports, not programs

In person-centered systems, funds that are available are connected to the person. Funds used to support a person are not locked into specific service models.

## ...AND THEIR APPLICATIONS

Person-centered systems explore options to connect people with community assets and opportunities. These community assets might include: churches, synagogues and mosques; schools and colleges; businesses; libraries; neighborhood associations, clubs and recreational councils; and other civic and volunteer organizations.

The system used for person-centered planning and the resulting plan are flexible. As people's interests and priorities change, the planning process is re-visited as often as necessary to ensure that both major life priority and day-to-day decisions also change in response. Feedback and input aimed at improving successful outcomes are sought and incorporated.

Person-centered systems view change as a natural part of the process of figuring out the life the person wants to live. People have the opportunity to experiment and re-visit decisions about priorities and supports. When a person decides to live differently or make changes or new choices in daily routines, there is no sense that the person, staff or organization was wrong in making the original choice.

Valid and reliable assessment, the identification of priority life outcomes and the person-centered plan result in the identification of supports needed to facilitate outcomes within the framework of the individual budget. Resources are provided to facilitate outcomes. The individual support provider is chosen to facilitate outcomes. Funding supports the attainment of outcomes for the person. For example, funding for residential services may be used to purchase services and supports in a variety of settings and are not tied to a particular type of setting. Likewise, people relocating can expect their budget to retain their individual budget allocation, and service/support options (recognizing the potential need to identify new providers).



# KEY FACTOR<sup>3</sup>

## Supports and Services

Person-centered organizations encourage people to follow their dreams and desires and goals. They support people to continually grow and develop. As people gain new experiences, supports are expanded to match new needs and choices.

People exercise self-determination and choice. People have the autonomy to make decisions that affect their own life situations and those of other people important to them.

### KEY TERMS

**choice | decision-making | control | autonomy | trust | access | responsiveness | individualized | options | coordination | outcomes**

### SUCCESS INDICATORS

- 3<sup>a</sup>** – People have authority to direct supports and services
- 3<sup>b</sup>** – Supports are flexible
- 3<sup>c</sup>** – Support options are accessible
- 3<sup>d</sup>** – People manage supports and providers
- 3<sup>e</sup>** – Supports are available in an emergency or a crisis
- 3<sup>f</sup>** – People can identify personal champions

## FACTOR 3 INDICATORS

### 3a People have authority to direct supports and services

People are in charge of what happens, which services and supports they receive and who provides them.

### 3b Supports are flexible

Person-centered supports routinely review and update personal priorities and support needs. People change and their priorities and support needs change. A person-centered system accommodates these changes. Person-centered supports and services recognize that there are alternative pathways to achieving individual goals.

## ...AND THEIR APPLICATIONS

Person-centered systems shift decision-making to the person, with support from family, friends and community. As needed, organizations adopt the fundamental premise that people are capable and willing to make the best decisions for themselves. Communities, organizations and families accept their role as a supportive partner who, when asked, provides support in ways the person requests.

People are in charge of their own lives. They make decisions about the types of supports and services they need and the organizations and staff who will provide those services. What people spend time doing day-to-day is directly related to the life goals they have chosen. There are no rules beyond those of basic safety and financial accountability – and even these are discussed to ensure that people agree they make sense. In residential settings, there are no imposed schedules for a set time that people must be in their rooms or go to sleep. There is no limit on time allowed for meals, television, phone use, visitors, or other leisure and recreational activities. People can choose not to participate in skill-building and training programs.

All behavior supports are fully positive and reflect evidence-based practice. All such supports are in response to behaviors that the person genuinely has an interest in changing and are clearly dangerous or interfere with the person's opportunities for participation in community life. The person receiving support has a voice in the design of any behavior supports and the option of discontinuing them.

Person-centered systems ensure that service and support planning, delivery and funding are flexible to respond to changes in circumstances and needs across the lifespan. Services and supports are customized around the particular needs and preferences of the person. Flexibility also includes the availability of supports that can be arranged when they are needed and discontinued when they are no longer relevant.

Regardless of the array of supports and services found within community and organizational systems, the attitude about people in these systems is, "You tell us what you need and we'll support you to get it." Organizations define their role as connecting people with community supports, resources and social networks. Services and supports are customized around the particular and changing needs and preferences of the person. Community and organizational practices promote universal customization of supports.



## FACTOR 3 INDICATORS

### 3c Support options are accessible

A system of person-centered supports provides an array of choices that are real, available and appropriate to the needs and priorities of the person.

### 3d People manage supports and providers

People can freely select among all qualified providers and can readily change providers when dissatisfied with provider performance.

### 3e Supports are available in an emergency or a crisis

Person-centered support systems anticipate emergency or crisis situations and are prepared to respond effectively in a respectful and individually-directed manner.

### 3f People can identify personal champions

Everyone needs someone in his or her life who cares, has his or her needs at heart and will step in to help when needed. These personal champions provide unconditional support.

## ...AND THEIR APPLICATIONS

Accessibility begins with clear information provided in a timely and convenient format that describes services and supports. Real access to supports is also determined by factors such as physical structure, geographical location, language and culture of support providers, and previous life experience. Some people – due to simple unfamiliarity with the location, provider or support personnel – may need some help from a friend, peer, family member or support coordinator to figure out the new support opportunities.

Person-centered systems offer choice from an array of services and supports. Communities and organizations are prepared to support people in obtaining needed supports beyond those in any particular organization or program. People select their staff and receive assistance as needed to make decisions about the people who support them. A person can discontinue a relationship with a staff if there is no longer comfort or trust and can change staff without negative consequences.

Crisis or emergency situations are often unpredictable. For that reason, people have opportunities to provide advance directives about how to support them in their time of crisis situations. Examples include: the aging or death of a loved one or caregiver, the collapse of a support network, extraordinary medical and/or behavioral challenges. The effectiveness of a service delivery system is measured by the extent to which these challenges are effectively addressed within the community without resorting to short-term or long-term hospitalization or institutionalization. Strategies for addressing such challenges include the operation of crisis networks and the development of centers that can provide clinical expertise to community organizations in addressing medical and behavioral challenges.

Organizations support people to identify and nurture relationships with other people who can be a personal champion. Personal champions are those people who have made a special connection with the person, will be in that person's life over time, and advocate for and/or will be the person's voice when the person cannot speak for him or herself. A personal champion can be a paid staff person or a friend or relative. What is important is that everyone has a person who is central in his or her life and clearly on his or her side.

# KEY FACTOR<sup>4</sup>

## Community Connection

Community encompasses place, people, culture, services and trust. Community connection means that the organization interacts with people, networks and resources beyond its physical boundaries. Person-centered organizations create networks between people and their communities. Organizational representatives do not differentiate themselves from the community – they are recognized and valued as members of the community.

Organizations support their members to connect to other people and resources within the community and perform leadership roles in return. In this way, organizations can both achieve their missions and practice good citizenship that strengthens the community as a whole.

### KEY TERMS

**inclusion | participation | community | relationships | family | friendship | access | social networks | resources | advocacy**

### SUCCESS INDICATORS

- 4a** – Community membership facilitates personal opportunities, resources and relationships
- 4b** – Peer support/mentoring is available
- 4c** – People receive information and training

## FACTOR 4 INDICATORS

### 4a Community membership facilitates personal opportunities, resources and relationships

Person-centered systems value and promote inclusion and participation in a community, recognizing that promoting community membership represents something different for each person. Communities and organizations support people to negotiate across several service and support organizations so they can effectively coordinate needed resources.

### 4b Peer support/mentoring is available

Person-centered systems assure the availability of peer support and mentoring options.

## ...AND THEIR APPLICATIONS

Across the lifespan, a person-centered system supports people in developing and sustaining their social relationships, including friendships, family connections, religious affiliations and romantic relationships. People who are connected to others who know and care about them live happier and healthier lives than people without those relationships. For one person, this might mean preserving an existing community (network of friends and family) as one enters into the service system. For another, it could entail creating opportunities to develop new relationships.

When people explore their interests in formal and informal gatherings, they are likely to meet people with whom they have shared interests. Communities, organizations, families and friends help people to build on their interests and increase their social relationships, networks and social capital.

Organizations committed to person-centered supports collaborate with others, including other service providers and generic community organizations, and define their organizational role as connecting people with other resources in the community and building social networks.

By listening, sharing personal experiences and offering ideas, people are uniquely able to help others like themselves. For example, people who have experienced a disability can better understand and relate to others trying to deal with a similar disability. Additionally, people with disabilities are viewed as contributing members of society.

Peer support programs differ in their approach, using peers as counselors, advocates, community connectors, tutors or simply visitors. They may also differ in whether peer support is an individual or group-based activity, and whether peer mentors are paid or volunteer. Regardless of the approach, many people value peer support and mentoring. They view the common experience as useful and the opportunity to reinforce one's own voice as positive.

Support for self-advocacy strengthens person-centered supports. Communities and organizations play an important role in helping people connect with one another, form networks, find their voice and advocate for change. Communities, organizations, families and friends support and encourage people to advocate on their own behalf, participate in peer support activities, and engage in political or advocacy efforts that interest them.

## FACTOR 4 INDICATORS

### 4C People receive information and training

Person-centered support systems provide information, education and training. People need timely and up-to-date information about their specific situation, about appropriate services and supports, and about eligibility requirements in order to make decisions about meeting today's needs and planning for the future.

## ...AND THEIR APPLICATIONS

A person-centered support system provides information, education and training. This support may come from peers, family members, friends, case managers and/or others. The level of support, information and education will vary with each person. Support may be needed intermittently, on a regular basis or not at all. Person-centered systems operate with the assumption that people will not automatically recognize opportunities for exercising autonomy, decision-making and leadership.

Complicated details within a person-centered system are minimized. For example, practices within a person-centered system (such as service planning or managing staff) can be so complex that people are unable to participate without more information, education and training. The result is that authority and decision-making shift from the person to professionals and organizations.

Policy makers take steps to simplify practices, work at making requirements easy to understand and satisfy and provide impartial supports to people when needed. Fiscal intermediaries can manage paying staff, tracking expenditures and other paperwork responsibilities without undercutting the person's desire to direct his or her own life. Other areas of information, training and support include: financial literacy support, self-advocacy support, and information on benefits, service options, and planning.

Support and service providers also need information about the person. However, people are only asked questions that are relevant. Questions do not unnecessarily invade their privacy and requests for information are clear and uncomplicated. The burden of supplying information does not exceed the benefit of services/supports offered.

# KEY FACTOR<sup>5</sup>

## Workforce

Person-centered organizations recruit, hire and train a diverse and competent paid and volunteer workforce. The organization provides feedback to, and recognition for, direct support professionals who support people to achieve their personal outcomes.

A person-centered focus is built on a continuous system of learning about, listening to and responding to people. The ongoing learning process about personal priorities and desires provides information for individual, organizational and system-wide planning. These systems capitalize on the diverse cultures and ideas of people served, employees and the overall community.

### KEY TERMS

**respect | fairness | stability | diversity | cultural competence | training | skills | professional growth | organizational change | culture change**

### SUCCESS INDICATORS

- 5a** – The workforce is stable and qualified
- 5b** – Practices are culturally competent
- 5c** – Personnel have the flexibility and autonomy to support people
- 5d** – Support for cultural/organizational change is provided
- 5e** – Advocacy efforts promote fair and affordable provider rates and responsive payment systems

## FACTOR 5 INDICATORS

### 5a The workforce is stable and qualified

Person-centered supports depend upon a well-trained, stable workforce.

### 5b Practices are culturally competent

Person-centered systems are respectful and skilled in anticipating and responding to the goals, needs and preferences of people across cultures, traditions and beliefs.

### 5c Personnel have the flexibility and autonomy to support people

Person-centered systems provide support personnel with appropriate levels of decision-making authority to support people without complicated and confusing approval and review requirements.

## ...AND THEIR APPLICATIONS

Person-centered systems depend on public, family and individual confidence in the quality of the provider system to bring state-of-the-art practice to the lives of people. The system also includes support professionals who can manage, broker and find appropriate services and supports. The visible presence of a stable and qualified workforce inspires confidence that the entire process – from identifying need to receiving supports – is planned and organized.

A well-trained, stable workforce promotes the quality of services. Problems in recruiting and retaining direct support professionals erode quality in services. Workforce stability and quality are enhanced when direct support professionals are: skilled; receive adequate training; are paid sufficiently (with benefits); are afforded the flexibility and authority to support people creatively to meet their needs; and are provided opportunity for career growth.

When organizations emphasize best practice in staff recruitment, they increase the probability that they can be selective and choose only those staff with relevant skills and values.

Person-centered systems recruit staff who know the community and who themselves have well-connected social networks, have diverse interests and cultures, and are engaged in a range of activities.

No two people, families or support networks are exactly alike. The meaning and structure of a “traditional” family have evolved and must be addressed in a culturally competent manner. Regardless of age or disability, household configurations and dynamics will be unique for each person. People will vary in their ethnic origins and primary languages spoken. Service systems must accommodate varying languages and customs. Some people live in sparse rural areas that may be hard to reach. Other people will live in dense urban areas that may be difficult to penetrate.

Staff understands that there is a wide range of human experience and that people of different backgrounds and cultures have different ways of seeing the world, interacting or celebrating. Staff learns about the people they support and assists them to celebrate their own culture and goals.

All staff members receive the supports they need to be effective. They are treated as valued, important members of the organization. Staff has the ability to make decisions with the person and take action in the best interests of the people they support. Person-centered systems provide training in values, ethics, decision-making, problem solving and negotiating skills for direct support professionals. Direct support professionals have the appropriate training and support to make important decisions.

## FACTOR 1 INDICATORS

### 5d Support for cultural/organizational change is provided

Individual and organizational leadership is committed to the principles and practices of person-centered support. The individualization of supports challenges how traditional services are organized. Communities and organizations recognize that transformation promotes an open dialogue, new management models and innovative patterns of support provision.

### 5e Advocacy efforts promote fair and affordable provider rates and responsive payment systems.

Each provider (individual or organization) of a support or service receives sufficient compensation to maintain the delivery of necessary services to each person. The payment request system is not complicated and payment for supports is prompt.

## ...AND THEIR APPLICATIONS

Support for person-centered principles and practices is demonstrated throughout the organization. This commitment is evident in the organization's vision, mission and values; policies and procedures; hiring, supervision and reward system for staff; and organizational support for volunteers, self-advocates, families and peers. Culture change and organizational transformation around person-centered supports is a central theme in all staff hiring, orientation, training, continuing education and promotion.

The organization also provides a forum and organizational opportunity for dialogue about the promise and reality of person-centered supports. People receiving supports, family members, peers, volunteers and community representatives engage in an ongoing review and assessment of progress in changing organization culture in a more person-centered direction.

Organizations engage in systems-wide public policy campaigns to promote fair and affordable provider rates and responsive payment systems. Organizations and communities foster coalitions across the fields of disability, aging and mental health. Coalitions promote fairness and equity across systems. Coalitions work with bottoms-up strategies to build on assets and influence networks in local communities. At the same time, these coalitions work with key opinion leaders in local and state/provincial government to develop rates and payment systems that promote quality services for people with mental illness, people with disabilities and older adults. Advocacy efforts are directed at ensuring that rates are equitable across provider settings and are responsive to local and state/provincial fiscal realities.

These advocacy efforts incorporate the views and voices of people receiving services and supports, their families, friends and allies. Advocacy efforts reach out across community networks and acknowledge the long range benefits for community growth and development.

As a wide range of individualized and decentralized supports are developed, reimbursement for services delivered by individual and organizational vendors is provided in an appropriate time frame. The reimbursement system is fair and easy to understand. Documentation requirements for services protect the interests of the person receiving the supports, the provider and the payer.





# KEY FACTOR<sup>6</sup>

## Governance

The person-centered organization engages in responsible governance and management practices. These practices are grounded in ethical, accountable and open systems. Leaders within the organization are responsible for managing the organizational culture, communicating a strategic vision, focusing on mission, and modeling behaviors that emphasize integrity, respect for people and an urgency for action.

The organization promotes leadership so that all employees, volunteers and family members play a role in facilitating person-centered supports. There are clear statements of the leadership responsibilities and opportunities for people receiving supports, board members, families, volunteers and community supporters.

The organization emphasizes renewal and communication of the mission, vision and values to achieve person-centered services and supports.

### KEY TERMS

**mission | vision | values | leadership | inclusion | participation | systems**

### SUCCESS INDICATORS

- 6a** – Organization mission, vision and values address person-centered supports
- 6b** – Organizational practices are both person-centered and system-linked
- 6c** – People and families play meaningful leadership roles

## FACTOR 6 INDICATORS

### 6a Organization mission, vision and values address person-centered supports

Organizations committed to person-centered supports clearly define their commitment in the mission, vision and values.

### 6b Organizational practices are both person-centered and system-linked

Organizations provide supports on an individual basis to all people receiving services. This commitment is matched by a corresponding understanding of the complexity of organizational systems that support such individualization. There is a clear connection between what the organization says it is about and the actions of its members (such as Board members, staff and volunteers).

### 6c People and families play meaningful leadership roles

Person-centered systems value and ensure meaningful leadership roles for people at all levels of the support and service system.

## ...AND THEIR APPLICATIONS

The organization establishes clear statements of mission, vision, values and goals. These are developed with broad stakeholder input. A vision statement identifies the projected result of wide-scale implementation of person-centered supports. The organization's mission statement clearly defines the organization's commitment to person-centered supports and its role and responsibilities for furthering the vision. All Board members, staff and volunteers understand and embrace the organization's mission, vision and values.

People supported, family members, volunteers and other stakeholders regularly assess progress toward organizational goals and the degree to which organizational priorities and practices support the stated mission, values and goals. The support system or organization establishes a feedback system or learning process through which it can learn about or identify policies and practices that impede person-centered practices, in order to make needed changes.

Leadership at the individual level is assured through personal authority to plan and direct services. Leadership is also demonstrated at the service delivery and systems level, when people are encouraged and supported to participate meaningfully on decision-making and policy-setting boards. Person-centered organizations and systems also promote meaningful participation from family members (such as parents, spouses, siblings and children). A person-centered model recognizes that families support people of all ages, and while some people may choose to disassociate from their families, others rely heavily on their families for support and advocacy.

Stakeholders on the Board of Directors and on committees are supported to participate fully and have valued input in policy making, strategic planning and practices.

# KEY FACTOR<sup>7</sup>

## Quality and Accountability

Organizations exercise a public trust and have a responsibility to people receiving services and supports, their families, the community, funders and employees. As resources become scarce, organizations must demonstrate a direct connection between organizational process and personal outcomes. Organizations have an obligation to organize and deliver supports that facilitate outcomes.

Every organization sets out to create strong, solid, high quality services and supports for the people it serves. In order to meet changing environments, regulations, new thinking and other unanticipated forces, organizations develop and follow quality enhancement strategies. People receiving supports, families, employees, volunteers, board members and community representatives play active roles in quality management systems.

### KEY TERMS

**openness | access | fairness | transparency | confidentiality | integration | evaluation | measurement | outcomes | impact | performance | feedback | improvement**

### SUCCESS INDICATORS

- 7a** – Quality management systems are integrated
- 7b** – Quality of supports is measured
- 7c** – Participants, families and advocates evaluate supports and providers
- 7d** – The public is kept informed
- 7e** – Personal information remains confidential

## FACTOR 7 INDICATORS

### 7a Quality management systems are integrated

Quality management contains features that address the person, organization and system levels. Quality management integrates personal quality of life with quality assurance and performance improvement. Particular attention is directed at issues of abuse, neglect and exploitation.

### 7b Quality of supports is measured

Person-centered systems demonstrate a commitment to service excellence and personal outcomes. Qualitative and quantitative mechanisms are in place to assess services and supports, both individually and in the aggregate.

## ...AND THEIR APPLICATIONS

Best practice in quality management now includes integrated systems that bring together data and information about personal quality of life outcomes, quality assurance processes and organizational quality improvement efforts to promote quality at the individual, provider and system levels.

Quality must be examined from each person's point of view. For example, people provide their own definition of quality. People receiving supports will have different definitions for such items as personal autonomy, feeling valued, using resources in a personally determined way, being satisfied with supports and achieving personal outcomes. A person-centered system addresses health and safety safeguards that are tailored to the individual uniqueness of each person directing his or her own services.

The focus on quality addresses and integrates two perspectives. The concern for quality is found in the focus on the individual. In addition, the concern for quality is also found in the design of responsive systems that can identify barriers to quality for the individual, alleviate those barriers, and activate efforts to improve quality. Responsive systems' initiatives include workforce training; basic assurances in health, safety and security; external third party evaluation; and information and data collection and analysis.

Data collection and analysis further the understanding of quality supports at the personal level. Data enables individuals and interested others to track what is happening, to understand how funds are being spent, to monitor movement toward outcomes that the person values and to identify areas in need of further attention.

Person-centered systems routinely and systematically ask (and respond to answers from) the questions, "Is the person better off for having participated?" and "What is the evidence that supports and services are clearly connected to priority outcomes for the person?"

Quality measures are tied to individual outcomes. Quality management includes ongoing feedback that connects measurement with support provision and then with outcomes. People, families and advocates are partners in evaluating services and providers. Complaint and grievance procedures are easy to understand and use.

Person-centered services value and ensure a sustained commitment to achieving service excellence. A commitment to service excellence is found in a highly skilled and trained workforce, consistent high quality services (across time and geography), easily accessible information and education for service recipients, and ongoing mechanisms for quality improvement.

## FACTOR 7 INDICATORS

### 7c Participants, families and advocates evaluate supports and providers

Organizations committed to person-centered excellence ensure that all stakeholders are included in the evaluation of supports and providers.

### 7d The public is kept informed

Clear and simple reports to the public regarding individual needs and outcomes (in the aggregate), budget allocation strategies, and assurances for service quality and economic efficiency and effectiveness are provided on a regular basis.

### 7e Personal information remains confidential

Organizations providing person-centered supports ensure the balance between public transparency and the protections of people's personal information. The privacy of personal information is always in focus and assured.

## ...AND THEIR APPLICATIONS

The organization has inclusive and ongoing processes for assessing the quality of the services offered. Representatives of all stakeholder groups are involved in the evaluation efforts and the outcomes of these efforts are shared broadly. The organization takes advantage of a range of methods including both internal and external and formal and informal methods of evaluation. Outcomes are carefully reviewed and the information gained is used to make changes in policy and practice.

The organization has processes in place for seeking and accepting complaints or concerns of people served, family members, staff and others who care about the people receiving support. The system for addressing complaints is accessible and offers confidential options. No one is punished for raising concerns. All complaints are carefully reviewed and addressed.

Organizations maintain ongoing transparency. The organization assesses all aspects of its operations and makes relevant information available to all stakeholders and the public regularly. Person-centered systems are particularly open to public and legislative criticism concerning appropriate use (and potential abuse) of public funds. The organization recognizes its responsibility as a publicly-funded entity and reviews practices to assure that funds are spent appropriately and effectively.

Individual information is always maintained confidentially and never shared without the person's permission. Only aggregate information about accomplishments and outcomes of people served by the organization are shared publicly.



# KEY FACTOR<sup>8</sup>

## Emerging Practices in Individual Budgets

This factor describes “emerging practices” in the delivery of person-centered excellence. We recognize the challenges for organizations to bring about the wide-scale adoption of individual control over budgets in person-centered supports. Organizations will achieve success through a commitment to the values and principles described in this section and through a strong focus on collaboration, advocacy and coalition building across all sectors and stakeholders.

Individualized budgets support the person to be the decision maker in how to live his/her life by choosing where and how he/she lives and what services and supports he/she buys. These may be new services or services he/she now receives. With self-direction, the person will have more choice, more control, more flexibility and more freedom in his/her life.

### KEY TERMS

**self-direction | decision-making | control | flexibility | systems advocacy**

### SUCCESS INDICATORS

- 8a** – People control their budget allocations
- 8b** – Individual budgets are both fair and ample
- 8c** – Budget, money and services/supports are portable

## FACTOR 8 INDICATORS

### 8a People control their budget allocations

Person-centered supports and services provide the person the option to manage a service budget, including distributing the budget among different types of supports and acting as the employer of those who provide support. Person-centered supports give people a greater degree of control while, at the same time, encouraging them to seek out the most economical supports and services.

### 8b Individual budgets are both fair and ample

Knowing what is available and having options for using those resources, puts control into the hands of the person where it belongs, even while all of the resources necessary for achieving the person's desires may not be available. Knowing one's allocation can improve supports planning, especially when coupled with an assessment that identifies support needs.

### 8c Budget, money and services/supports are portable

Funds that are available to support a person are not locked into specific service, organizations or locations. They are connected to the person. People who change services or service providers take their money with them.

## ...AND THEIR APPLICATIONS

The amount of a person's funding is determined by taking into account individual characteristics, support needs, and usual and customary expenditures for people who have similar characteristics and support needs. The assignment of individual budget amounts creates a framework within which person-centered plans are developed without sacrificing budget predictability.

The person-centered system supports people to understand how much money is available to them, where it comes from and in what ways it can be used. People are provided with the knowledge and skills necessary to administer their own budgets through appropriate education and support. People also have the option of having others manage the details of their budget, if they wish.

With a personal budget based on the assessment, people are better able to consider their needs in relation to the size of the budget and then to prioritize the available supports. Linking a fair and valid assessment with quality of life priorities and an individual budget facilitates an individual, organizational and public understanding of person-centered supports. The individual budget also allows people to make well-planned decisions about what services they choose. Simply having an individualized budget, however, is not sufficient. The budget must be ample enough to purchase the supports needed.

Support organizations are viewed as an "offerer" rather than as a "provider" of support. They are prepared to offer supports or services that a person wants to purchase. People choose the organization(s) from which they receive support and decide when to change organizations.

Personal outcomes drive the identification of needed supports, the allocation of an individual budget and the identification of support organizations. Resources are linked to outcomes and not to particular organizations, providers or supports. People can redirect budget allocations to alternative organizations, providers or supports to facilitate outcome attainment.





## GLOSSARY OF TERMS

**Advance directives** – instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity, and appoint a person to make such decisions on their behalf.

**Assessment** – a process used to determine the person's need, desires, goals and dreams

**Assets** – a useful or valuable quality; used to describe the qualities, gifts and talents of an individual

**Behavior supports** – emphasis on skills needed by the person to behave in a more appropriate manner and provide motivation rather than simply control the behavior; addresses both the source of the problem and the problem itself

**Case manager** – the primary point of contact who coordinates services, resources and communications among the person, family, provider and other stakeholders

**Circle of support** – a technique used to enlist the involvement and commitment of peers in developing and supporting effective inclusion

**Cultural competence** – set of values and actions that provide accessible information and services and take into account people's cultural and linguistic needs

**Culture change** – a national movement for the transformation of services, based on person-directed values and practices where the voices of people and those working with them are considered and respected; core person-directed values are choice, dignity, respect, self-determination and purposeful living

**Direct support professionals** – those who provide guidance and support to people; provide support to a wide range of individuals including people with disabilities or chronic illness, children and youth who are at risk, and families who need assistance in supporting family members

**Effectiveness** – the measure of goal attainment

**Efficiency** – the reasonable use of resources

**Evaluation** – the process of making judgments based on criteria and evidence

**Evidence-based practice** – practice that is supported by research findings and/or demonstrated as being effective through a critical examination of current and past practices

**Fiscal intermediary** – person or organization that manages funds, makes payments and accounts for expenditures made on behalf of the consumer as directed by the consumer, family, or circle of support

**Generic services** – services that are available to and used by all people in the community

**Individual budget** – the total dollar value of the services and supports, as specified in the plan, under the control and direction of the person; supports the person to be the decision maker in how to live his/her life by choosing where and how he/she lives and what services and supports he/she buy; represents the translation of the person's hopes and dreams into a budget document controlled by the person/family, with assistance when needed

**Individual support plan** – a plan that identifies personal outcomes and arranges for services and activities to help the person pursue or achieve them

**Intermittent supports** – provided to individuals who need a level of staff support that can range from a few hours a day to several hours a week

**Mission statement** – a formal, short, written statement of the purpose of an organization; the mission statement should guide the actions of the organization, spell out its overall goal, provide a sense of direction, and guide decision-making

**Natural supports** – the relationships that occur in everyday life; usually involve relationships with family members, friends, co-workers, neighbors and acquaintances, and are of a reciprocal (give-and-take) nature

**Organization culture** – a set of common understandings around which action is organized

**Organizational change** – occurs when a company makes a transition from its current state to some desired future state; managing organizational change is the process of planning and implementing change in organizations in such a way as to minimize resistance and cost to the organization while simultaneously maximizing the effectiveness of the change effort

**Outcome** – the impact on people's lives as a result of supports

**Peer supports/Mentors** – a voluntary relationship, typically between colleagues of more similar age and experience; support is provided by a group of colleagues or two colleagues provide each other with mutual support

**Personal champion** – someone who has made a special connection with the person, will be in that person's life over time, and advocate for and/or will be the person's voice when the person cannot speak for him or herself

**Personal outcomes** – the major expectations that people have in their lives

**Person-centered plan** – process designed to assist someone to make plans for the future; used most often as a life planning model to support individuals to increase their personal self-determination and improve their own independence

**Policy maker** – individual, especially in official bodies, who has the authority to make decisions about which problems within a particular sector that are to be addressed and how these problems are to be handled

**Public transparency** – a set of policies, practices and procedures that allow citizens to have access to, understanding of and confidence in information

**Qualitative** – refers to the characteristics of something being described, rather than exact numerical measurement; qualitative research is based on individual, often subjective, analysis

**Quality assurance** – systematic monitoring and evaluation of the various aspects of a project, service or facility to ensure that minimal standards are being met; demonstrations of successful operation in the areas of health, safety and welfare

**Quality improvement** – methods undertaken in order to increase efficiency of actions and procedures with the purpose of achieving additional benefits for the organization and its people

**Quality management** – a process focused not only on product or service quality, but also the means to achieve it

**Quality of life** – the opportunities and supports to live a good life

**Quantitative** – measurement based on some quantity or number rather than on some quality

**Recovery** – mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential

**Reliable** – correctly measures an item each time

**Self-advocate** – a person working on behalf of oneself to take an active role in decisions about one's own life

**Self-direction** – rooted in increased quality, increased power for individuals, increased status within the community for these same individuals and, at the policy and organizational level, a fairer, more equitable distribution of public service dollars

**Self-determination** – a process that differs from person to person according to what each individual determines is necessary and desirable to create a satisfying and personally meaningful life; self-determination is both person-centered and person-directed; it acknowledges the rights of people with disabilities to take charge of and responsibility for their lives

**Service system** – an array of services and supports coordinated and provided within a geographical area or a political jurisdiction; reflects diversity in types of services that are planned, coordinated, financed and delivered directly or through contracts with other organizations

**Social capital** – the amount of trust and "reciprocity" in a community or between individuals and in the relationships that arise from them

**Social networks** – are made up of individuals (or organizations) connected in one or more ways, such as, friendship, kinship, common interest, or other relationships

**Stakeholder** – person, group, organization or system who affects or can be affected by an organization's actions

**Support broker** – works directly for the individual, assisting the individual to develop and manage the supports they are self-directing; provides supports in ways that are flexible, responsive to and controlled by the individual

**Support coordinator** – works with individuals and their families to develop service and support plans, based on the individual's needs and wishes, and to coordinate and monitor the services and supports that are provided to the individual

**Supports** – the range of assistance, training, settings, equipment or care that enable an individual to live as independently as possible

**System-linked** – the process of integrating information, data, and practices resulting from talking and learning with people into organizational systems of planning, communication and support

**Systems advocacy** – the concerted action to change policies, rules or laws which determine how services are provided; effort to change system of services in the community, such as school system or transportation system; also includes legislative advocacy

**Systems change** – the process of improving the capacity of services to work with many sectors to improve the quality of life for all people in a community

**Valid** – ensures an item really measures what it is intended to measure

**Vision statement** – outlines what the organization wants to be, or how it wants the world in which it operates to be; concentrates on the future and is a source of inspiration

## BACKGROUND

For over four decades CQL has taken the leadership initiative in developing progressive measures of quality in services and supports, quality of life outcomes and community life.

### **Past Contributions, Current Foundations 1970s and 1980s – Assuring the Basics**

CQL | The Council on Quality and Leadership originated in the late 1960s in an effort to stop the abuses and inhumane treatment in large public institutions. During the 1970s and 1980s, CQL performed a national leadership role in developing national consensus standards for organizations providing services to people with intellectual disabilities. The standards reflected the principles and values of professionals, families, provider organizations and government agencies. CQL standards (1971, 1973, 1978, 1981, 1985, 1987 and 1990) were incorporated into federal court rulings, the Health Care Financing Administration's (now CMS) Medicaid standards, and numerous state licensing requirements.

### **1990s – Personal Outcome Measures®**

CQL signaled a new era in quality measurement when it shifted the definition of quality from compliance to responsiveness and began work on the Personal Outcome Measures® in 1991. To develop these measures, CQL's Board of Directors and staff first held focus group meetings with people with disabilities and people with mental illness. CQL piloted the new Personal Outcomes in the United States and Canada and then introduced the Outcome Based Performance Measures in 1993. The modified Personal Outcome Measures® were published in 1997.

CQL's design and publication of the Personal Outcome Measures® represented both a strong leadership initiative and a broad national trend. The measures reflected CQL's decision to go beyond the quarter century tradition of defining quality in terms of organizational process standards. CQL's initiative in redefining quality in terms of personal outcomes influenced subsequent development of person-centered approaches in numerous states, at the Centers for Medicare and Medicaid Services (CMS) and within the intellectual disabilities and mental health communities.

### **2000s – Social Capital and Community Life®**

Through our work in promoting person-centered outcomes, CQL determined that our methods for interviewing and gathering information and for measuring these outcomes are well established. The principles that support person-centered quality of life – self-determination, choice and self-advocacy – gained increased momentum.

CQL's experience in promoting personal outcomes led us to new challenges. We recognized that personal outcomes take place within communities of concerned and supporting people. Our work focused on the social or community context for the attainment of personal quality of life.

This connection between personal outcomes and community builds on the research and practices of social capital. The term “social capital” describes the ties and trust that we have with other people, including our families, friends, neighbors, social groups, colleagues and service providers. Strong social capital enables all of us to live healthier and happier lives, increase our community affiliations, and exercise choice and self-determination. The research and practices associated with social capital provide a solid footing for placing a person-centered approach within the context of community – with an emphasis on social capital, formal and informal support networks and peer support.

### **2010 – What Really Matters Initiative**

More than fifteen years of research on the CQL Personal Outcome Measure® national database revealed the importance of person-centered services and social networks in facilitating personal quality of life outcomes for people. CQL introduced the dialogue on social capital and disability in 2000, and we redefined quality within the context of community inclusion. We argued that people find meaningful life opportunities and alternatives outside of programs and organizational services. The role of organizations is to connect people with resources and social networks in their communities. Unfortunately, our data and experience indicate that many organizations have difficulty making these connections.

This led CQL to embark on the development of new definitions, metrics and improvement methods focused on person-centered supports through the What Really Matters Initiative, resulting in the publication of this Guide to Person-centered Excellence.

While we are committed to a central set of indicators – we recognize that the fields of aging, mental health and substance use disorder, and intellectual and developmental disabilities each have their own culture, language, assumptions and priorities. For that reason, we developed three different applications, one for each setting: services and supports for older adults, for people with mental illness and substance use disorder, and for people with intellectual and developmental disabilities. The 34 Success Indicators are consistent across all three settings, while the narratives are tailored to apply to the specific audience and service setting.

Over a 12-month period, we sought out the best thinkers and innovators across a wide range of human services to guide our work. We:

- commissioned a number of research and content reports from external experts
- conducted an international Delphi survey
- convened advisory groups from different fields
- held listening sessions, focus groups, and discussions with key stakeholders across the United States, in Canada and overseas
- conducted pilot tests and field tests of the applications in the US and Canada with organizations providing disability, aging, and/or mental health services and supports

The written materials were developed by experts in each field and reviewed by CQL Advisory Panels and people receiving services.

The figure below identifies those sources of input.





## WHAT REALLY MATTERS INITIATIVE GOALS:

CQL identified preliminary information gathering objectives for the What Really Matters Initiative across service settings for people with mental illness and substance use disorder, older adults, and people with intellectual and developmental disabilities.

- To seek advice on the trends, issues, concerns, needs and goals of a wide range of people receiving human services – as well as those of organizations/service providers, public officials, advocates and workers
- To obtain input about, and reaction to, these questions:
  - What is the current thinking about person-centered services and supports? How would you define it?
  - Where are the commonalities across different groups? Where are the differences?
  - Where are the successes in your field in terms of person-centered services and supports? Why do you think it's working? What are the barriers?
  - How do you define quality in person-centered services and supports?
  - Who should measure quality (and how)?
  - What do consumer, families, and/or providers (stakeholders) want in terms of a quality measurement system?
- To convert this input into insight and action that will ultimately improve the lives of all stakeholders
- To connect and engage with diverse perspectives and ideas

In the Fall of 2010, CQL published this *Guide to Person-centered Excellence* as the culmination of our work. With this Initiative, our focus lands squarely on the real meaning of quality in person-centered services and supports. CQL works with organizations, systems and communities who are dedicated to achieving excellence through person-centered service models – across all disciplines. We support those entities through assessment, consultation, measurement and improvement strategies.

CQL core values and principles remain unchanged and are at the center of this Initiative. People receiving services play an integral role in this new work.

We continue to place Personal Outcome Measures® at the foundation of our work. One-to-one conversations with people receiving supports are the most powerful source of knowledge and understanding when it comes to defining excellence and person-centeredness. In our work with organizations, CQL teams meet with individuals to learn about the outcomes in their lives and we support organization staff to learn from this approach.

For over 40 years CQL has provided international leadership in designing progressive practices in services for people with intellectual and developmental disabilities and people with mental illness. We have provided a comprehensive approach to quality assurance, quality improvement and personal quality of life, with an emphasis on social capital and community inclusion.

Our work remains focused on organizations and helping them make real change. The What Really Matters Initiative also engages people, their families and supporters in the development of resources and strategies that they can use to define and demand excellence in their lives.

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